Icelandic stroke survivors: Functioning and contextual factors and ActivABLES for home-based exercise and physical activity

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Færni og aðstæður einstaklinga eftir heilaslag og ActivABLES fyrir heimaæfingar og daglega hreyfingu

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Ágrip

Markmið: Markmið doktorsverkefnisins voru að: (1) lýsa færni og aðstæðum einstaklinga sem búa í heimahúsum 1-2 árum eftir að hafa fengið fyrsta heilaslag, á grundvelli alþjóða flokkunarkerfisins ICF um færni, fötlun og heilsu og með áherslu á mögulegan mun á milli einstaklinga í þremur aldurshópum, (2) lýsa þróun á tæknibúnaðinum ActivABLES sem miðar að því að auka þátttöku einstaklinga sem hafa fengið heilaslag í markvissum heimaæfingum og daglegri hreyfingu og (3) meta fýsileika ActivABLES með því að rýna í ásættanleika, eftirspurn, útbúnað og hentugleika tæknibúnaðarins.

Aðferðir: Þversniðskönnun á landsvísu þar sem upplýsingar um mögulega þátttakendur komu úr sjúkraskrám um þá sem höfðu verið lagðir inn með sjúkdómsgreininguna *heilaslag* í fyrsta sinn á tímabilinu 1.apríl 2016 – 31.mars 2017. Útilokunarskilyrði voru búseta á hjúkrunarheimili, vitræn skerðing samkvæmt sjúkdómsgreiningu, íslenska kennitölu vantar og búseta erlendis. Þátttakendur voru 114 (56,2% þátttökuhlutfall), 50% karlar, á aldrinum 27-94 ára (71,6±12,9 ára) og úr þremur aldurshópum: 75 ára og eldri (n=51), 65-74 ára (n=34) og yngri en 65 ára (n=29). Könnunin samanstóð af spurningum um heilsufar, færni (líkamsstarfsemi, athafnir og þátttöku) og aðstæður (persónubundnar og umhverfistengdar) ásamt tveimur stöðluðum spurningalistum; Mælistiku um áhrif heilaslags (SIS) og Spurningalista um viðhorf til æfinga (BREQ-2). Þróun ActivABLES var byggð á persónumiðaðri nálgun og líkani um þróun og mat á margþátta íhlutunum frá *Medical Research Council* í Bretlandi. Blandað snið var notað til að rannsaka fýsileika ActivABLES með tíu einstaklingum (55-79 ára) sem höfðu fengið heilaslag og notuðu sex frumgerðir af tæknibúnaðinum til æfinga og hreyfingar yfir fjögurra vikna tímabil með aðstoð aðstandenda. Jafnvægi, hreyfifærni og færni handa var metin með stöðluðum mælitækjum fyrir og eftir tímabilið, dagleg hreyfing var metin með hreyfimælum og þátttakendur skráðu notkun og athugasemdir í dagbók. Í lokin voru tekin hálf-stöðluð viðtöl við þátttakendur og aðstandendur. Við þemagreiningu viðtalsgagna var tekið tillit til fjögurra þátta fýsileika; ásættanleika, krafna, útbúnaðar og hentugleika. Megindleg og eigindleg gögn voru síðan sameinuð og greint hvort niðurstöður voru samhljóma.

Niðurstöður: Niðurstöður könnunarinnar sýndu margbreytilegt og flókið samspil færni og aðstæðna hjá þátttakendum. Algengasta einkennið strax í kjölfar heilaslags var skerðing á jafnvægi. Við samanburð á færni og aðstæðum milli aldurshópa kom fram munur en einnig líkindi á milli hópa.

Elsti hópurinn hafði meiri fjölkvilla, notaði frekar gönguhjálpartæki og síður snjalltæki en yngri hóparnir. Jafnframt fékk elsti hópurinn færri stig en yngri hóparnir í þáttum í SIS-spurningalistanum sem lúta að athöfnum dagslegs lífs og hreyfanleika. Þróunarferli ActivABLES skilaði sex frumgerðum sem voru prófaðar í fýsileikarannsókninni: (1) ActivFOAM fyrir jafnvægisæfingar, (2) WalkingSTARR til að ýta undir göngu, (3) ActivBALL til að æfa færni handa og efri útlima, (4) ActivSTICKS til að æfa færni efri útlima, og (5) ActivLAMP og (6) ActivTREE sem veittu endurgjöf í formi ljóss eftir því sem þátttakandanum miðaði áfram í heimaæfingum og hreyfingu. ActivFOAM, ActivBALL og ActivSTICKS voru öll tengd við spjaldtölvu sem sýndi æfingarnar. Þær fjórar frumgerðir sem voru til æfinga og þjálfunar voru tengdar við ActivLAMP eða ActivTREE sem veittu sjónræna endurgjöf um magn æfinga og hreyfingar. Stillingar voru einstaklingsmiðaðar og einfalt var að breyta ráðleggingum um tímalengd og/eða fjölda endurtekninga fyrir viðeigandi stignun. Í fýsileikarannsókninni komu fram bætingar í stöðluðum mælingum að lokinni fjögurra vikna notkun og hreyfimælar sýndu meiri líkamlega virkni. Greining á niðurstöðum fyrir hvern þátt fýsileika leiddi í ljós eftirfarandi þemu: (1) ásættanleiki: þakklæti, meiri færni, frumkvæði í virkni og möguleg notkun fyrir einstaklinga sem munu fá heilaslag í framtíðinni; (2) eftirspurn: raunveruleg notkun, áhugi á frekari notkun og þörf fyrir eftirfylgd; (3) útbúnaður: mikilvægi endurgjafar, fjölbreytni í æfingu og framgangur í æfingum; og (4) hentugleiki: þörf á aðstoð og tæknileg vandkvæði. Megindlegar og eigindlegar niðurstöður voru mjög samhljóma og studdu vel við fýsileika ActivABLES.

Ályktun: Þetta verkefni er gott dæmi um hvernig nýta má alþjóðlega flokkunarkerfi ICF fyrir heildræna lýsingu á færni og aðstæðum ákveðins hóps af einstaklingum og hvernig þróa má tæknibúnað tengdan snjalltækjum fyrir einstaklinga sem hafa fengið heilaslag fyrir markvissar heimaæfingar og daglegra hreyfingu. Fýsileiki ActivABLES fyrir einstaklinga sem hafa fengið heilaslag rennir stoðum undir mikilvægi tæknibúnaðar í endurhæfingu þessa hóps og kallar á frekari rannsóknir í stærri hópum til að fullvinna tæknibúnaðinn og koma honum á markað. Frekari rannsóknir á færni og aðstæðum eldri einstaklinga eru einnig nauðsynlegar til að sýna fram á þá staðreynd að endurhæfing einstaklinga eftir heilaslag þarf að vera fjölbreytt og einstaklingsmiðuð.

Lykilorð: mat á fötlun, endurhæfing eftir heilaslag, tæknibúnaður, æfingameðferð, öldrun

Abstract

Aims: The aims of this thesis were: (1) to describe functioning and contextual factors of community-dwelling stroke survivors 1-2 years after their first stroke, based on the International Classification of Functioning, Disability and Health (ICF) with focus on potential differences between age-groups, (2) to describe the process of developing ActivABLES, which aims to increase home-based therapeutic exercise and daily physical activity among stroke survivors, and (3) to investigate the feasibility of ActivABLES in terms of acceptability, demand, implementation and practicality.

Methods: A cross-sectional national survey was used to collect data. Potential participants were identified through registries from the two main hospitals in Iceland and included community-dwelling stroke survivors who had been admitted with their first stroke 1-2 years earlier. Exclusion criteria included living in nursing homes, diagnosis of dementia, not having an Icelandic national insurance number and living abroad. Participants were 114 (56.2% response rate), 50% men, 27 to 94 years old (71.6±12.9 years), and categorized into the age-groups: ≥75 years(n=51), 65-74 years (n=34) and <65 years (n=29). They answered questions on health, functioning (body function, activities, participation) and contextual factors (environmental, personal) along with two standardized questionnaires, the Stroke Impact Scale (SIS) and the Behavioural Regulation Exercise Questionnaire-2 (BREQ-2). The process of developing ActivABLES was guided by principles of human-centred design and the Medical Research Council framework for development and evaluation of complex interventions. A mixed methods design was utilized to test the feasibility of ActivABLES among ten stroke survivors (55–79 years) who used six prototypes for four weeks with support from their informal caregivers. Data collection included measures on balance, mobility and hand function before and after the four-week period, along with adherence diaries and motion detectors. Semi-structured interviews were conducted with the stroke survivors and their caregivers after the four-week period. Themes were identified related to four domains of feasibility: acceptability, demand, implementation and practicality. Data was integrated by examining any (dis)congruence in the quantitative and qualitative findings.

Results: The results from the cross-sectional survey revealed a complex and informative pattern of functioning and contextual factors in the lives of community-dwelling stroke survivors, where the most common symptom immediately after the stroke was balance impairments. Some differences and similarities in functioning and contextual factors were found between the age-groups. The oldest participants reported more comorbidities, used more walking devices and fewer smart devices than both younger groups. In the SIS, the oldest participants had lower scores than both younger groups in the domains of activities of daily living and mobility. The development of ActivABLES resulted in six prototypes which were tested in the feasibility study: (1) ActivFOAM for balance exercises, (2) WalkingSTARR to facilitate walking, (3) ActivBALL for hand exercises, (4) ActivSTICKS for upper arm exercises, and (5) ActivLAMP and (6) ActivTREE which both give visual feedback on progress of exercise and physical activity. ActivFOAM, ActivBALL and ActivSTICKS were all connected to a tablet which gave exercise instructions. All the exercise prototypes could be connected to ActivLAMP and ActivTREE to give feedback on the magnitude of exercise. Settings could be individualised and recommended in daily time and/or repetition could easily be progressed to match higher activity levels. In the feasibility study, improvements in functional measures were shown after the four-week use and more physical activity was detected with motion detectors. The themes identified from the interviews for each feasibility domain were: (1) acceptability: appreciation, functional improvements, self-initiated activities and expressed potential use for future stroke survivors; (2) demand: reported use, interest in further use and need for follow-up; (3) implementation: importance of feedback, variety of exercises and progression of exercises; and (4) practicality: need for support and technical problems. The quantitative and qualitative findings converged well with each other and supported the feasibility of ActivABLES.

Conclusion: This thesis is a good example of how the international language of ICF can be used to holistically describe functioning and contextual factors of a population and how a technical application can be developed and used by stroke survivors to increase exercise and physical activity. Our results show that stroke survivors are highly capable of using ActivABLES in community rehabilitation. Future research should focus on further studies in larger samples to prepare full development and marketing of ActivABLES. Thereby, it is important to focus on heterogeneity among older stroke survivors and the fact that they need person-centred rehabilitation but not “one fit for all”.

Keywords: disability evaluation, stroke rehabilitation, technology, exercise therapy, aging

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"It takes a village to raise a child" and I was fortunate to have a group of people participating and supporting me on my PhD journey.

I wish to express my deepest graditude to my two main supervisors, Sólveig and Þóra, who had infinite enthusiasm and gave me invaluable support and guidance throughout this whole process. I would especially like to thank Helga, Ingibjörg and Rose, the members of my committee for their unity, support and approachability whenever I needed their knowledge and opinion.

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Last but not least I say “takk” to my Eyjólfur who has had endless faith in me and encouragement to give – and thanks to our three grown-up sons for being there. Hopefully, one day, they will realize that it only takes intention and courage to do whatever the mind is made up to, regardless of age.

Contents

List of abbreviations

5xSST = Five Times Sit to Stand Test

ABC = Activities-specific Balance Confidence Scale

ADLs = Activities of Daily Living

BBS = Berg Balance Scale

BBT = Box and Block Test

BREQ-2 = Behavioural Regulation Exercise Questionnaire-2

CERISE = Collaborative Evaluation in Rehabilitation of Stroke across Europe

IADL = Instrumental Activities of Daily Living

ICF = International Classification of Functioning, Disability and Health

MRC = Medical Research Council

RHA = The University of Akureyri Research Center

SIS = Stroke Impact Scale

SS = Stroke Survivor

SDT = Self-Determination Theory

TUG = Timed Up and Go

VR = Virtual Reality

WHO = World Health Organization

List of figures

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List of original papers

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I-III):

I. Olafsdottir, S.A., Hjaltadottir, I., Galvin, R., Hafsteinsdottir, T.B., Jonsdottir, H. and Arnadottir, S.A. Age differences in functioning and contextual factors in community-dwelling stroke survivors: A national cross-sectional survey. Submitted for publication.

II. Olafsdottir, S.A., Jonsdottir, H., Magnusson, C., Caltenco, H., Kytö, M., Maye, L., McGookin, D., Bjartmarz, I., Arnadottir, S.A., Hjaltadottir, I. and Hafsteinsdottir, T.B. (2020). Developing ActivABLES for community-dwelling stroke survivors using the Medical Research Council framework for complex interventions. *BMC Health Services Research, 20*(1), 463. https://doi.org/10.1186/s12913-020-05198-2

III. Olafsdottir, S.A., Jonsdottir, H., Bjartmarz, I., Magnusson, C., Caltenco, H., Kytö, M., Maye, L., McGookin, D., Arnadottir, S.A., Hjaltadottir, I. and Hafsteinsdottir, T.B. (2020). Feasibility of ActivABLES to promote home-based exercise and physical activity of community-dwelling stroke survivors with support from caregivers: A mixed methods study. *Health Services Research, 20*(1), 1-17. https://doi.org/10.1186/s12913-020-05432-x

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Declaration of contribution

Along with writing this thesis, I have been involved in all parts of the research presented. ActivABLES was an inspiration for me to go on this PhD-journey, along with my experience and interest in home-physiotherapy and health promotion among older people. Prior to my enrolment Thóra B. Hafsteinsdóttir, Helga Jónsdóttir and Ingibjörg Hjaltadóttir had secured funding to conduct the ActivABLES project in collaboration with partners in Sweden and Finland. At this stage the project had started and some basic data had been collected. While the development of the ActivABLES prototypes mainly took place in Sweden and Finland, the preliminary testing and feasibility study took place in Iceland. My work on ActivABLES was mainly supervised by Thóra B. Hafsteinsdottir, along with Helga Jonsdottir. I organized the preliminary testing and the feasibility study, including choosing and performing the measurements used, as well as supervising the four-week use of the prototypes. I also organized and analysed all data and, together with the supervisors, interpreted the results. I wrote two manuscripts in ActivABLES and revised them based on the co-authors´ feedback and answered the reviewers´ comments. Later, in collaboration with my PhD committee, we decided to conduct the survey to gain vital information on the future users of ActivABLES in Iceland.

Work on the survey was mainly supervised by Solveig A. Arnadottir, along with Ingibjorg Hjaltadottir. As a preparation for the survey, I contributed to ethics and collaborations applications. I was the main researcher for the selection of the survey variables and analysis of the results with support from statisticians. I wrote the manuscript of the paper, revised based on the co-authors´ feedback and answered the reviewers´ comments.

1 Introduction

1.1 Stroke

The human brain (Figure 1) is a magnificent organ that makes people physically and intellectually active. This spongy organ gets its nutrition through flow of blood like any other organ of the body. A stroke occurs when this blood flow is disrupted, either by an occlusion in the arteries or a rupture of an artery and a bleeding into the brain tissue (Sacco et al., 2013). Stroke is one of the main reasons for chronic disability and death in the Western world (Feigin et al., 2014).

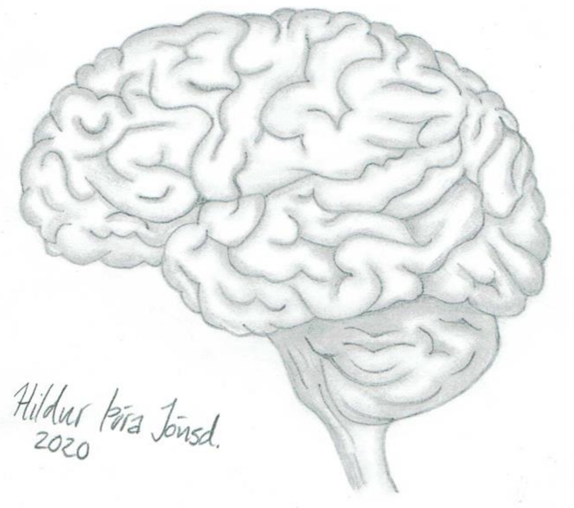

Figure 1. Drawing of the human brain.

A stroke causes impairments in the brain function and can lead to permanent damage of the brain tissue. A stroke is a very heterogenous condition, and the stroke impact on the health and functioning of an individual depends on the size and location of the impairment and/or damage in the brain (Warlow et al., 2003). Stroke survivors often report an increase in disability and lowered quality of life after a stroke (Robinson & Jorge, 2016; Ayerbe et al., 2013; Hackett & Pickles 2014). They are confronted with a broad range of disabilities which may include paralysis of one side of the body, eating and swallowing difficulties, depression and cognition or communication problems. Recovery from a stroke is very individual but is usually more rapid in the acute stage of the disease than in the chronic phase (Miller et al., 2010). Individuals who survive from a first stroke have an increased risk for a recurrent stroke over the general population (Mohan et al., 2011).

According to the Global Burden of Disease 2010 study, the global incidence of stroke was estimated 258/100,000 per year with significantly lower incidence in high-income countries, or 217/100,000 (Béjot et al., 2016). The incidence of stroke is expected to rise in the coming years, due to higher age of the population as well as from lifestyle behaviour. The number of individuals surviving a stroke is also expected to rise due to better medical treatment and less severe strokes (Wafa et al., 2020). Still, in Iceland, the incidence of stroke was 144 per 100,000 inhabitants in 2008 (Hilmarsson et al., 2013) which is considerably lower than the international numbers. No study has been conducted on community-dwelling individuals in Iceland who have had a stroke and there is a lack of knowledge on their functioning and disability.

1.2 Community-dwelling stroke survivors and the International Classification of Functioning, Disability and Health

The majority of stroke survivors are discharged to their homes after hospitalization and/or inpatient rehabilitation (Mathisen et al., 2017), with different levels of disability. Chronic disability after stroke affects individuals in many different ways. Some stroke survivors have none or minor disability and are independent in activities of daily living (ADLs), whereas others have severe disability and are dependent on others with ADLs for the rest of their life (Miller et al., 2010). Stroke is associated with a wide range of individual disability and is considered to be the most common cause of complex impairments in functioning (Adamson et al., 2004). Functioning and disability of an individual are results of the interaction between the health condition of the person and their environment. Thus, daily functioning of stroke survivors is reflected by the interplay between their health condition and contextual factors. The International Classification of Functioning, Disability and Health (ICF) is a biopsychosocial framework published by the World Health Organization (WHO, 2002) which addresses functioning and chronic disability in a holistic way and can thus be used to describe the health and health-related state of individuals as well as a population. The ICF framework covers all major dimensions of functioning and disability including body functions and structures, activities and participation as well as contextual factors of environmental and personal factors. By using the ICF framework, impairments in body functions and structures along with limitations in activities and restrictions in participation are identified.

To facilitate a systematic and comprehensive description of functioning and disability for different health conditions, ICF Core Sets have been developed (Bickenbach et al., 2012). The ICF Core Set for stroke includes 130 categories (Figure 2); 46 for *body structure* (s) and *body function* (b), 51 for *activities and participation* (d) and 33 for *environmental factors* (e) (Geyh et al., 2004).

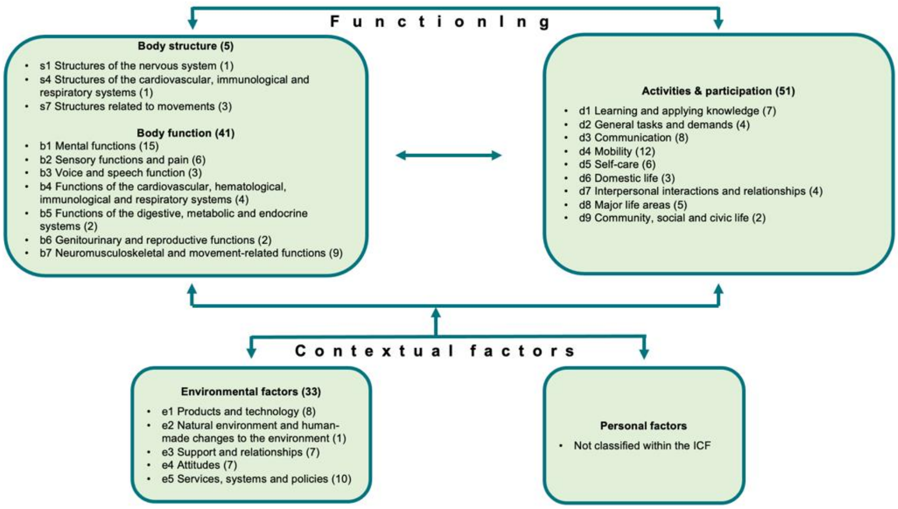

Figure 2. Components and chapters of the Core Set for stroke presented using the ICF framework.

The letters *b, s, d* and *e* represent the different components and the numbers within the brackets show the number of categories within each ICF component.

1.2.1 Contextual factors of community-dwelling stroke survivors

Contextual factors of the ICF framework include personal and environmental factors which represent the complete background of an individual´s life and living (WHO, 2001). These factors may affect functioning of an individual either in a positive way as facilitators or in a negative way as barriers.

1.2.1.1 Personal factors

Personal factors represent factors that can influence functioning and how disability is experienced by the individual (WHO, 2001). These factors are not represented in ICF and have not been classified and coded, mainly because of large societal and cultural variance and lack of clarity in the scope of these factors (WHO, 2013). In this thesis, examples of personal factors include age and experience of falls.

Older age can be described as a personal factor that affects functioning as a barrier. Age-related changes in physical, cognitive, personal and psychosocial function affect the health and functioning of each individual and people often experience more barriers as they grow older (Feldman et al., 2019). Consequently, older stroke survivors may be more challenged than younger ones with stroke-related impairments in addition to age-related disability. Approximately 75% of people who suffer from stroke are older than 65 years, although the incidence among younger people has been increasing (Roger et al., 2012; George et al., 2017). In the Western world, 65 years of age is often defined as *old age* and many researches use 65 years as a cut-off point for old age. According to gerontological research, the population of individuals older than 65 years old is very heterogenetic, with different functioning and social roles (Hooyman & Kiyak, 2014a; Hooyman & Kiyak, 2014b). Based on increased life expectancy, functional independence and more employment among older people, there has been a call for changing the definition of old age to 75 years of age (Orimo et al., 2006; Ouchi et al., 2017; Pilipiec et al., 2020). Research on stroke survivors may benefit from exploring how the cut-off point of 75 years fits the population of older stroke survivors who are healthy enough to be community-dwelling.

Experiencing a fall is a personal factor which can influence functioning and disability. Falls can induce fear of falling and can cause injuries both of which can act as a barrier to functioning. Falls are frequent among individuals within the first year after stroke. In a cohort study among community-dwelling stroke survivors in Ireland (mean age 68.5±13.5 years), the falls incidence was 44.5% (95% CI 35.1–53.6) and 25.6% of them had recurrent falls (95% CI 18.5–34.4) (Walsh et al., 2018). In two Swedish studies, 33% of stroke survivors experienced a fall (mean age 64 ±14) within one year after stroke (Minet et al., 2015) and 40% of stroke survivors (mean age 75.6 years ±11.1) fell within the first year after stroke (Samuelsson et al.,, 2019). The personal factor of balance self-efficacy among stroke survivors (mean age 64 years ±8.8) had significant impact on activities and participation more than six months after a stroke (Schmid et al., 2012). Balance self-efficacy was correlated with balance and stroke survivors with impaired balance who were at risk of falling had more impairments in activity and participation.

1.2.1.2 Environmental factors

Environmental factors cover the physical, social and attitudinal environment (WHO, 2001) and are important for community-dwelling stroke survivors as they may facilitate or hinder functioning. Because these factors are often modifiable, it is important to reveal them to maximize functioning and improve the quality of life of community-dwelling stroke survivors. Examples of environmental factors that are emphasized in this thesis are health services in the community and access to smart devices.

Health services for stroke survivors after discharge from rehabilitation seem to vary. The CERISE study (Collaborative Evaluation in Rehabilitation of Stroke across Europe) compared stroke care practices and their outcomes among European centres in the United Kingdom, Switzerland, Germany and Belgium (Schupp et al., 2012). The study showed that was the most used follow-up service after inpatient rehabilitation at 2, 4 and 6 months in all four countries, besides medical care from general practitioners. The authors concluded that services provided in the community need to be better documented to facilitate a more precise comparison of the effectiveness of rehabilitation programmes and follow-up services. In a study conducted in Sweden, 35% of stroke survivors were receiving outpatient rehabilitation one year after stroke (Törnbom et al., 2017).

Simple technical applications in rehabilitation based on use of smart devices is a growing field. Therefore, access to a smart device can give stroke survivors opportunities to participate in technical rehabilitation interventions. In a study conducted among community-dwelling stroke survivors in Canada (mean age 67.6 ±11.0), 64.2% of participants owned a computer, 43.2% a cell phone, and 33% a tablet. However, of Canadian stroke survivors of the “baby-boomer” generation (born 1946-1964), 84% reported having a cell phone or a tablet (Bird et al., 2018).

1.2.2 Functioning of community-dwelling stroke survivors

According to the ICF framework, functioning includes body structure, body function, activities and participation (WHO, 2001). High functioning is an interplay with contextual facilitators and/or a good health condition while impaired functioning is an interplay with contextual barriers and/or a bad health condition.

1.2.2.1 Body structure

Body structure represents anatomical parts of the body. Body structures related to movements, the nervous system and the cardiovascular, immunological and respiratory systems are referred to in the Core Set for stroke (Geyh et al., 2004) (Figure 2). Stroke is caused by an impairment in a body structure, namely the arteries in the brain, but since the aetiology of stroke is not a part of this thesis, these categories will not be introduced further.

1.2.2.2 Body function

Body function is the physiological aspect of the body systems. Impairments in body function after stroke depend on the location and size of the area affected in the brain (Warlow et al., 2003). Many stroke survivors have some motor impairments such as hemiparesis, spasticity and impaired coordination as well as some cognitive and psychological impairments. Balance impairments are common in the acute phase of stroke and more that 80% of those who had strokes had balance impairments when admitted to a hospital (Tyson et al., 2006). In the chronic phase of stroke, fatigue is a widespread problem among stroke survivors and estimated prevalence is 43%-57% (Cumming et al., 2016). Depression is also common in the chronic phase and about one-third of stroke survivors are confronted with depression (Hackett & Pickles, 2014). These factors influence the patient’s well-being and recovery and affect motivation for exercise and physical activity.

Motivation is a body function which can influence functioning of stroke survivors, including participation in physical rehabilitation (Maclean et al., 2000). Stroke survivors with high motivation are more likely to engage in therapeutic exercise and physical activity than those with low motivation. However, studies have shown that stroke survivors often have little motivation and confidence in continuing with therapeutic exercise on their own (Krishnan et al., 2017; Nicholson et al., 2013).

1.2.2.3 Activities and participation

In the ICF framework, activities include actions and tasks executed by individuals and participation includes involvement in life situations and always involves execution of an action or task (WHO, 2002). Therefore, WHO presents activities and participation as a fully overlapping list. In addition to body function, both personal and environmental factors can influence activities and participation and can present barriers as well as facilitators (Hoyle et al., 2012).

Stroke can have considerable impact on how people can maintain their activities and participation after a stroke. Stroke survivors with minimal impairment have reported on average a 20% decrease in activity and participation after their stroke, both in the quantity and nature of activity and participation (Wolf et al., 2012). However, in the same study, there was not a difference in changes in activities and participation between young (under 65 years old) and old stroke survivors (older than 65 years). In another study of stroke survivors, where the mean age was 57 years, almost half of the stroke survivors experienced participation impairments in physical exercise, household tasks and outdoor activities (Van Der Zee et al., 2013). Greater physical and cognitive independence were both significant predictors for all types of participation and a longer time since stroke was related to more impairments in participation.

1.3 Physical rehabilitation for community-dwelling stroke survivors

Physical activity is important for everybody´s health, and even more important for stroke survivors (Langhorne et al., 2011; Pollock et al., 2014). Physical activity has been defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” (Caspersen et al., 1985). However, exercise has been defined as “physical activity that is planned, structured, repetitive and purposive” (Caspersen et al., 1985) and can be “a physical activity program that involves the client undertaking voluntary muscle contraction and/or body movement with the aim of relieving symptoms or improving function, or improving, retaining or slowing deterioration of health” (Taylor et al., 2007).

No clear definition has been found for the term *physical rehabilitation*, but a Cochrane review stated that “physical rehabilitation, using a mix of components from different approaches, is effective for recovery of function and mobility after stroke” (Pollock et al., 2014). Therapeutic exercises and daily physical activity can be defined as physical rehabilitation, which should be a lifelong process for stroke survivors (Teasell et al.,, 2014). However, the prevalence of stroke survivors continuing outpatient rehabilitation is low (Go et al., 2014). Studies have shown that 30-60 minutes training per day, five to seven days per week, is effective to improve functional recovery after stroke (Pollock et al., 2014). Therefore, guidelines recommend that stroke survivors exercise their balance and do some strength and functional exercise one to three times per week (Grimby et al., 2010). In addition, they should walk or do some aerobic activities for 10–60 minutes two to five times per week, throughout life.

The importance of physical activity and physical rehabilitation emerges where patients and members of the public have been engaged to identify health research priorities (MacFarlane et al., 2017). The James Lind Alliance Priority Setting Partnership (2020) including stroke survivors, caregivers and healthcare professionals identified that treatments to improve balance, gait and mobility, including physiotherapy and gait rehabilitation post-stroke, were among the top ten research priorities for stroke (2020).

1.3.1 Physical activity and sedentary behaviour

It is a well-known fact that physical activity is important for cardiovascular health and the general negative effects of sedentary behaviour on the human body are constantly appearing in research (English et al., 2014; Fini et al., 2017). It is not only about the total time spent in a sitting position, but also the long continuum of sedentary behaviour which is most detrimental to health (English et al., 2014). Factors related to physical inactivity and sedentary behaviour are among the main risk factors of a first and a recurrent stroke (Go et al., 2014). For stroke survivors, like healthy individuals, there is also an increased risk of other non-communicable diseases caused by physical inactivity (Ding et al., 2016) and sedentary behaviour (Dempsey et al., 2020).

According to a systematic review on physical activity after stroke, stroke survivors do not meet general guidelines for physical activity and their physical activity levels are lower than age-matched individuals who have not had strokes (Fini et al., 2017). Stroke survivors are sedentary during the majority of the day, regardless of the time since stroke. Physical ability, however, only accounts for 6.8% of the variance in total sitting time, which indicates that there are loads of other factors that influence the physical inactivity and sedentary behaviour of the stroke survivors (English et al., 2016).

1.3.2 Therapeutic exercises

Physical rehabilitation after stroke aims to aid recovery from motor as well as cognitive and psychological impairments. During recovery, neurological reorganisations take place in the brain which affect both physiological and psychological aspects of the individual. Neuroplasticity in the motor control areas of the brain is more likely to be caused by the effects of the therapeutic exercises than spontaneous recovery of the brain (Schaechter, 2004). Studies focusing on neurophysiological changes of the brain show that a considerable amount of therapeutic exercise is needed to induce neuroplastic change and functional recovery of motor deficits resulting from stroke. In their extensive review of research on activity-dependent neural plasticity, Kleim and Jones (2008) suggested ten principles that might impact rehabilitation of the neural system (Table 1). Shumway-Cook & Wollacott (2017) discussed these principles in their book on motor control and emphasized the importance of training new and old tasks repeatedly, with sufficient intensity and variation at appropriate times.

Table 1. Principles of exercise impacting neuroplasticity: Implications for rehabilitation after brain damage.

Principle	Description
1. Use it or lose it	Failure to drive specific brain functions can lead to functional degradation.
2. Use it and improve it	Training that drives a specific brain function can lead to an enhancement of that function.
3. Specificity	The nature of the training experience dictates the nature of the plasticity.
4. Repetition	Induction of plasticity requires sufficient repetition.
5. Intensity	Induction of plasticity requires sufficient training intensity.
6. Time	Different forms of plasticity occur at different times post-stroke during training.
7. Salience	The training experience must be sufficiently salient to induce plasticity.
8. Age	Training-induced plasticity occurs more readily in younger brains.
9. Transference	Training-induced plasticity can enhance the acquisition of similar behaviours.
10. Interference	Training-induced plasticity can interfere with the acquisition of other behaviours.

Table adapted and published with permission from Dr. J.A. Kleim in November 2020.

Several reviews have been conducted investigating physical rehabilitation approaches and their effectiveness in recovery in stroke survivors. Physical rehabilitation has been shown to have beneficial effects on functional recovery after stroke, but no approach has proved to be any more effective than any other in promoting functioning of stroke survivors (Pollock et al., 2014). Therapeutic exercises can improve functioning of stroke survivors in all phases post-stroke and strong evidence has been found for interventions favouring intensive high repetitive task-oriented and task-specific training in all phases after stroke (Veerbeek et al., 2014; Thomas et al., 2017; Teasell et al., 2020). Cardiorespiratory training and mixed training reduce disability during or after usual stroke care by improving mobility and balance (Saunders et al., 2013). Various clinical practice guidelines (Lindsay et al., 2014; Hebert et al., 2016; Winstein et al., 2016) and systematic reviews (Langhorne et al., 2011; Pollock et al., 2014; Veerbeek et al., 2014; Mathiowetz et al., 1985; Rensink et al., 2009) summarize the evidence of positive effects of therapeutic exercise on the various outcomes of patients with stroke. According to the Canadian Stroke Best Practice Recommendations (Teasell et al., 2020), stroke survivors with mild to moderate disability who are discharged early from an acute hospital unit can be rehabilitated in the community by an interdisciplinary stroke rehabilitation team and attain similar or superior functional outcomes when compared to stroke survivors receiving inpatient rehabilitation. In the same guidelines, it is concluded that home-based therapeutic exercise and physical activity mediated by a family member or a friend (hereafter referred to as caregivers) can improve functioning of stroke survivors.

Despite this knowledge on the importance of therapeutic exercise, community-dwelling stroke survivors only receive a limited amount of outpatient therapeutic exercise after inpatient rehabilitation (Teasell et al., 2009). Still, studies have shown that is the most frequently used follow-up health service after inpatient rehabilitation, aside from medical care provided by the general practitioner (Schupp et al., 2012). services, however, may only be available for a limited amount of time per week, which does not fulfil stroke survivors' daily need for therapeutic exercise. Therefore, ways to encourage this population to engage in therapeutic exercise are highly needed.

1.3.3 Motivation for therapeutic exercise and daily physical activity and caregivers´ support

As mentioned above, stroke survivors are highly physically inactive and engage in sedentary behaviour. Lack of motivation has been described as a barrier for stroke survivors to engage in therapeutic exercise and daily physical activity (Nicholson et al., 2013; Miller et al., 2017). Depression, which is common after stroke, negatively influences stroke survivors´ recovery as they are less motivated to take part in rehabilitation (Hackett & Pickles, 2014).

A systematic review synthesized the evidence from six studies, exploring perceived barriers and motivators to therapeutic exercise and physical activity after stroke (Nicholson et al., 2013). Lack of motivation was a barrier to exercise and physical activity as well as environmental factors and health concerns. Lack of motivation and understanding on how to incorporate daily activities into an exercise plan have been reported as reasons for the limited unsupervised exercise adherence of stroke survivors (Miller et al., 2017). Social and emotional support from family members, patient-therapist relationship, goal-setting and music are important factors that can influence stroke survivors´ level of motivation. Factors having negative impacts on their motivation are lack of social support from family members and friends, cost of rehabilitation, difficulty in travelling to a rehabilitation centre and lack of a caregiver who can look after them (Pyae et al., 2014). A qualitative study including stroke survivors showed that personal and environmental factors influence the motivation for exercise after stroke (Poltawski et al., 2015). The findings suggested that enjoyment and psychological benefits may be more effective as motivators than the prospect of increased fitness or functional benefits, especially for those with poor motivation for exercise. Looking at therapeutic exercise as a healthy leisure activity rather than form of treatment may be more appealing to long-term stroke survivors and even though exercising in a group can be motivating, some stroke survivors prefer to exercise alone (Poltawski et al., 2015). An in-depth understanding of these potential motivating and hindering factors is essential for rehabilitation professionals when designing appropriate therapeutic exercise and daily physical activity options and applications for stroke survivors.

Caregiver mediated home-based therapeutic exercise can give good functional results (Vloothuis et al., 2016; Lee et al., 2018) and using telerehabilitation can have a positive impact on anxiety and depression of both the stroke survivor and the caregiver (Vloothuis et al., 2019). In addition, caregivers are willing to be more involved in the rehabilitation process at home if they get information on how they can support and motivate their stroke survivor to exercise and be more physically active (Hjelle et al., 2017; Mackenzie & Greenwood, 2012; Galvin et al., 2009). Still, the caregivers often lack resources and need more professional support and/or supervision to feel secure with the support they provide their family member after stroke (Lutz & Camicia, 2016; Hafsteinsdóttir et al., 2011). Therefore, it is highly important to come up with resources for caregivers to support stroke survivors to be physically active and participate in home-based therapeutic exercises.

1.4 Innovations and new technology in stroke rehabilitation

The ways stroke survivors engage in physical rehabilitation is of central importance for their participation in therapeutic exercise and daily physical activity. Different approaches to motivate stroke survivors to engage in therapeutic exercise and physical activity throughout their lives are called for. There are indications that use of technology to facilitate therapeutic exercise and physical activity can motivate stroke survivors to engage in physical rehabilitation (Mirza-Babaei et al., 2014). Technical applications can offer repetitive and challenging therapeutic exercise which are necessary for brain plasticity and motor learning (Shumway-Cook & Woollacott, 2017; Kleim &

Jones, 2008) as presented in Table 1. Use of technical interventions have shown positive results for stroke survivors, including functional improvements (Laver et al., 2015; Cheok et al., 2015). Community-dwelling stroke survivors using technical applications at home have shown good adherence to physical activity and therapeutic exercise (Held et al., 2018; Bower et al., 2015; Putrino et al., 2017).

1.4.1 Technical applications for therapeutic exercise and daily physical activity

Technical applications that can be used for therapeutic exercise and physical activity are increasingly being developed targeting different groups, including stroke survivors. Many rehabilitation professionals have also been pushed into trying out some new methods during the COVID-19 pandemic (Koh & Hoenig, 2020; Sheth et al., 2020). In studies, the definition of technical applications in rehabilitation is very broad and interventions can include virtual reality, computer games, E-health, telerehabilitation, robots, wearable devices and smart devices. In a recent Cochrane review, telerehabilitation is used as an umbrella term for “alternative method of providing rehabilitation” (Laver et al., 2020). Technical applications have positive effects on functioning and seem to have similar effects as conventional treatments (Laver et al., 2020; Rintala et al., 2019). Results have indicated similar effects on functioning, including ADLs, upper and lower extremities, balance, physical activity and participation, when using technology in distance rehabilitation compared to conventional treatments where technical applications are not used (Rintala et al., 2019). It is important to continue to develop technical applications that can be used to encourage therapeutic exercise and physical activity and may affect quality of life in a positive way.

Virtual reality (VR) therapy has been defined as “technological interventions that alter properties of the physical world” and moderate evidence indicates positive effects of VR therapy on functioning of stroke survivors (Lohse et al., 2014). VR interventions were effective across domains of the ICF especially in the categories of body function and activity. In a Cochrane review, the use of VR and interactive video gaming were found to be beneficial in improving upper limb function and ADL function of stroke survivors when used additionally to conventional treatments (Laver et al., 2017). It was, however, unclear which characteristics of VR were the most important or how long the effects lasted. Systematic reviews have supported the theory that technical applications and use of telerehabilitation are effective to improve functioning and have similar or better effects than conventional treatments (Sarfo et al., 2018; Laver et al., 2020). However, when technical applications are added to traditional interventions, the improvements were more due to the increased time spent in doing therapeutic exercises, along with more repetitions (Laver et al., 2017).

1.4.2 Motivation and use of technical interventions

Motivation for physical activity and exercise is an important factor for stroke survivors to take part in therapeutic exercise and the key to success of an intervention is to motivate stroke survivors for continuous engagement and accessible interfaces (Mirza-Babaei et al., 2014; Kyoungwon et al., 2014). When designing a technical application for therapeutic exercise and daily physical activity, it is crucial to keep in mind *engagement* which includes external and internal motivational factors, and *environment* which includes social context and practical challenges (Chen et al., 2019). When users are engaged in therapeutic exercise and physical activity, they are more likely to benefit and improve functioning. At the same time, it is important that the environment is supportive and without technical barriers.

Many studies have been conducted on how games through technical applications can motivate stroke survivors in performing home-based therapeutic exercise (Kyoungwon et al., 2014; Mirza-Babaei et al., 2014; Lohse et al., 2014). Motivational feedback seems to be the most important factor of the technical applications to promote therapeutic exercise (Mawson et al., 2016). Playing games through technical applications can motivate stroke survivors in participating in home-based therapeutic exercise (Laver et al., 2015; Seo et al., 2014; Alankus et al., 2010) and have been shown to be effective in improving balance and independence of stroke survivors (Saywell et al., 2017). A systematic review showed that it is important to combine mental support, motivation and accessible interfaces when games are used in order to have a positive impact on participation in therapeutic exercise and physical activity (Mirza-Babaei et al., 2014).

A summary of design efforts in human-computer interaction and games research emphasized accessibility, motivation and enjoyment to support physical rehabilitation (Mirza-Babaei et al., 2014). The main results showed that games and similar technologies have potential to provide significant external motivation for stroke survivors. Games may help motivate stroke survivors to perform therapeutic exercise and playing games at home can empower stroke survivors to take ownership of their therapy since they can play games and exercise at any time on their own terms.

1.4.3 Medical Research Council framework

Most of the innovations and interventions used in healthcare nowadays are complex, meaning there are a number of interactive components which produce a range of different outcomes when applied to the intended target population (Richards & Hallberg, 2015). When developing innovative interventions to use in healthcare, including for the rehabilitation of community-dwelling stroke survivors, it is important to follow a thorough guidance or a framework that can help researchers to evaluate the interventions and identify practical and methodological difficulties during the process of developing. The Medical Research Council (MRC) framework is useful for developing complex interventions in healthcare (Craig et al., 2008).

The MRC framework consists of four key phases (Craig et al., 2008): (1) *development* which includes identification of the evidence base, development or identification of a theory and modelling of the process and outcomes, (2) *feasibility and piloting* which include testing procedures, estimation of recruitment and retention and determination of a sample size, (3) *evaluation* which includes assessing effectiveness and understanding change process, and (4) *implementation* which includes dissemination and long term follow-up. Further detailed extension on the development phase was provided by Bleijenberg and colleagues (2018). They identified four elements in the development phase: (1) problem identification and definition, (2) determination of recipients & providers' needs, (3) examination of current practice and context, and (4) intervention design. The key phases of the MRC framework are not necessarily linear or circular and each phase should be repeated until the researchers are satisfied with the intervention (Craig et al., 2008). In this way, researchers are requested to continually evaluate their work and process.

1.5 Novelty and importance of this thesis

In this thesis two different subjects are explored that relate to the heterogenous group of community-dwelling stroke survivors: (1) daily functioning and contextual factors, and (2) development and feasibility of an interactive technical application called ActivABLES to increase home-based therapeutic exercise and daily physical activity of this population.

To come up with a successful new technical application, it is important to know the functioning of the end-users and how they are prepared for its use, concerning personal and environmental factors. In this thesis, therefore, a description of community-dwelling stroke survivors´ functioning and contextual factors is provided. The results decrease the knowledge gap on functioning and disability of community-dwelling stroke survivors and reveal information on stroke survivors in different age-groups. This description is a valuable contribution to the international literature and is well suited for replication. National surveys among community-dwelling stroke survivors that reflect on daily life and functioning are scarce, and our research is the first national research conducted in Iceland on this population. The ICF framework is used to describe stroke survivors´ functioning and contextual factors which is also a novel way to describe stroke survivors.

When developing ActivABLES, emphasis was put on addressing issues around neuroplasticity and reorganisation of the brain, underlining repetitions of new and old tasks, with sufficient intensity and variation at appropriate times. Stroke survivors and their caregivers were also consulted and their priorities around the exercise and physical activity were identified and used in the development. For technical applications to be successful, they need to address issues around neuroplasticity and reorganisation of the brain (Kleim & Jones, 2008) as well as meet the needs of the users .

The results of this thesis contribute knowledge on functioning and disability of community-dwelling stroke survivors and thereby can positively impact individually-tailored rehabilitation services in the future. Although this thesis is based on Icelandic reality, the use of the ICF framework, the MRC framework and internationally recognized standardized measures adds to the global knowledge base on community-dwelling stroke survivors. These methods also facilitate wider interpretation and make the results highly comparable with international studies.

2 Aims and research questions

This thesis is based on two research projects which both concern the same population of community-dwelling stroke survivors. The projects have separated yet interrelated aims. The aim of the former project was to explore the health and health-related state of this population. This was conducted by mapping of functioning and contextual factors using ICF, including the potential to use a technical application to motivate home-based therapeutic exercise and daily physical activity. In the other project, the aim was to develop ActivABLES, which is an interactive technical application to motivate community-dwelling stroke survivors for home-based therapeutic exercise and daily physical activity. In this thesis the process of developing ActivABLES is described including preliminary testing and feasibility of ActivABLES.

2.1 Specific aims

The aims of the individual studies were:

1. To use ICF to map functioning and contextual factors of community-dwelling stroke survivors 1-2 years after their first stroke and explore whether functioning and contextual factors of this population differ between older-old (75 years and older), younger-old (65-74 years), and young stroke survivors (18-65 years).
2. To describe the process of developing a technical application, ActivABLES, which aims to increase home-based therapeutic exercise and daily physical activity for community-dwelling stroke survivors, with support from their caregivers.
3. To investigate the feasibility of ActivABLES in terms of acceptability, demand, implementation and practicality.

2.2 Research questions

The research questions were:

Paper I

- How are the health, functioning and contextual factors of stroke survivors residing at home in Iceland, 1-2 years after first stroke?
- Is 65 years the optimal cut-off age to assess functioning and contextual factors of community-dwelling stroke survivors?

Paper II

- How can a technical application, aiming to increase home-based therapeutic exercise and physical activity for community-dwelling stroke survivors, be developed with the involvement of future users?

Paper III

- Is ActivABLES feasible for community-dwelling stroke survivors to use for home-based therapeutic exercise and daily physical activity, with support from their caregivers?

3 Materials and methods

The two research projects described in this thesis had different research designs and separate collections of standardized measures (self-reported and performance-based). All standardized measures and other variables were linked to ICF. In the following subchapters, first the research designs and mutual elements of the two projects will be described, followed by detailed descriptions of each individual study of both research projects.

3.1 Design of research projects and use of standardized measures

A cross-sectional design was used for a national survey to describe the health condition, functioning and contextual factors of community-dwelling stroke survivors 1-2 years after first stroke. The international language of the ICF framework was used to describe body function, activities and participation along with personal and environmental factors. In this context, personal and environmental factors were described first, since they reflect the main characteristics and demography of each individual. This study is described in detail in Paper I.

For the process of developing ActivABLES, the two first phases in the MRC framework for complex interventions were used. These phases include (1) the development of ActivABLES, which is described in details in Paper II; and (2) the feasibility of ActivABLES, which was tested in a mixed methods design and is described in detail in Paper III.

Where applicable, the same standardized measures were used in both research projects. The summary of the standardized measures used in this thesis is presented in Table 2. Detailed descriptions of each measure are found in the chapters where the methods of the survey and ActivABLES are presented.

Table 2. Standardized measures used in the thesis and presentation in papers.

	Survey (Paper I)	Preliminary testing (Paper II)	Feasibility testing (Paper III)
Questionnaires:			
SIS	X	X[a]	X[a]
BREQ-2	X		X
ABC		X	X
Functional measures:			
BBS		X	X
BBT		X	X
TUG			X
5xSST			X

SIS=Stroke Impact Scale, BREQ-2=Behavioural Regulation Exercise Questionnaire 2, BBS= Berg Balance Scale, BBT=Box and Block Test, TUG=Timed-Up-and-Go, ABC=Activities-specific Balance Confidence Scale, 5xSST=Five times Sit to Stand
[a]not presented in the papers

3.2 Linking of research variables to ICF using the Linking Rules

The biopsychosocial model of ICF was used as a framework to map all the research variables in this thesis and to organize the complex elements potentially influencing functioning of community-dwelling stroke survivors. The ICF Linking Rules (Cieza et.al, 2002) were used for this mapping of the variables to the most appropriate ICF components of functioning and contextual environmental factors (Figure 3). Since the contextual personal factors have not been classified and coded, the Linking Rules can only be used indirectly to map the personal factors variables that can influence functioning but are not classified and coded elsewhere in ICF (Cieza et.al, 2002).

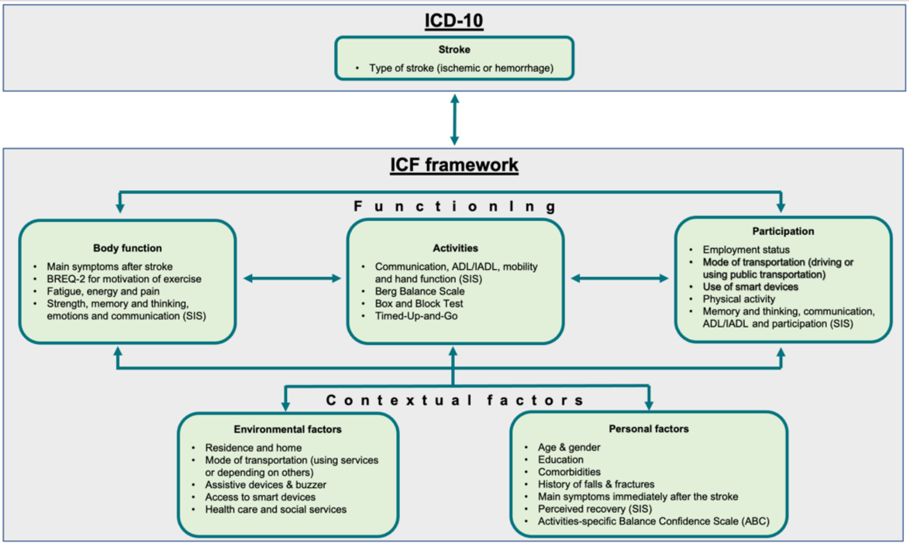

Figure 3. Linking of different research variables to the ICF framework.

BREQ-2=Behavioural Regulation Exercise Questionnaire 2, SIS=Stroke Impact Scale, ADL=Activities of Daily Living, IADL=Instrumental Activities of Daily Living, ABC=Activities-specific Balance Confidence Scale

The ICF Linking Rules were first published in 2002 (Cieza et.al, 2002) and have been updated (Cieza et.al, 2005) and refined (Cieza et.al, 2019). The aim of the rules is to provide a method to link health-related outcomes to the ICF´s universal codes and thus provide a common language for researchers and clinicals (Cieza et.al, 2002). The newest version includes ten rules (Cieza et.al, 2019) and covers the process of linking variables to different ICF categories and appropriate codes. In Table 3, two examples are given for the process of linking variables in this thesis, using these ten rules.

Table 3. Examples of the process of linking variables from the thesis to ICF.

		Examples of research variables	
	Execution of the linking rules[a]	**Do you have an access to a smart device?**	**Are you physically active or do you exercise on regular basis? If yes, how often in a week?**
1	The researchers acquired good knowledge of concepts and taxonomy of ICF		
2	The purpose of the main concept of each variable was identified	The purpose was to know if the individual had access to a smart device and thus a potential for telerehabilitation; the main concept identified was *smart device*	The purpose was to know if the individual was physically active or did exercise; the main concept identified was *physical activity*
3	If there were additional concepts of the variable, they were identified	N/A	Additional concpets were *regular basis*
4	The perspective of the variable was identified by deciding if it reflected: (a) performance or capacity of an individual, (b) appraisal or opinion of an individual (c) need or dependency of an individual	The perspective included the neccessity of having a smart device and reflected *need or dependency*	The perspective included the task of physical activity or exercise and reflected *performance*
5	The response option of the variable was identified as (a) intensity, (b) frequency, (c) duration, (d) confirmation or agreement, or (e) qualitative attribute	The response option were *yes* and *no* and identified as *confirmation or agreement*	The response option were *yes* and *no* and identified as *confirmation or agreement*. Additional response was identified as *frequency*
6	All meaningful concepts of the variable were linked to the most precise ICF catagory	e125 Products and technology for communication Inclusions: general and assistive products and technology for communication	d570 Looking after one's health Inclusions: ensuring one's physical comfort; managing diet and fitness; maintaining one's healt
7	If the concepts were not found within an ICF catagory, the „other specified“ or „unspecified“ categories were used	N/A	N/A
8	A variable should be assignes as *not definable* if the meaningful concept was not sufficiently coverend in an ICF category	N/A	N/A
9	I the meaningful concept of the variable was not found within an ICF category, but was clearly a personal factor, it was assigned to the personal component	N/A	N/A
10	A variable should be assigned as *not covered* if the meaningful concept of the variable was not found within an ICF category	N/A	N/A

[a] Based on the newest version of the linking rules (Cieza, Fayed et al. 2019)

Some variables were complicated to link and could potentially be linked in different ways or even addressed in more than one category. An example is the statement on mode of transportation; *I use public transportation.* If the main concept is defined as *use*, the outcome can be considered as *activities and participation* as defined in chapter d4 on *mobility: moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking, running or climbing, and by using various forms of transportation*. The code d470 is defined as: *Using transportation to move around as a passenger, such as being driven in a car, bus, rickshaw, jitney, pram or stroller, wheelchair, animal-powered vehicle, private or public taxi, train, tram, subway, boat or aircraft and using humans for transportation.* If the main concept is defined as *public transportation,* the outcome should be identified as an environmental factor and defined in chapter e5 on *services, systems and policies* with a code for *transportation services, systems and policies (e540).* With complicated variables like this one, the identifications of the main concepts are a key to decide on how the variable should be linked. The ICF online browser on the WHO-website (https://apps.who.int/classifications/icfbrowser/) and the Icelandic version of the browser (http://skafl.is/) was used to find an appropriate code and detailed description for each variable. This information is also available in the original ICF publication (WHO, 2001).

According to the Core Set for stroke (Geyk et al., 2004), the variables in this thesis cover all components of ICF except for *body structure*. Six of eight chapters of body function, all chapters of activities and participation and four of five chapters of environmental factors are covered in this thesis. In Table 4, all variables in this thesis are classified and coded with the ICF codes.

Table 4. ICF classification and codes of all research variables.

	Study item	Contextual factors: Personal factor	Contextual factors: Environmental factor	Functioning: Body function	Functioning: Activities and participation
Various background information	Age	X			
	Gender	X			
	Place of residency		e215		
	Residents in home		e398		
	Education level	X			
	Main symtoms immediately after the stroke	X			
	Current comorbidities	X			
	Fatigue & energy			b130, b455	
	Pain			b280	
	Change of housing after the stroke		e155		
	Access in home		e155		
	Motivation for exercise			b130	
	Balance self-efficacy	X			
Falls	Experience of falls in the last 12 months	X			
	Number of falls	X			
	Fractures from falls	X			
Emplyment /social status	Working full-time				d850
	Working part-time				d850
	Student				d820
	Volunteer				d855
	Old age pension		e570		
	Disability pension		e570		
Mode of transport	Drive a car				d475
	Use public transport / taxi				d470
	Transport service for disabled		e575		d470
	Depend on others for transport		e575		d470
Assistive devices	A cane or crutches		e120		
	A walker		e120		
	Regular wheelchair		e120		
	Electric wheelchair		e120		
	A scooter		e120		
	Other assistive devices		e115		
	Personal security buzzer		e115		
Smart devices	Access to a smart phone		e130		
	Access to a tablet		e130		
	Access to a laptop/computer		e130		
	Use a smart phone regularly				d360
	Use a tablet regularly				d360
	Use a laptop/computer regularly				d360
Physical activity	In a gym/sport center				d570
	Group-based in a PT-clinic or a day center				d570
	In a swimmingpool				d570
	Home-based exercises				d570

Table 4. (continued).

	Study item	Contextual factors: Personal factor	Contextual factors: Environmental factor	Functioning: Body function	Functioning: Activities and participation
Current services	Physical therapy		e580		
	Occupational therapy		e580		
	Speech therapy		e580		
	Ambulant nursing		e580		
	Home nursing		e580		
	Social domestic		e575		
	Day clinic /day care		e580		
	Fullfilled needs		e580		
Stroke Impact Scale	Strength			b730	
	Memory and thinking			b114, b140, b144, b160	d230
	Emotions			b152	
	Communication			b167	d350, d360
	Activities of daily living / Instrumental ADL			b525, b620	d510, d520, d530, d540, d550, d620, d640
	Mobility				d410, d415, d450, d455
	Hand function				d430, d440, d445
	Participation				d750, d760, d850, d855, d920
	Perceived recovery	X			
Function	Berg Balance Scale				d410, d415, d420
	Box and Block Test				d440
	Timed-Up-and-Go				d410, d450

3.3 Survey (Paper I)

The national study on community-dwelling stroke survivors had a cross-sectional design. Participants were individuals in Iceland who had a stroke 1-2 years earlier and the results describe functioning and contextual factors of stroke survivors who were living in their own homes.

3.3.1 Selection of participants and ethics

To approach all individuals who had a stroke within a one-year period, a collaboration was established with the two main hospitals in Iceland, Landspitali – The National University Hospital of Iceland and Akureyri Hospital, on accessing data from the hospitals´ registries. Potential participants were identified through the registries, which gave the opportunity to approach the whole population diagnosed with stroke in Iceland in one year. The inclusion criteria for participants were: admission to one of the two hospitals from April 1st 2016 to March 30th 2017, with the diagnosis of a stroke (ICD I60-I64) and being at least 18 years of age at the time of the diagnosis (Figure 4). Excluded were stroke survivors with prior stroke diagnosis, diagnosis of dementia (ICD F00-F03), without an Icelandic identification number or living outside of Iceland and stroke survivors living in nursing homes. Exclusion of the individuals living in nursing homes was based on register information from the Directorate of Health. The participants were divided into three age-groups; 75 years and older, 65-74 years and younger than 65 years.

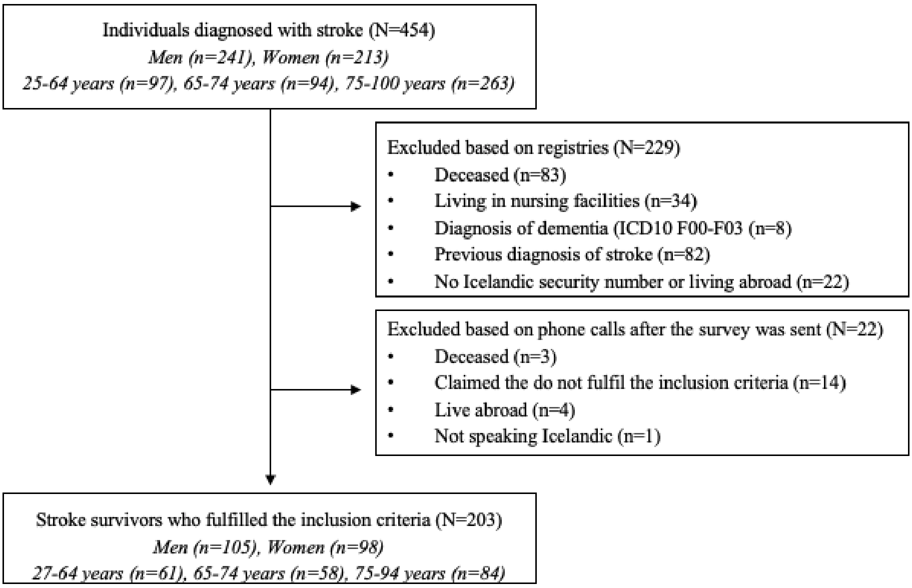

Figure 4. Flowchart of inclusion of participants.

The study was conducted according to the ethical principles of the Declaration of Helsinki (World Medical Association, 2016). Permissions were attained from the National Bioethics Committee (VSNb2017110024/03.01) and the Icelandic Data Protection Authority (20171111625HSÞ/). The information letter that was sent along with the survey, explained that voluntary participation in the survey would serve as an informed consent.

3.3.2 Survey variables

The survey was designed to collect responses from community-dwelling stroke survivors on their health, functioning and contextual factors. The literature on surveys among stroke survivors was reviewed to support selection of individual survey variables. Along with questions associated with demographics, physical activity and use of health and social services, we used two standardized measures; Stroke Impact Scale (SIS) (Duncan et.al,

1999) and Behavioural Regulation Exercise Questionnaire-2 (BREQ-2) (Markland & Tobin, 2004). In addition, a few questions were used from existing questionnaires including a question on history of falls from the Prevention of Falls and Injury Trial (Bruce et.al, 2017), questions on fatigue and energy from Fatigue Assessment Scale (Cumming & Mead, 2017) and Fatigue Severity Scale (Lerdal, 2014), and a question on pain from EuroQol-5D (Obradovic et.al, 2013). These measures were chosen to make the results more comparable with international studies.

The Stroke Impact Scale (SIS) is an ICF-based stroke-specific self-reported health status measure which includes questions about impairments caused by the stroke, how the stroke has affected quality of life and perceived recovery from the stroke (Duncan et.al, 1999). SIS consists of eight domains which each include a different number of items, with response options on a five-point Likert scale: (1) the *strength* domain has four items on the rate of strength in the affected extremities, rating from 5="A lot of strength" to 1="No strength at all"; (2) the *memory and thinking* domain has seven items rating from 5="Not difficult at all" to 1="Extremely difficult"; (3) the *emotion* domain has nine items rating from 5="None of the time" to 0="All of the time"; (4) the *communication* domain has seven items rating from 5="Not difficult at all" to 1="Extremely difficult"; (5) the *activities of daily living (ADL) and instrumental activities of daily living (IADL)* domain has ten items rating from 5="Not difficult at all" to 1="Extremely difficult"; (6) the *mobility* domain has nine items on mobility at home and in the community rating from 5="Not difficult at all" to 1="Could not do at all"; (7) the *hand function* domain has five items on hand function of the affected hand rating from 5="Not difficult at all" to 1="Could not do at all"; and (8) the *participation* domain has eight items rating from 5="None of the time" to 0="All of the time". Finally, SIS includes a single item on *perceived recovery* with the response option assessed on a scale of zero to 100%, where zero indicates *no recovery* and 100% *full recovery*. Duncan et al. (1999) used a formula to calculate a score for each of the domains. In the instructions for SIS, which is available on the Rehabilitation Measures Database (https://www.sralab.org/rehabilitation-measures/stroke-impact-scale), the following formula is suggested and was used to calculate the transformed score of each SIS-domain. The ratings in each domain were summed up to get the raw score. The raw score was then transformed to a scaled score according to a formula:

$$\text{Transformed score} = \frac{\text{Actual raw score - Lowest possible raw score}}{\text{Possible raw score range}} \times 100$$

The transformed score for each domain can range from zero to 100, where zero is *an inability to complete the items* and 100 means *no difficulties experienced at all*. Each domain includes a different number of questions (range 4-10) and if less than half of the questions had missing responses, the domain score was calculated as suggested by the author, but otherwise the domain was assigned as missing (Duncan et.al, 1999). The composite physical domain (CPD) was created by summing the score from the domains for strength, hand function, mobility and ADL/IADL. SIS has shown satisfactory validity (Doyle et.al, 2007; Duncan et.al, 2002), inter-rater/intra-rater reliability (Carod-Artal et.al, 2009), test-retest reliability (Duncan et.al, 1999; Edwards & O´Connell, 2003), and internal consistency (Duncan et.al, 1999) and has been tested for use as a mailed questionnaire (Richardson et.al, 2016). SIS has recently been translated into Icelandic using a translation/back-translation method (Behling & Law, 2000).

The Behavioural Regulation Exercise Questionnaire-2 (BREQ-2) was used to measure motivation for exercise (Markland, 2009). It includes 19 statements about engagement in exercise, scoring on a five-point Likert scale (0=”not true for me”, 4=”very true for me”). BREQ-2 is based on the self-determination theory (SDT), which is a popular framework to assess motivation in exercise psychology (Deci & Ryan, 2004). BREQ-2 has five subscales: (i) amotivation indicating lack of any intention to engage in exercise, (ii) external regulation where the individual engages in exercise only to satisfy external pressures or get externally imposed rewards, (iii) introjected regulation indicating self-imposed pressures to avoid guilt or maintain self-esteem, (iv) identified regulation where the individual accepts exercise as an important factor to achieve personally valued outcomes, and (v) intrinsic regulation where the individual is taking part in exercise for the enjoyment and satisfaction (Markland & Tobin, 2004). In line with SDT, *identified* and *intrinsic regulation* address self-determination while *amotivation, external regulation* and *introjected regulation* address non-self-determination (Table 5). The score for each subscale is added up with the total raw score range of the self-determination being 0-32 and the mean range 0-8. The total raw score for the non-determination being 0-44 and the mean range 0-11. In this thesis, the results of BREQ-2 are presented as means for self-determination and non-self-determination. Higher scoring of self-determination is positively linked with adaptive health behaviour while higher scoring of non-self-determination indicates lack of intention to engage in exercise (Wilson et.al, 2012). The psychometric properties of the BREQ-2 have been investigated in a sample of healthy people (Markland & Tobin, 2004; Ingledew et.al, 2009) as well as in different patient groups (Milne et.al, 2008; Vancampfort et.al, 2013). BREQ-2 has been used to study regulation of exercise in different patients group as well as of healthy individuals (Teixeira et.al, 2012). To date, no data is available on psychometric properties when used for stroke survivors, but the content and format support its relevance within this population. The BREQ-2 was translated into Icelandic using a translation/back-translation method prior to this study (Behling & Law, 2000).

Table 5. Statements of BREQ-2 in line with the self-determination theory.

		Statements
Non-self-determination	Amotivation (total raw score 0-16)	I don't see why I should have to exercise
		I can't see why I should bother exercising
		I don't see the point in exercising
		I think exercising is a waste of time
	External regulation (total raw score 0-16)	I exercise because other people say I should
		I take part in exercise because my friends/family/partner say I should
		I exercise because others will not be pleased with me if I don't
		I feel under pressure from my friends/family to exercise
	Introjected regulation (total raw score 0-12)	I feel guilty when I don't exercise
		I feel ashamed when I miss an exercise session
		I feel like a failure when I haven't exercised in a while
Self-determination	Identified regulation (total raw score 0-16)	I value the benefits of exercise
		It's important to me to exercise regularly
		I think it is important to make the effort to exercise regularly
		I get restless if I don't exercise regularly
	Intrinsic regulation (total raw score 0-16)	I exercise because it's fun
		I enjoy my exercise sessions
		I find exercise a pleasurable activity
		I get pleasure and satisfaction from participating in exercise

3.3.3 Procedure

The survey was sent to the individuals who fulfilled the inclusion criteria in the first week of May 2018 (see Appendix I), but, prior to sending the survey was pilot-tested on four community-dwelling stroke survivors (47-78 years old) who gave feedback concerning clearer wording and options for answers. Along with the survey, the participants received an information letter where all details were described including the purpose of the survey, information on the researchers, and the arrangement of the survey. Permissions were declared, anonymity was secured and voluntary participation was emphasized. To ensure anonymity, each survey sent out had a code linked to an individual.

The University of Akureyri Research Center (RHA) administrated the format and printing of the survey, mailing to participants and collection of answers. A stamped envelope for return to RHA was included. RHA monitored the participation rate and kept the researchers informed. If eligible stroke survivors had not responded within three weeks, a researcher followed up with a phone call and encouraged participation and offered assistance.

Those who refused to take part were kindly asked to share the reason for rejection. RHA also processed scanning and verification of the answers into a data file.

3.3.4 Data analysis

The *R-statistical software* was used for the analysis of the results, the level of significance was set at $P<0.05$ and no corrections were made for multiple statistical tests (Perneger, 1998). Imputation was used for missing data in the BREQ-2, using predictive mean matching (Landerman et.al, 1997). Age in years was used to create an ordinal variable with three categories; older-old (75 years and older), younger-old (65-74 years) and young (<65 years). Descriptive analyses were conducted, including mean and standard deviation for age, frequencies and proportions for the categorical variables, and medians and range to describe continuous data for the different age-groups. Fisher´s exact test was used for categorical variables, t-tests for participants and non-participants and analysis of variance (ANOVA) for continuous data. A post hoc text, TukeyHSD, was used for comparing possible age-group pairings to explore the differences between different age-groups.

3.4 Development and feasibility of ActivABLES (Paper II and III)

The purpose of ActivABLES was to motivate and support community-dwelling stroke survivors with therapeutic exercise and daily physical activity, with support from their caregivers. The process of developing is described in detail in Paper II and the feasibility study is presented in Paper III.

ActivABLES was a NordForsk-funded collaboration project between University of Iceland (Faculty of Nursing, Department of Physical Therapy), Lund University in Sweden (Department of Design Sciences) and Aalto University in Finland (Department of Computer Science).

3.4.1 Process of developing

The project started in 2015 with a qualitative study of the experience of stroke survivors and their caregivers of facilitators and barriers for motivation for exercising and physical activity (Dongen et.al, 2021). This study laid the groundwork for the process of developing the complex intervention of ActivABLES, which is described in this thesis (Figure 5).

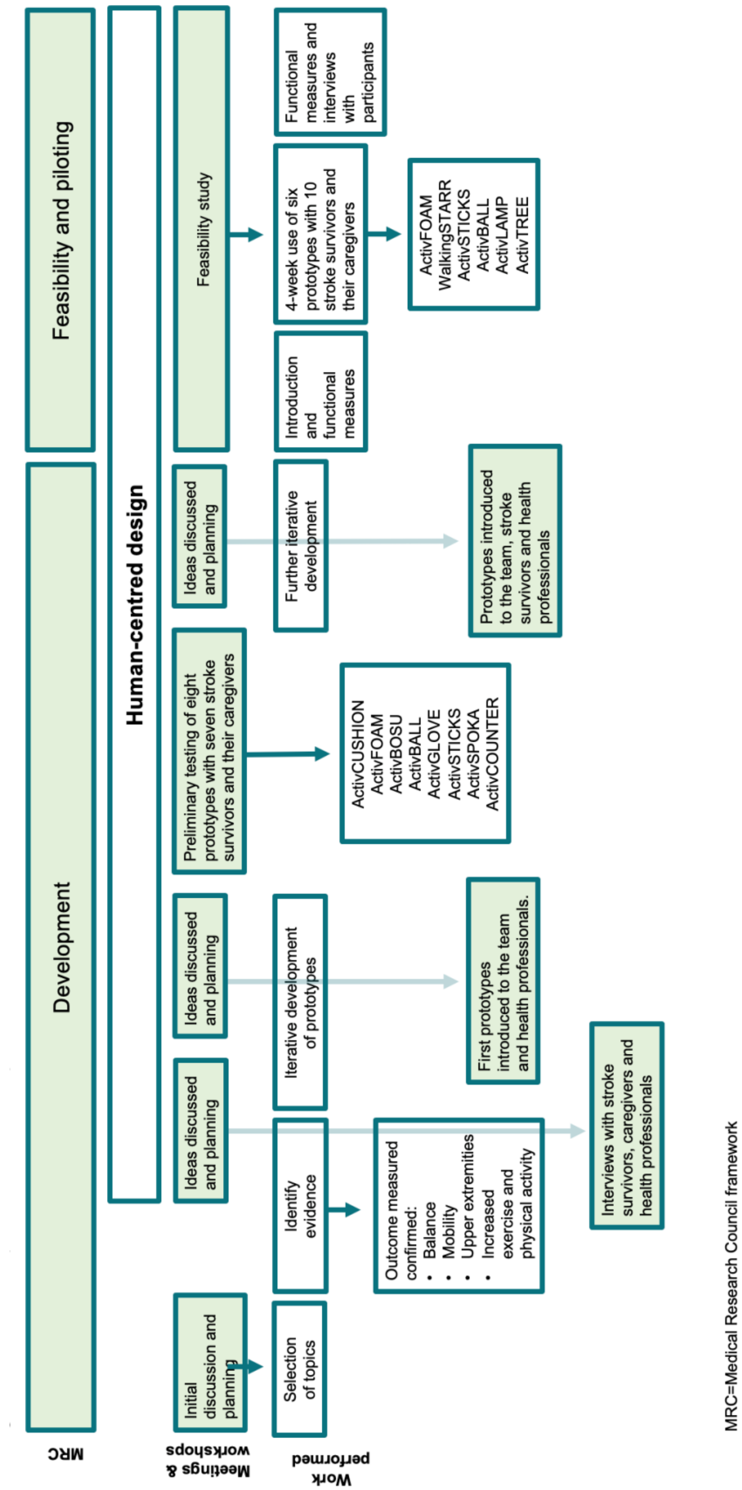

Figure 5. Process of developing ActivABLES.

The phases included in this thesis on ActivABLES describe the *development* and *feasibility and piloting* according to the MRC framework (Figure 6) and are reported in Paper II. The development phase included identifying the evidence on the needs for effective therapeutic exercises and the outcomes important for community-dwelling stroke survivors, along with preliminary testing of prototypes and iterative development. Outcome measures decided to emphasize with ActivABLES were balance, mobility, body function of upper extremities and motivation for exercise and physical activity. The designers and computer scientists made prototypes to meet these outcome measures. The technical development was guided by the principles of human-centred design, which emphasizes the human perspective in all steps of the problem-solving process (Maguire, 2001). Thus, the end-users, community-dwelling stroke survivors, their caregivers and rehabilitation professionals were involved in the process of developing at all times. The prototypes were introduced regularly and tested iteratively during the development phase, in the labs, clinics and in the stroke survivors´ homes. The feasibility and piloting phase included a feasibility study, which was conducted in the spring of 2018, among ten stroke survivors who used six prototypes of ActivABLES in their homes for four weeks, with support from their caregivers.

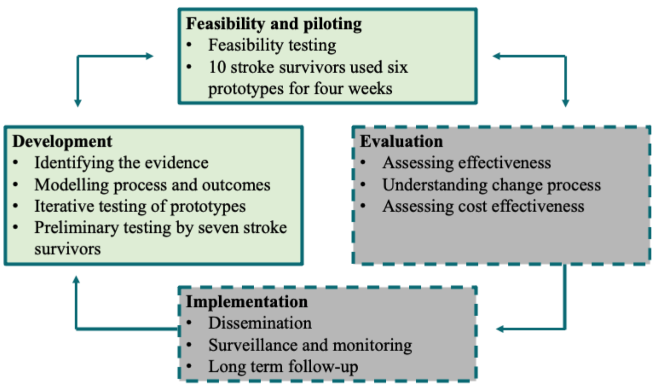

Figure 6. Medical Research Council framework for ActivABLES.

3.4.2 Selection of participants and ethics

The preliminary testing, which was a step in the development phase of MRC, and the feasibility study took place in the homes of the participants. The preliminary testing was conducted approximately half-way through the process and, following further modification of the prototypes, the feasibility study was conducted.

Participants who took part in the preliminary testing and the feasibility study were approached through inpatient rehabilitation clinics, outpatient clinics and Heilaheill (the Icelandic Stroke Association). Included were: community-dwelling stroke survivors, at least 18 years of age, at least four months since discharge from hospital or inpatient rehabilitation, with slight or moderate impairment defined by a score of 2–3 on the Modified Rankin Scale (Bonita & Beaglehole, 1988), no severe cognitive deficits defined by the Mini Mental State Examination (score >24) (Folstein et.al, 1975), no severe comorbidities or pre-existing conditions affecting function or ability to speak and understand Icelandic. Also, included were caregivers who were at least 18 years of age and able to communicate and assist the stroke survivor. Seven stroke survivors and six caregivers took part in the preliminary testing and ten stroke survivors and their caregivers in the feasibility testing.

The ActivABLES studies were conducted according to the ethical principles of the Declaration of Helsinki (World Medical Association, 2016). All the stroke survivors and caregivers received verbal and written information and signed an informed consent prior to participating in the studies. Participation was voluntary and anonymous, and participants were informed about their rights to withdraw from the studies at any time without any consequences. Ethical approval for the study was granted by the National Ethics Committee of Iceland (Ref. VSNb2015110001/03.01), the Regional Ethics Committee in Lund, Sweden (dnr 2015/678) and the City of Helsinki, Finland (HEL 2016–002570).

3.4.3 Procedure of the preliminary testing and the feasibility study

The preliminary testing and the feasibility study included collection of both quantitative and qualitative data (Figure 7). In the preliminary testing, the baseline data was collected prior to the testing and used to describe the functioning of the participating stroke survivors. Semi-structured interviews at the end of the preliminary testing were used to interpret the stroke survivors´ and caregivers´ experiences of testing the prototypes (see Paper II for detailed description). The feasibility study had a mixed methods design. Quantitative data was collected prior to, during and after the four-week use of the ActivABLES prototypes and qualitative data was collected with semi-structured interviews which were conducted with each stroke survivor and caregiver after the four-week period. The quantitative and qualitative results were integrated to gain deeper understanding of the results (see Paper III for detailed description).

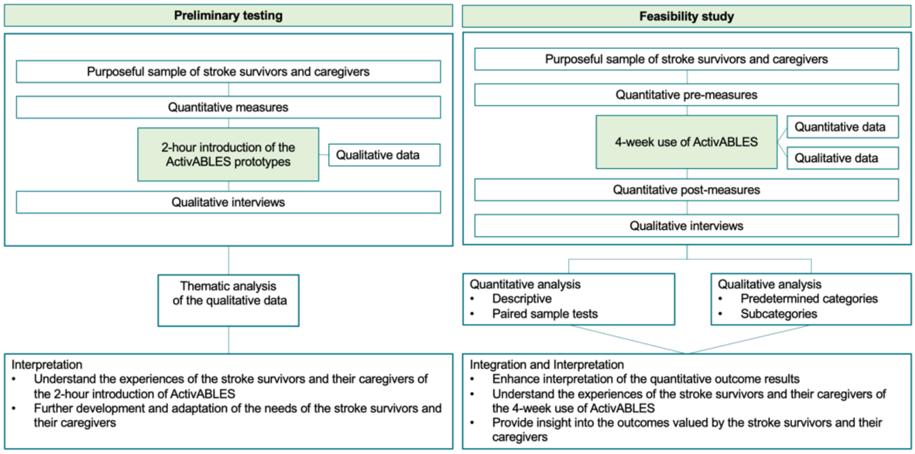

Figure 7. Diagrams of the studies on the process of developing ActivABLES.

3.4.3.1 Quantitative data

In addition to the two standardized questionnaires, SIS and BREQ-2, the following standardized measures were used in the preliminary testing to describe the participants and as pre- and post-measures in the feasibility testing (Table 2).

Balance was measured with the Berg Balance Scale (BBS) (Berg et.al, 1992). BBS consists of 14 static and dynamic activities of varying difficulty with each item giving a score of 0-4. The item scores are added up to form a total score which can range from zero to 56, with a higher number indicating better functional balance. Scores of 0-20 represent balance impairments, 21-40 represent acceptable balance, and 41-56 represent good balance (Blum, & Korner-Bitensky, 2008). Studies have shown that older individuals who have less than 45 points are at more risk of falling (Lima et.al, 2018), but research is needed to find a cut-off score for community-dwelling stroke survivors. The psychometric properties of the BBS for stroke survivors show excellent internal consistency (ICC=0.92-0.98) (Berg et.al, 1995; Blum & Korner-Bitensky, 2008), inter-rater (ICC=0.95-0.98) /intra-rater reliability (Berg et al., 1995; Flansbjer et al., 2012; Blum & Korner-Bitensky, 2008), and test-retest reliability (ICC=0.98) (Flansbjer et al., 2012; Blum & Korner-Bitensky, 2008).

General mobility was measured with the Timed Up and Go (TUG) (Mathias et al., 1986). In TUG, the participant stands up from a chair, walks a distance of three meters, turns around, walks back to the chair and sits down. The time required to perform the TUG is recorded. Podsiadlo and Richardson (1991) presented a categorization based on scores of frail older adults in TUG; those who finish in less than 20 seconds tend to have good mobility, those who finish in 20-30 seconds need further assessment on mobility and those who need more than 30 seconds to finish generally have impairments in basic activities. TUG has also been used to assess the risk of falling, and reported cut-off points for older adults vary from 12.5-15 seconds (Hafsteinsdóttir et al., 2014) but studies on the cut-off point of increased risk of falls of stroke survivors are inconclusive. The psychometric properties of the TUG for stroke survivors show excellent test-retest reliability (ICC=0.96) (Flansbjer et al., 2005; Hafsteinsdóttir et al., 2014) and good convergent validity (Hafsteinsdóttir et al., 2014).

Balance self-efficacy was measured with the Activities-Specific Balance Confidence Scale (ABC**)** (Powell & Myers, 1995). ABC is a 16-item self-report measure in which participants rate their balance confidence on a scale of 0–100% for performing different activities. The mean score for stroke survivors is 68.2 ±17.5% (Botner et al., 2005). The psychometric properties of ABC for stroke survivors show excellent internal reliability (ICC=0.94) and construct validity (Salbach et al., 2006), excellent internal consistency (ICC=0.94) and test-retest reliability (ICC=0.85) (Botner et al., 2005). The Icelandic version also shows good reliability and validity for older people in Iceland (Arnadottir et al., 2010).

Functional lower limb muscle strength was measured with the Five Times Sit to Stand Test (5xSST) (Csuka & McCarty, 1985). The participant stands up and sits down five times while the tester is timing using a stopwatch. The psychometric properties of the 5xSST for stroke survivors show excellent test-retest reliability (ICC=0.94-0.99) and inter/intra-rater reliabilities (ICC=0.97-0.99) (Silva et al., 2014).

Arm and hand function was measured with the Box and Block Test (BBT) (Mathiowetz et al., 1985). In the BBT, the participant moves as many cubes between boxes as possible in 1 minute. The psychometric properties of the BBT for stroke survivors with arm paresis show high inter-rater and test–retest reliability (ICC>0.95) (Platz et al., 2005).

In the feasibility study, data on sedentary, upright and ambulatory activities was collected using ActivPAL motion detectors (PAL Technologies Ltd., Glasgow, UK). The stroke survivors wore the motion detectors around their non-affected thigh for seven days (24 hours) at three different time points to assess all physical activity and sedentariness; a week prior to the start of the four-week use of ActivABLES, midway through the study and a week after the four-week period. The data generated represents a 24-hour summary of time spent in sitting/lying and standing positions, taking steps, number of transitions from sitting to standing and number of steps taken. Motion detectors have been used in many studies to explore physical activity among adults (Edwardson et al., 2017; Yang & Hsu, 2010) including stroke survivors (Field et al., 2013).

The actual use of ActivABLES during the four-week period was evaluated by connecting all the ActivABLES prototypes to a server, which collected digital data on the frequency and length of use of ActivABLES. To assess the experience of the use, the caregivers were asked to fill in adherence diaries during the four-week use of ActivABLES, which provided both quantitative and qualitative data. The adherence diaries had a format for each of the prototypes which included questions on the frequency and length of use (in minutes), which exercises were done with each tool, the execution of the exercises and the need for support and motivation. In addition, the caregivers were asked to write down their thoughts and comments on their experience of the exercises and the feasibility of using ActivABLES these four weeks.

3.4.3.2 Qualitative data

The aim of collecting qualitative data was to gain feedback and deeper understanding on how the participants experienced using ActivABLES and their preferences for the exercises and the tools. Qualitative data was collected during the preliminary testing, with noting comments from the participants, as well as after the testing when semi-structured interviews (Holloway & Galvin, 2016) were conducted with each stroke survivor and caregiver. The interview guides included questions on previous experience of home-based therapeutic exercise and what they thought of each prototype of ActivABLES. The interview guides are available in Appendix II.

Semi-structured interviews were also conducted after the four-week use of ActivABLES with each stroke survivor and caregiver in the feasibility study. In addition, qualitative data was collected using the adherence diaries during the four-week use. The interview guides included questions which focused on the feasibility of ActivABLES in terms of acceptability, demand, implementation and practicality according to Bowen et al (2009). The interviewers emphasized honesty and openness in sharing the experience of using the prototypes to elicit both positive and negative issues. The interview guides are available in Appendix II. All interviews after the preliminary testing and in the feasibility study were recorded and transcribed verbatim.

3.5 Data analysis

Jamovi software was used for the analysis of the quantitative data in the feasibility study. Imputation was used for missing data in the BREQ-2, using predictive mean matching (Landerman et al., 1997). Descriptive statistics were used to analyse quantitative data, including medians and interquartile range for continuous data. The qualitative data from the interviews with the stroke survivors and their caregivers after the preliminary testing were analysed using thematic analysis (Brown and Clark, 2006). This method was used to gain in-depth knowledge about what features and properties were experienced as important by the stroke survivors and the future users. On the other hand, the data from the interviews conducted after the four-week use of ActivABLES were analysed using direct content analysis (Hsieh & Shannon, 2005) to gain detailed information on each prototype based on the four domains of feasibility: acceptability, demand, implementation and practicality (Bowen et al, 2009). The themes were identified according to the domains of acceptability, demand, implementation and practicality and discussed until agreement on the content was reached. In the feasibility study, quantitative and qualitative data were then integrated by looking for common concepts across the data, comparing the data and examining any (dis)congruence in the findings. A case vignette was made by synthesis of participants to reflect further on the feasibility study.

4 Results

4.1 Characteristics of participants in the survey and in the process of developing ActivABLES

Characteristics of the stroke survivors who participated in the survey (Paper I) and the process of developing ActivABLES, which included the preliminary testing (Paper II) and the feasibility study (Paper III), are summarized in Table 7 and 8. In addition, caregivers participated in the preliminary testing and the feasibility study. Further individual descriptions of all participants in the preliminary testing and the feasibility study are found in Paper II and Paper III.

The community-dwelling stroke survivors who participated in the survey and the process of developing ActivABLES had comparable gender proportions and a wide age span, with a similar median age in the survey and the feasibility study (Table 6). The participants in the preliminary testing were a bit younger but the gender proportion was similar. Only 62.3% of the participants in the survey reported one side of the body being more affected from the stroke, but all participants in the ActivABLES studies were diagnosed with hemiparesis.

Table 6. Characteristics of the stroke survivors in the survey and in the process of developing ActivABLES.

	N (%[a]) or Median [Min, Max]		
		Process of developing ActivABLES	
	Survey (Paper I)	Preliminary testing (Paper II)	Feasibility study (Paper III)
N	114	7	10
Men	50%	43%	50%
Median age (range)	73 (27-94)	63 (31-76)	72 (55-79)
>75 years	51 (45%)	1 (14%)	2 (20%)
65-74 years	34 (30%)	2 (29%)	6 (60%)
<65 years	29 (25%)	4 (57%)	2 (20%)
Live in capital area	76 (66.7%)	7 (100%)	6 (60%)
Range of the time since stroke	1-2 years	9 months – 22 years	5 months – 30 years
Left hemiparesis[b]	37 (32.5%)	6 (86%)	6 (60%)
Right hemiparesis[b]	34 (29.8%)	1 (14%)	4 (40%)

[a]Proportions are based on valid data for each variable.
[b]Reported as an immediate symptom after the stroke in the survey

The participants in the feasibility study reported more use of walking devices inside their homes (Table 7) but similar use of smart devices was reported in all studies, where majority of participants reported regular use. The stroke survivors in the feasibility study had a higher score in self-determination in BREQ-2, indicating they may have more motivation for exercise than the participants in the survey. Although the score from BBS were similar among participants in the preliminary testing and the feasibility study, the range is wider among the stroke survivors in the feasibility study. The participants in the feasibility study also have lower scores in ABC, which indicate less balance confidence.

Table 7. Use of devices and results from standardized measures of the stroke survivors in the survey and in the process of developing ActivABLES.

	N (%[a]), Median [Min, Max] or Mean (SD)		
		Process of developing ActivABLES	
	Survey (Paper I) N=114	Preliminary testing (Paper II) N=7	Feasibility study[b] (Paper III) N=10
Walking devices inside	18 (15.7%)	2 (29%)	4 (40%)
Regular use of smart devices	73 (64%)	5 (71.4%)	6 (60%)
BBS		43 [37.0, 56.0]	43.5 [31.0, 49.0]
BBT[c]		12 [6.0, 53.0]	33.5 [29.0, 62.0]
ABC		65 [29.4, 76.3]	56 [30.0, 66.9]
Self-determination BREQ-2			
total raw score	19.2 (9.7)		28 [24.3, 29.5]
mean	4.8 (2.4)		7 [3.5, 7.8]
Non-self-determination BREQ-2			
total raw score	10.6 (8.0)		9 [8.3, 12.8]
mean	3.0 (2.1)		3.0 [1.9, 7.2]

BREQ-2=Behavioural Regulation Exercise Questionnaire, BBS=Berg Balance Scale, BBT=Box and Block Test, ABC=Activities-Specific Balance Confidence Scale
[a]Proportions are based on valid data for each variable.
[b]Baseline measure prior to the four-week use of ActivABLES
[c]Only few participants were able to do the BBT in the preliminary testing (n=3) and the feasibility study (n=6).

In Table 8 the scoring of SIS is presented. The highest score in all three studies was in the *communication* domain. The lowest score in the survey was in the *emotions* domain and in the *hand function* domain in the preliminary testing and the feasibility study.

Table 8. Results from the Stroke Impact Scale in all studies.

	Median [Min, Max]		
Domains of SIS	**Survey (Paper I)**	**Preliminary testing (Paper II)**	**Feasibility testing (Paper III)**
Strength	75.0 [18.8, 100]	37.5 [12.5, 68,8]	50.0 [3.3, 68.8]
Memory and thinking	85.7 [3.6, 100]	67.9 [57.1, 89.3]	82.2 [50.0, 96.4]
Emotions	63.9 [30.6, 87.5]	72.2 [44.4, 83.3]	66.7 [55.6, 88.9]
Communication	92.9 [10.7, 100]	96.4 [50.0, 100]	89.3 [57.1, 100]
ADL/IADL	87.5 [27.5, 100]	60.0 [30.0, 72.5]	61.3 [47.5, 77.5]
Mobility	83.3 [11.1, 100]	86.1 [47.2, 88.9]	75.0 [50.0, 97.2]
Hand function	90.0 [0, 100]	0 [0,55]	40.0 [0, 75.0]
Participation	78.1 [9.38, 100]	56.3 [25.0, 93.4]	51.6 [31.3, 81.3]
Recovery	80.0 [15.0, 100]	50.0 [35.0, 80.0]	47.5 [40.0, 65]
CPD[a]	78.7 [15.6, 100]	48.5 [26.8, 70.6]	53.6 [34.0, 72.9]

SIS=Stroke Impact Scale, ADL=Activities of Daily Living, IADL=Instrumental Activities of daily living, CPD= Composite Physical Domain

[a]CPD is made by summing up the score from the strength, ADL/IADL, mobility and hand function domains.

4.2 Survey

The results from the survey among community-dwelling stroke survivors in Iceland are presented in detail in Paper I. The results highlight the functioning and contextual factors among this population 1-2 years after their first stroke and reveal some interesting differences and similarities between three different age-groups of survivors; older-old (75 years and older), younger-old (65-74 years), and young stroke survivors (18-65 years). Table 9 summarizes the main results from the survey which are presented in detail in Tables 1-5 in Paper I.

The participants in the survey were slightly older than the non-participants (mean age 71.6 ±12.9 years versus 62.1±13.5 years; P=0.050) with a comparable proportion of men and women (P=0.691). Of the 78 individuals who received a phone call to facilitate their participation, 31 responded to the survey and 30 gave the following reasons for not participating: good/full recovery (n=11), not interested (n=7), difficult to remember the past (n=6) and dependent on others (n=6). Forty-one (36.0%) individuals received assistance with completing the survey, with more participants being ≥75 years old (P=0.007) than <65 years old, but with no difference between the genders (P=0.329).

The most common symptom immediately after the stroke was balance impairments which was reported by 61.4% of the participants. Almost one-third of the participants had experienced a fall during the last 12 months and 7% had fractures from the falls. The youngest group (<65 years) had fewer falls than the older groups (*P*=0.038). The oldest group (75 and older) had more comorbidities than the younger groups (*P*<0.001).

When looking at the environmental factors, less than one-third reported use of walking devices. The oldest individuals (≥75 years) had more walking devices (<65 years old *P*=0.007, 65-74 years old *P*=0.020) and more security buzzers (<65 years old *P*=0.001, 65-74 years old *P*<0.001) than those in the younger age-groups.

The majority of participants had access to various smart devices and reported regular use. A tablet was the smart device that fewest participants had access to and used in all age-groups, but computers were the most common. Compared to both younger groups, the oldest individuals used computers and smart phones less. Sixty-two participants answered the question on what they used their smart devices for. Most of them used their smart devices for social media and communication with family and friends (n=31, 50%). Twenty participants reported *general use* with no details on specific meaning of that (included general use, daily life, recreation and entertainment). Many reported use of the internet which included reading the news (n=18), and using the devices for work (n=17). Ten reported using smart devices for games and solitaires but only one reported use for a specific kind of treatment which was speech therapy. Thirty-six (31.6%) of the participants thought the smart devices could be used for rehabilitation.

During the last month prior to answering the survey, 52 participants (45.6%) had some kind of health and social services and 50 (43.9%) answered the question on if the services they had received fulfilled their needs. The majority of those participants reported having fulfilled needs (n=33) while 17 of them reported unfulfilled needs. Eighteen responded to the question on how to change/improve the services. Six of them (1/3) reported a greater need of physiotherapy and five individuals needed more of other services, including adult day-care and more frequent bathing. Lack of individually-tailored services and follow-up were also mentioned.

Motivation for exercise, which was assessed with BREQ-2, showed more self-determination than non-self-determination in all age-groups. No difference was found in self-motivation between the age-groups but the oldest age-group reported more non-self-determination than the youngest group (*P=0.034).* Majority of participants reported being physically active three times a week but a little less than half reported physical activity at least five times a week. No difference was found between the age-groups

Table 9. Contextual factors and functioning of participants in the survey.

	Mean (SD) or N (%[a])				
	All (N=114)	75-94 years (n=51)	65-74 years (n=34)	27-65 years (n=29)	*P*-value[b]
Personal factors					
Age	71.6 (12.9)				
Balance impairment as a main symptom after stroke	70 (61.4%)	31 (60.8%)	26 (76.5%)	13 (44.8%)	0.038[c,d]
Experienced one or more fall	34 (29.8%)	18 (35.3%)	12 (35.3%)	4 (13.8%)	0.013[c,e]
Number of comorbidities	1.5 (1.2)	2.0 (1.2)	1.4 (1.2)	0.8 (0.8)	< 0.001[c,f]
Environmental factors					
Walking devices	33 (28.9%)	24 (47.1%)	6 (17.6%)	3 (10.3%)	< 0.001[c,g]
Buzzer	33 (28.9%)	28 (54.9%)	3 (8.8%)	2 (6.9%)	< 0.001[c,g]
Laptop or computer	78 (68.4%)	24 (47.1%)	29 (85.3%)	25 (86.2%)	< 0.001[c,g]
Smartphone	69 (60.5%)	17 (33.3%)	28 (82.4%)	24 (82.8%)	< 0.001[c,g]
Tablet	50 (43.9%)	14 (27.5%)	16 (47.1%)	20 (69.0%)	0.001[c,h]
Services during last month	52 (45.6%)	32 (62.7)	14 (41.2%)	6 (20.7%)	0.001[c,h]
Physiotherapy	39 (34.2%)	22 (43.1%)	12 (35.3%)	5 (17.2%)	0.054
Social domestic	16 (14.0%)	13 (25.5%)	1 (2.9%)	2 (6.9%)	0.006[c,g]
Adult daycare	5 (4.4%)	5 (9.8%)	0 (0%)	0 (0%)	0.056[c,g]
Transportation services	7 (6.1%)	6 (11.8%)	0 (0%)	1 (3.4%)	0.071
Body function					
BREQ-2: Self-determination	4.8 (2.4)	4.9 (2.3)	4.8 (2.3)	4.6 (2.8)	0.786
BREQ-2: Non-self-determination	3.0 (2.1)	3.3 (2.2)	3.3 (2.0)	2.1 (2.0)	0.028[c,h]
Activities and participation					
Regular use of a laptop/computer	62 (54.4%)	14 (27.5%)	25 (73.5%)	23 (79.3%)	< 0.001[c,g]
Regular use of a smartphone	59 (51.8%)	14 (27.5%)	23 (67.6%)	22 (75.9%)	< 0.001[c,g]
Regular use of a tablet	38 (33.3%)	9 (17.6%)	14 (41.2%)	15 (51.7%)	0.003[c,h]
PA/exercise at least 3x a week	77 (67.5%)	33 (64.7%)	25 (73.5%)	19 (65.5%)	0.559
PA/exercise at least 5x a week	54 (47.4%)	23 (45.1%)	17 (50.0%)	14 (48.3%)	0.888

SD=Standard deviation, BREQ-2=Behavioral Regulation Exercise Questionnaire-2, PA=Physical activity
[a]Proportions are based on valid data for each variable.
[b]Fisher´s Exact Test for categorical variables.
[c]TukeyHSD, for differences between different age-groups.
[d]Difference between <65 years old and 65-74 years old.
[e]Difference between <65 years old and both older groups.
[f]Difference between all three groups.
[g]Difference between ≥75 years old and both younger groups.
[h]Difference between ≥75 years old and <65 years old.

The results from the SIS are presented in Table 10, where a higher score indicates better functioning. The highest score was in the communication domain (median=92.9, range 10.7-100) and the lowest score was in the emotion domain (median=63.9, range 30.6-87.5). Differences were found between the age-groups in three domains: ADL/IADL (*P*=0.002), mobility

(*P*<0.001) and participation (*P*=0.020) as well as in the CPD (*P*=0.040). The oldest individuals (≥75 years) deviated from the two younger age-groups in ADL/IADL (<65 years old *P*<0.001, 65-74 years old *P*=0.037) and mobility (<65 years old *P*<0.001, 65-74 years old *P*=0.016) and from the youngest group (<65 years) in participation (*P*=0.005) and CPD (*P*=0.015). The scoring from the emotion domain of SIS did not show difference between the age-groups (*P*=0.530) even though the oldest group (75 and older) reported more diagnosed anxiety/depression than the younger groups.

Table 10. Results from the Stroke Impact Scale with comparisons between the age-groups.

Domains of Stroke Impact Scale	Median [Min, Max] All (N=114)	75-94 years (n=51)	65-74 years (n=34)	27-65 years (n=29)	*P*-value[a]
Strength	75.0 [18.8, 100]	75.0 [25.0, 100]	65.6 [37.5, 100]	93.8 [18.8, 100]	0.096
Memory and thinking	85.7 [3.57, 100]	89.3 [3.57, 100]	78.6 [39.3, 100]	89.3 [28.6, 100]	0.403
Emotions	63.9 [30.6, 87.5]	61.1 [33.3, 86.1]	68.1 [33.3, 87.5]	69.4 [30.6, 86.1]	0.530
Communication	92.9 [10.7, 100]	92.9 [10.7, 100]	91.1 [14.3, 100]	92.9 [20.0, 100]	0.387
ADL/IADL	87.5 [27.5, 100]	82.5 [27.5, 100]	90.0 [45.0, 100]	100 [27.5, 100]	0.002[c,d]
Mobility	83.3 [11.1, 100]	72.2 [11.1, 100]	83.3 [47.2, 100]	100 [25.0, 100]	<0.001[c,d]
Hand function	90.0 [0, 100]	85.0 [5.00, 100]	80.0 [0, 100]	100 [0, 100]	0.167
Participation	78.1 [9.38, 100]	75.0 [9.38, 100]	75.0 [28.1, 100]	98.4 [40.6, 100]	0.020[c,e]
Perceived recovery	80.0 [15.0, 100]	77.5 [15.0, 100]	75.0 [35.0, 100]	87.5 [30.0, 100]	0.143
CPD[b]	78.7 [15.6, 100]	73.8 [27.4, 100]	76.1 [39.9, 100]	93.8 [15.6, 100]	0.040[c,e]

ADL/IADL=Activities of daily living/Instrumental activities of daily living, CPD=Composited Physical Domain
[a]Linear Model ANOVA
[b]CPD includes the domains of strength, ADLs/IADLs, mobility, and hand function.
[c]TukeyHSD, for differences between different age-groups.
[d]Difference between ≥75 years old and both younger groups.
[e]Difference between ≥75 years old and <65 years old.

Results from gender comparisons of SIS are presented in Table 11. The results are similar between the genders, but women score lower in the domains of mobility and hand function.

Table 11. Results from the Stroke Impact Scale with comparisons between the genders.

Domains of Stroke Impact Scale	Median [Min, Max] All (N=114)	Men (n=57)	Women (n=57)	*P*-value[a]
Strength	75.0 [18.8, 100]	75.0 [37.5, 100]	75.0 [18.8, 100]	0.462
Memory and thinking	85.7 [3.57, 100]	89.3 [3.57, 100]	85.7 [3.57, 100]	0.386
Emotions	63.9 [30.6, 87.5]	65.3 [33.3, 86.1]	62.5 [30.6, 87.5]	0.567
Communication	92.9 [10.7, 100]	89.3 [20.0, 100]	92.9 [10.7, 100]	0.544
ADL/IADL	87.5 [27.5, 100]	90.0 [27.5, 100]	82.5 [27.5, 100]	0.217
Mobility	83.3 [11.1, 100]	88.9 [36.1, 100]	75.0 [11.1, 100]	0.006
Hand function	90.0 [0, 100]	95.0 [0, 100]	80.0 [0, 100]	0.025
Participation	78.1 [9.38, 100]	81.3 [25.0, 100]	78.1 [9.38, 100]	0.391
Perceived recovery	80.0 [15.0, 100]	77.5 [15.0, 100]	80.0 [20.0, 100]	0.681
CPD[b]	78.7 [15.6, 100]	79.9 [15.6, 100]	77.8 [25.6, 100]	0.163

ADL/IADL=Activities of daily living/Instrumental activities of daily living, CPD=Composite physical domain
[a]Linear Model ANOVA
[b]CPD includes the domains of strength, ADLs/IADLs, mobility, and hand function.

4.3 ActivABLES

The purposive sampling for the process of developing ActivABLES was approached through stroke clinics, clinics and Heilaheill, which is a non-profit organization in Iceland for people interested in cerebrovascular disease. Most individuals were willing to take part, although a few who were contacted refused to take part in the feasibility study. The reasons given were *not interested, not having the time* – and caregivers who thought “their” stroke survivor would not be able or willing to participate. Those who accepted showed interest and were keen to start trying out the tools.

4.3.1 Process of developing the prototypes

The process of developing the ActivABLES prototypes lasted for approximately two years and is described in detail in Paper II. During the process, prototypes were iteratively introduced to stroke survivors, caregivers and rehabilitation professionals. Feedback was used to continue the process of developing or cancelling further development. The final yield resulted in six prototypes which were used in the feasibility study and described in detail in Paper III.

Eight prototypes were introduced in the preliminary testing which is a part of the development phase in the MRC framework: ActivFOAM, ActivBOSU and ActivCUSHION for balance exercises and positioning; ActivBALL, ActivSTICKS and ActivGLOVE for hand and arm exercises; and ActivLAMP and ActivSPOKA for feedback. Four of these prototypes; ActivFOAM, ActivBALL, ActivSTICKS and ActivLAMP were found suitable for further developing. During the preliminary testing, the stroke survivors and their caregivers reported the need for a tool to encourage walking. Pursuant to their request, the iPhone application WalkingSTARR was developed, which has a step-counter and games to encourage walking. In the interviews after the preliminary testing, the stroke survivors emphasized the importance of integration of therapeutic exercise into activities of daily living in the interviews while the caregivers expressed their lack of resources to assist with home-based therapeutic exercise (see Figures 3 & 4 in Paper II). Both these perspectives supported the idea of ActivABLES.

The development process resulted in four exercise prototypes and two feedback prototypes (Figure 8) which were used in the four-week feasibility study: ActivFOAM for balance exercise, WalkingSTARR for walking, ActivBALL for hand and wrist exercise, ActivSTICKS for arm and shoulder exercise, and ActivLAMP and ActivTREE which give visual feedback on the daily amount of exercise done. Each prototype can be individually-tailored to the user´s needs in regards of frequency of exercises and progress of activity.

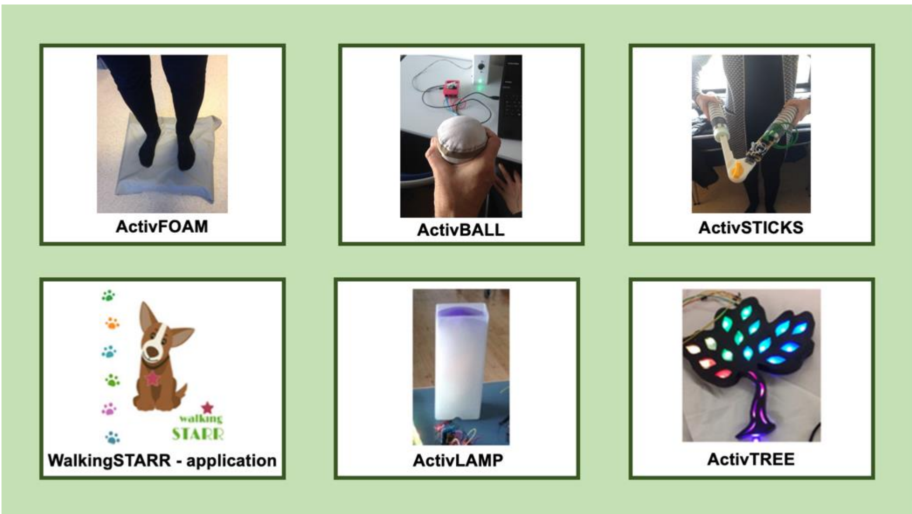

Figure 8. ActivABLES prototypes tested in the feasibility study.

4.3.1.1 ActivFOAM

To exercise balance and weight-bearing in a standing position we developed ActivFOAM (Figure 9) which is made of a foam balance mat (Airex balance-pad). Pressure sensors were placed and covered on the top of the mat and connected to a tablet. The tablet gave visual and audio feedback on weight shifting and information on the centre of mass while standing. In the preliminary testing, the user could also play one game, but two games were added prior to the feasibility testing. Also, there were possibilities to use different music to encourage weight shifting and stepping on the mat. In the feasibility study, it was possible to adjust the difficulty level in some of the games. In the feasibility study, three interactive games and different types of audio feedback could be selected and used for exercising:

(i) In the Pong-game, the user moves a paddle by shifting the amount of weight on each foot in an attempt to hit a ball which comes at different speeds from unknown direction. The user has to shift more weight to the other foot to make the paddle move. The size of the paddle can be adjusted, with smaller paddle making the game more difficult. The user collects a point each time he/she hits the ball.

(ii) In the Escape-game, the user moves a ball by putting more weight onto one foot to avoid barriers which are in the way. The user collects a point for each barrier he/she escapes.

(iii) In the Bomb-game, the user moves a ball in and out of a circle by putting more weight onto one foot, as much as the user is able to, and then back into the circle by adjusting the weight onto both feet. The ball needs to be back in the circle before an audio feedback indicates a bomb explosion.

(iv) More possibilities include use of different types of audio feedback like jazz, samba and guitar tones while looking at a screen showing how much weight is being put on each leg.

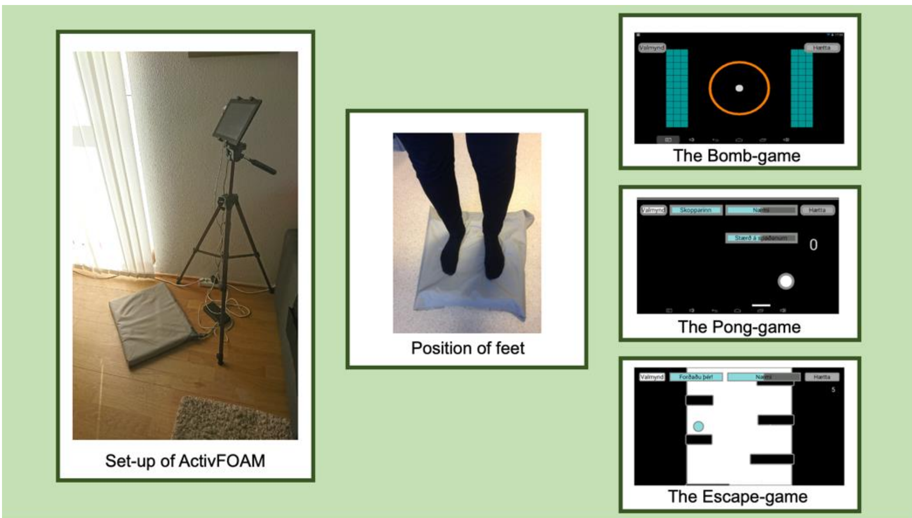

Figure 9. Set-up of ActivFOAM and screenshots of games included.

4.3.1.2 WalkingSTARR

The iPhone application WalkingSTARR (Rassmus-Gröhn et al., 2017) was used to encourage walking (Figure 10). Prior to use, the user, in collaboration with a rehabilitation professional, needs to decide on daily goals related to walking, like steps, distance walked and/or time of walking. During the day, the dog in the app barks to remind the user of walking. When walking, the main screen shows a dog walking in an ellipse, which fills up with a colour while the user is walking. When the ellipse is fully coloured, the daily goal has been reached. The user can also earn stars while walking, and if the user wants to play a game while walking, the dog for example barks to tell if he needs to pee.

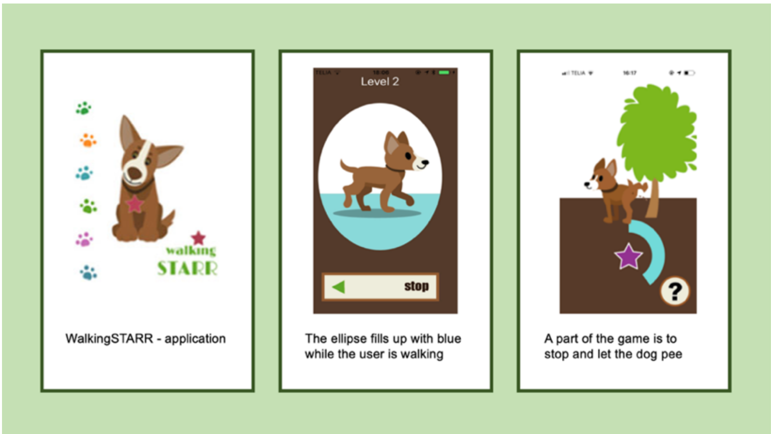

Figure 10. Screenshots from the WalkingSTARR application

4.3.1.3 ActivBALL

ActivBALL was developed to emphasize the motor control of the hand, wrist and shoulder (Figure 11). Pressure sensors cover the ball which is connected to a smart device. In the preliminary study, the ball was introduced as a tool to use on a computer. The user had to squeeze the ball regularly to “charge” the computer while watching a selected programme. It could also be used for playing games like Tic-Tac-Toe. It was not possible to develop these possibilities further prior to the feasibility study and therefore a different approach was used for the exercises. The exercises included in the feasibility study were internal/external rotation of the shoulder, flexion/extension and pronation/supination of the wrist and extension/flexion of the fingers. Prior to use, the user, in collaboration with a rehabilitation professional, needs to decide on daily goals related to frequency of each exercise. In the feasibility study, ActivBALL was connected to a tablet which showed the daily goals and counted for the user while he/she did the exercises.

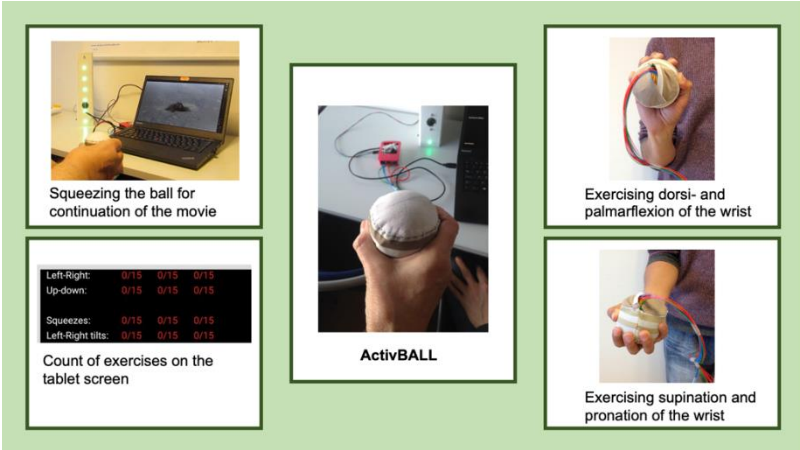

Figure 11. ActivBALL for exercises of upper extremities.

4.3.1.4 ActivSTICKS

ActivSTICKS (Figure 12) were developed to exercise motor control of the arms and upper body. During the preliminary study, ActivSTICKS were introduced as a tool to use on a computer. The user could, for example, use the sticks to manoeuvre on Google-Street and play a solitaire. It was not possible to develop these possibilities further prior to the feasibility study and therefore the sticks were connected to a tablet in the study, similar to ActivBALL. The exercises were repetitive movements where the recommended daily frequency of exercises was that which the user, in collaboration with a rehabilitation professional, had decided. The exercises included abduction and adduction of the shoulder, flexion of the shoulder, elbow flexion and extension, along with coordination of the left and right arms while doing “scissors” and rotation of the upper body.

Figure 12. ActivSTICKS for exercises of upper extremities.

4.3.1.5 ActivLAMP and ActivTREE

ActivLAMP and ActivTREE (Figure 13) give visual feedback on the stroke survivor's daily progress by gradually lighting to indicate the proportion of exercises completed. ActivLAMP is connected to one exercise prototype and gradually lights up with the more exercises done or steps taken. After the preliminary testing, it was decided to develop ActivTREE to provide feedback on multiple exercises at the same time. ActivTREE has three branches and can be connected to three different exercise prototypes. Each branch is connected to one exercise and gradually lights up as the user exercises or walks. These feedback prototypes reset every day at midnight.

In the interviews, both the stroke survivors and their caregivers emphasized the importance of feedback and encouragement:

You need to see when you are doing well with a sound or a light or something. [stroke survivor]

It is encouraging to see what you have been doing, to see the report. [stroke survivor]

If something is measuring the time, I think it would help him continue with the exercises. Otherwise, he would maybe do the exercise five times and feel like he has done a good job. [caregiver]

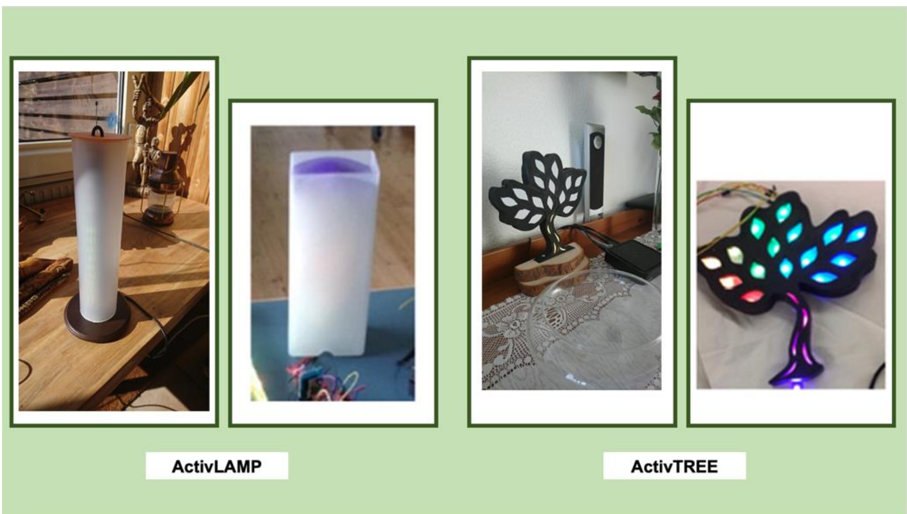

Figure 13. ActivLAMP and ActivTREE for feedback of exercise and physical activity.

4.3.1.6 Excluded prototypes

The prototypes that were excluded after the preliminary study were ActivGLOVE, ActivCUSHION, ActivBOSU and ActivSPOKA (Figure 14).

ActivGLOVE was for exercising extension of the fingers. The user put the glove on and when doing the exercises, it gave feedback with lights and/or sound. The glove-finger gradually lit up when the finger was extended and/or played a sound when it was fully extended. The glove was quite tight and it was difficult for the user to put it on. The design of the glove needed to be further developed to make it more suitable and therefore it was excluded from further development prior to the feasibility study.

ActivCUSHION was a thin cushion, covered with pressure sensors, to put on a seat. The cushion could give a feedback on positioning while the user was sitting, for example, if the user would lean towards one side. In the preliminary testing, the participants found the cushion was not challenging enough and, after testing, it was excluded for further development.

ActivBOSU consists of an inflated hemisphere which is attached to a rigid plate. The inflated half ball is put on the floor and the user stands on the plate for balance exercise, making an unstable base. The participants in the preliminary testing found the ActivBOSU too difficult to use and it was considered to be unsafe for stroke survivors to use in their home. It was quite challenging to keep balance while standing on it and could potentially increase risk of falling while doing the exercise. Therefore, ActivBOSU was excluded from further development.

ActivSPOKA was a small light that could remind the user of exercising and/or give feedback when the daily recommended exercises or walking were finished. Due to similarities with ActivLAMP, it was not further developed.

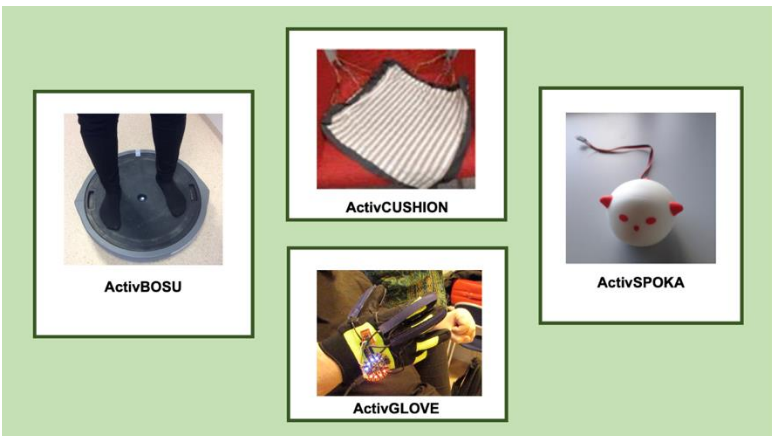

Figure 14. Excluded prototypes.

4.3.2 Feasibility study

The main characteristics of the ten stroke survivors who participated in the feasibility study, which included use of the prototypes of ActivABLES for four weeks, are presented in Table 6 and 7. All participants used the ActivFOAM for balance exercises, two used the ActivSTICKS for exercising the upper arms and two used the ActivBALL for exercising the arm and hand. Four stroke survivors used the walking application to follow their step counts while walking, six used the ActivLAMP and five used the ActivTREE for visual feedback.

4.3.2.1 Quantitative results

All ten stroke survivors took part in the functional pre-measures but nine took part in the post-measures since one stroke survivor was hospitalised for a few days during the four-week period and was not able to participate in the post-measures. Individual measures before and after the four-week period are presented in Figure 15 and 16.

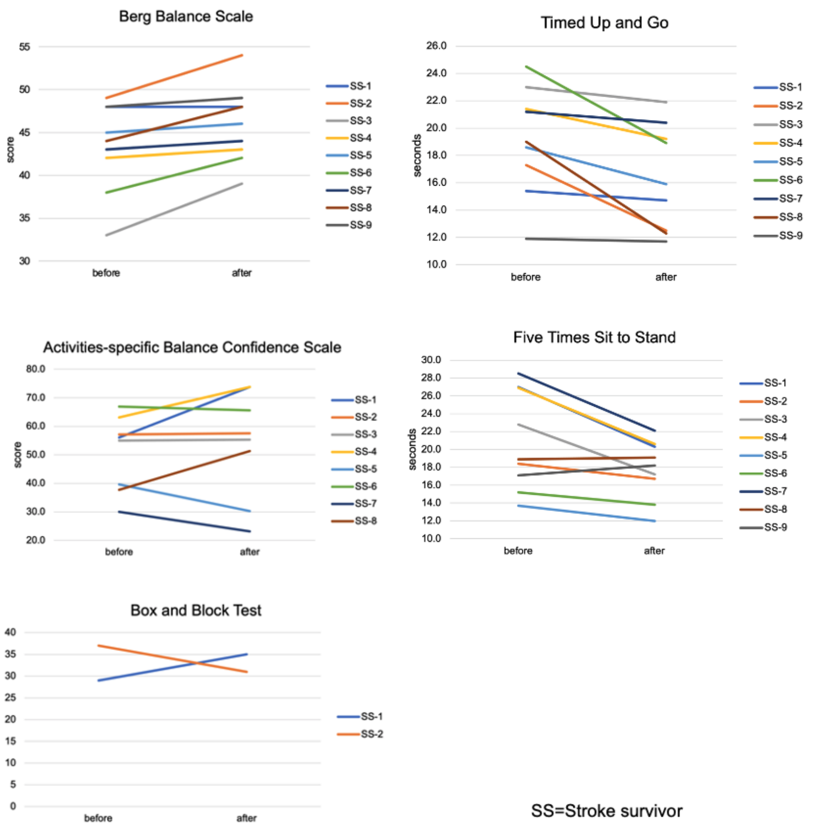

Figure 15. Individual quantitative measures before and after the four-week use of ActivABLES.

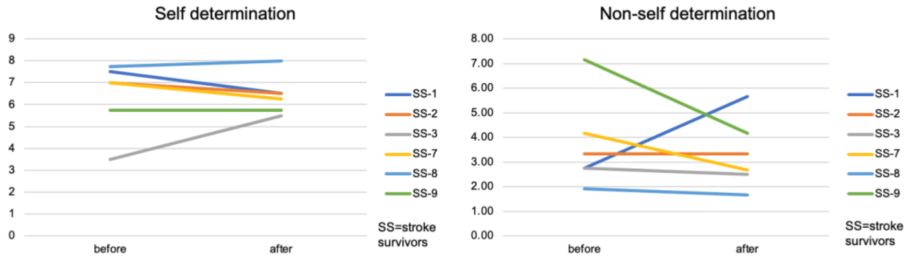

Figure 16. Individual results from Behavioural Regulation Exercise Questionnaire-2 before and after the four-week use of ActivABLES

Seven stroke survivors improved their score or performance in two or more quantitative measures. The median was also higher in all the measures after the four-week use. The summary of changes is presented in Table 12. According to the ActivABLES digital server, seven stroke survivors used ActivABLES for the recommended five days a week for the four weeks with the median use of 23 days (range 5–27 days). The results from the BREQ-2 for motivation to exercise showed valid pre- and post-measures for six stroke survivors (Figure 16). In the pre-measure, five stroke survivors had higher scores for self-determined motivation than non-self-determined motivation to exercise indicating that they value the benefits of exercise. In the post-measure, all six had higher self-determined motivation. Four of the adherence diaries were thoroughly filled in and reflected well the data on the digital servers regarding number of days. However, the average daily use per participant reported in the diaries was in the range of 14–48 minutes, whereas on the servers the average daily use range was nine to 28 minutes.

Technical difficulties were reported 19 times by the participants during the four-week period. Generally, the users were able to solve the problem with technical guidance through the phone, but on seven occasions the researcher had to visit the users and figure out the problem.

4.3.2.2 Qualitative interviews

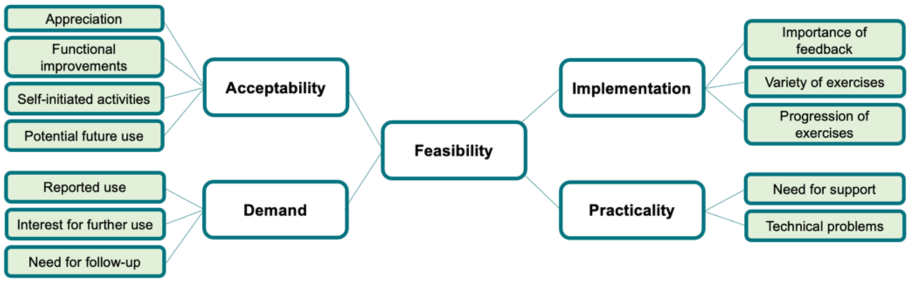

Figure 17. Themes identified in line with the feasibility domains.

The four feasibility domains of acceptability, demand, implementation and practicality were addressed in the interviews with the ten stroke survivors and their caregivers. Twelve themes were identified within the four feasibility domains (Figure 17). In Paper III, the thematic analysis is described in detail with quotes from the participants which illustrate the themes within each domain.

Acceptability:

Four themes were identified that illustrated acceptability: (1) *appreciation,* (2) *functional improvements,* (3) *self-initiated activities,* and (4) *expressed potential use for future stroke survivors* (Figure 17).

The stroke survivors and caregivers expressed appreciation for being offered an opportunity to take part in the development of ActivABLES to promote home-based therapeutic exercise and physical activities. Only few stroke survivors reported undesirable symptoms at some point while using ActivABLES, including increased spasms in their foot and pain in their back and shoulder. Both the stroke survivors and their caregivers approved of ActivABLES, and they described improvements in function of the stroke survivors. Some described noticing changes in physical activity and self-initiated activities, which included activities that the stroke survivors had not performed in some time prior to the study and were not encouraged especially to perform. For example, the stroke survivors described increased motivation to try themselves in new situations like washing the floor, being more aware of using the affected arm and walking indoors without using a cane/crutch. Participants were asked if they thought ActivABLES has potential use for future stroke survivors. All the participants considered ActivABLES had potential use for future stroke survivors.

Demand:

Three themes were identified that illustrated demand: (1) *reported use,* (2) *interest in further use,* and (3) *need for follow-up* (Figure 17).

The stroke survivors reported that they had tried to use ActivABLES at least five days per week and both the stroke survivors and their caregivers agreed on the potential of ActivABLES for further use in their homes. Those who had their stroke a longer time ago did say that ActivABLES might be more useful for future stroke survivors other than themselves. The need for follow-up services was emphasized by the stroke survivors and those who used assistive walking devices inside were more vocal about the need. This indicates that those with more impairments in functioning might need more follow-up than those with higher functioning.

Implementation:

Three themes were identified that illustrated implementation: (1) *importance of feedback,* (2) *variety of exercises,* and (3) *progression of exercises* (Figure 17).

The participants said the feedback was very important while doing the exercises. The stroke survivors reported how many points they had scored in the games and their enthusiasm for competing for more points. They also described that the visual feedback from ActivTREE and ActivLAMP was encouraging. *Variety of exercises* was identified when discussing the exercises. The stroke survivors thought variety was lacking in the exercises and would have liked to have more diversity. The stroke survivors were asked if they had used the *progression of exercises*. Half of the stroke survivors reported they had progressed with the exercises, making them more challenging. In the adherence diaries, the stroke survivors were asked how difficult they thought the exercises were on a 0-10 scale (10 indicating very difficult). In the beginning, the first days, the stroke survivors rated the exercises as more difficult (up to eight) but as the time passed, they rated the exercises as low as one, indicating that the exercises were more difficult during the first days but got easier with repetitions.

Practicality:

Two themes were identified that illustrated practicality: (1) *need for support* and (2) *technical problems* (Figure 17). The caregivers were asked if they had to encourage or assist their stroke survivor with the use of ActivABLES. The caregivers said they only had to assist with turning on ActivABLES and/or charging the tablet, and the stroke survivors reported they were almost independent with using ActivABLES and doing the exercise. The stroke survivors only needed minor reminders or assistance with the exercises. The participants experienced technical problems at some time during the four-week use which frustrated some of the stroke survivors. The ActivABLES tools were prototype technology, and thus somewhat fragile and vulnerable to minor tumbling.

4.3.2.3 Integration of the quantitative and qualitative results

The integration of the quantitative and qualitative data in the feasibility study is presented in Table 12, showing congruence in most of the data according to the feasibility terms of acceptability, demand, implementation and practicality.

Table 12. Integration of the results from the feasibility study.

Feasibility domains	Quantitative results			Qualitative themes	Integration
	Measure	Change in median from pre to post		Functional improvements	
Acceptability	BBS (score) TUG (sec) ABC (score) 5xSST (sec) BBT (score)	43.5-46 20.1-15.9 55.5-56.4 20.9-18.2 33-33	↑ 2.5 ↑ 4.2 ↑ 0.9 ↑ 2.7 0	Stroke survivors reported improvements in function. Caregivers reported improvements in function of their stroke survivors.	The quantitative functional measures confirm the experience of the participants of improved function.
	Motion detectors: Standing up /sitting down Number of steps Standing (hours/day) Sitting/lying (hours/day)	 47-49 1836-2063 2.3-2.6 21.3-21.0	 ↑ 2 ↑ 227 ↑ 0.3 ↑ 0.3	Self-initiated activities Stroke survivors described increased motivation to engage in self-initiated activities.	The quantitative data from the motion detectors suggest that the stroke survivors were more mobile which might indicate they engaged in more activities.
Demand	Use according to digital servers • Seven stroke survivors used ActivABLES for the recommended five days a week. Use according to adherence diaries • Median use 23 days.			Reported use Stroke survivors and their caregivers reported use of ActivABLES at least five times a week.	The quantitative data from servers and diaries were congruent with each other while reported use in the interview tended to be more than from the servers and diaries.
	Measure	Change in mean from pre to post			
	BREQ-2: Self-determined motivation Non-self-determ. motivation	 28-26 9-8.5	 ↓ 2.0 ↑ 0.5	Interest in further use Stroke survivors reported interest in further use. Caregivers thought their stroke survivor would be interested in further use.	The quantitative results from BREQ-2 does only partially support the qualitative results on interest in further use.
Implementation	In the adherence diaries, the stroke survivors rated the exercises as more difficult in the beginning (5-8) and less difficult (1-5) during the last days of use.			Progression of exercises Stroke survivors reported they had used different levels of the exercises to make them more challenging	In the diaries, the stroke survivors report the exercises becoming less difficult, which is convergent with what they reported in the interviews. Progression should lead to at least the same level of difficulty.
Practicality	Little need for assistance and frequent technical problems was reported in the adherence diaries in forms of yes/no.			Stroke survivors and caregivers reported minimal assistance needed and technical problems of the tools	Quantitative and qualitative data confirm little need for assistance and frequent technical problems.

BBS= Berg Balance Scale, TUG=Timed-Up-and-Go, ABC=Activities-specific Balance Confidence Scale, 5xSST=Five times Sit to Stand, BBT=Box and Block Test, BREQ-2=Behavioural Regulation Exercise Questionnaire 2

Little need for assistance and frequent technical problems was confirmed in the adherence diaries in forms of yes/no, giving quantitative data. The information reported in the diaries supported the data from the interviews about the minimal assistance needed from the caregivers and technical problems of the tools.

4.3.2.4 Case vignette

David was a 71-year-old stroke survivor who had symptoms of hemiparesis. He was discharged from inpatient rehabilitation with a score of three on the Modified Rankin scale (Bonita & Beaglehole, 1988) to his home where he lived with his well-functioning wife, Rose. He had a drop foot splint on his foot and used a crutch when walking. He had problems with his balance and one arm was not functional due to spasticity. He attended an exercise class at the rehabilitation centre twice a week, had a session once a week and went to the swimming pool once a week. Prior to the four-week use of ActivABLES, he stood up on average 29 times per day according to the motion detector, took 1706 steps (57 steps/min) and spent 6.9% of every 24 hours in a standing position, including walking. He sat a lot during the day and used a computer to pass the time. He spent 93.1% of every 24 hours in a sitting or lying position. He relied on Rose with many things indoors and called her frequently during the day for some small errands. David was very interested in testing ActivABLES since he thought there is a big need for follow-up for stroke survivors. He also wanted to contribute to the resources for future stroke survivors.

His main problem was balance impairment and he really wanted to be able to walk without the crutch. He felt his balance was not good enough and, prior to the four-week use of ActivABLES, he rated his balance self-efficacy on the ABC-scale as 55% which is lower than the mean for stroke survivors. He scored 33/56 on BBS balance test which indicates impaired balance and that he might be at risk for falling. He finished TUG in 23 seconds with a crutch, which indicates need for further assessment on mobility and supports the indicated fall risk from BBS. Because of his balance impairment, he was asked to test ActivFOAM, which aims to improve balance. Since he felt his balance was not very good, he really appreciated the opportunity to work on his balance at home.

According to the ActivABLES server, David used ActivFOAM on 26 days in the four-week period and on average for 17 minutes per day. Rose filled out the physical activity diary for most of the days of the four weeks. Rose reported she had to assist David with the exercises during the first days since she felt he was quite unstable when doing the exercises. David was very open-minded, and on his own initiative, he made the exercise area more secure by putting some support next to the exercise foam, which made Rose more comfortable with leaving him alone with the exercises. In the beginning, David was encouraged to do the exercises five times a week for at least 15 minutes per day and he had an ActivLAMP which lit as he progressed with the time of exercise. By the second week, he was encouraged to increase the exercise time to 30 minutes. The lamp reminded him of doing the exercises if it was not all lit up. Gradually, the lamp seemed not to be working and at that time David felt he needed a timer on the screen, so he could follow the time spent in exercising. David thought the scoring during the exercises encouraged him to continue and do better. Rose reported she did not have to encourage him to do exercises.

After the four-week use of ActivABLES, David reported he did the exercises most of the days and Rose agreed with that. He felt his balance had improved and was using his crutch less than before. He also reported he was more confident walking with his cane and even walking without support. He scored higher on BBS (39/56) and needed less time to finish TUG (21.9 seconds), indicating improved balance. In contrast, he scored the same on the ABC (55.3%). Rose reported that she noticed improvement in his balance, he was more independent in different activities and was not calling her as often as before. David wore a motion detector for seven days after the four-week use of ActivABLES. He stood up 33 times on average per day which is 13.8% more than he did a week prior to the intervention.

5 Discussion

5.1 Summary and importance of results

In this thesis, a detailed overview of community-dwelling stroke survivors' functioning is provided, along with both facilitating and hindering contextual factors of their daily lives. Some important differences and similarities in functioning and contextual factors among different age-groups of stroke survivors are introduced in order to direct the focus of rehabilitation and research towards the heterogeneous group of older stroke survivors. Different facilitating contextual factors are described, for example, health services and access to smart devices which have potential to be used for technical interventions in community-based rehabilitation. The process of developing a technical application called ActivABLES to promote therapeutic exercise and daily physical activity is also thoroughly described in this thesis. As a facilitating contextual factor, ActivABLES aims for increased home-based therapeutic exercise and daily physical activity of community-dwelling stroke survivors. The main message from the process of developing is that a technical application like ActivABLES, which is based on use of smart devices, is feasible for stroke survivors to use in their homes and a good asset in the toolbox of rehabilitation professionals who serve community-dwelling stroke survivors.

5.2 Community-dwelling stroke survivors and age

The results from the survey among community-dwelling stroke survivors emphasize the need for exploring functioning and disability among stroke survivors who are older than 65 years of age in different age-groups. We found some differences between the older-old (≥ 75 years old) and younger-old (65-74 years old) individuals as well as some similarities between the younger-old (65-74 years old) and young stroke survivors (<65 years old). These results indicate that 65 years might not be the only ideal cut-off age in research of community-dwelling stroke survivors, even though it is often used when studying this population.

Our survey is the first national survey conducted among stroke survivors in Iceland and the mapping of functioning and contextual factors using ICF along with comparisons across age-groups seems to be a novel approach. Surveys among community-dwelling stroke survivors have been conducted at different time points post-stroke in Australia (Andrew et al., 2014), Ireland (Walsh et al., 2015), Sweden (Tistad et al., 2012; Jönsson et al., 2014) and the United Kingdom (McKevitt et al., 2011). These surveys used different approaches to reveal the personal, social and economic impact of stroke and reflect various factors influencing how long-term clinical and social needs are being met.

5.2.1 Age-groups of stroke survivors

Stroke survivors are often described as one group of people with a wide age span and if there is some comparison between age-groups, there is a wide range of methods of age-groupings (Table 13), which makes comparisons of results difficult. Yet, the results indicate important differences and similarities between the age-groups. At the same time older individuals may be more challenged with stroke related impairments since they may have underlying age related impairments. We should expect the older stroke survivors to be different from the younger ones when looking at activities and participation in their lives. Moreover, there are indications that the oldest stroke survivors are underrepresented in research. As an example, a review on stroke rehabilitation showed that the mean age of stroke survivors participating in studies is almost ten years lower than the global mean age of stroke survivors who use health services (Gaynor et al., 2014).

Table 13. Various grouping of age in studies on stroke survivors.

Definitions of age-groups		
younger and older	<65 and ≥65	(Andrew et al., 2014)
	<70 and ≥70	(de Graaf et al., 2018)
10-year interval	<50, 50-59, 60-69, 70-79, ≥80	(Francois et al., 2014)
20-year interval	20-40, 41-60, 61-80, >80	(Morris et al., 2017)
	<45, 45-64, 65-84, ≥85	(Stein et al., 2020)
Young, young-old, old-	<65, 65-74, 75-84, ≥85	(Jönsson et al., 2014)
old, oldest-old	≤65, 66-75, 76-85, ≥86	(Schnitzer et al., 2015)

Some studies have investigated two different age-groups of stroke survivors, those who are older and younger than 65 years old (Andrew et al., 2014; Bettger et al., 2015), which is a common retirement age and reflects change of roles when people stop working (Hooyman & Kiyak, 2014a; Hooyman & Kiyak, 2014b). Those studies often only reveal some differences in functioning and contextual factors between the age-groups but are not giving a thorough description of the stroke survivors who are 75 years and older. This supports the idea of applying age-groups that are commonly used in gerontological research where the older population is often divided into young-old, old-old and oldest-old. However, in our study the older population (>65 years) was divided into only two age-groups, younger-old (65-74 years old) and older-old (≥ 75 years old), since the oldest participants who were 85 years and older were too few to make a group (n=19).

5.2.2 Balance and falls of older stroke survivors

Balance impairments are common in stroke survivors and affect general mobility and walking ability (Pollock et al., 2011). In our survey, balance impairments were reported as the most frequent main symptom immediately after the stroke (61.4% of participants) and the incidence among individuals in the two older groups was higher than in the youngest group (<65 years old). In total, 29.8% reported having experienced one or more falls in the past year. Falls are important barriers to functioning (Walsh et al., 2015; Andrew et al., 2014; McKevitt et al., 2011). A recent review reported the frequency of falls among community-dwelling stroke survivors to range between 40-58% in the first year after stroke (mean age 69 years) (Xu et al., 2018). The lower fall rate in our study can be explained by a potential recall bias since the stroke survivors had to recall their falls, but in some studies that focus on falls, the data is collected with diaries (Walsh et al., 2018; Xu et al., 2018). Another explanation could be that among the participants are stroke survivors who had their stroke at least one year ago and up to two years ago, which can potentially lower the mean if we expect that falls during 12-24 months after stroke are fewer than during the first year.

Our findings from the SIS-domain of mobility, which includes items on current balance impairments, show that the scoring of the older-old individuals was significantly lower than of the other two age-groups, indicating more impairments with mobility among the oldest group. In a study by Tistad et al. (2012) the total score of the mobility domain was higher than in our study (92 vs 83.3), but there was no comparison between age-groups (mean age 68 years). In another study, where stroke survivors were divided into two age-groups (younger and older than 65 years of age), the mean mobility score was significantly lower among the older group compared with the younger group (Wolf et al, 2012). It would have been interesting to see the results for different age-groups of the older individuals to reflect better the mobility of the individuals older than 75 years.

In our survey, 28.9% of the participants reported use of walking devices and the older-old individuals reported significantly more use than both younger groups. No information can be found on the use of walking devices of community-dwelling stroke survivors in the literature. Due to mobility restrictions of stroke survivors, walking devices have been described as facilitators to activities and participation (Jellema et al., 2016). The older-old (≥75 years) stroke survivors in our survey had more impaired mobility and more walking devices than the younger-old (65-74 years) individuals, which supports the idea of exploring stroke survivors older than 65 years old in more age-groups.

One of the outcomes identified in ActivABLES was balance, based on the literature which shows that stroke survivors often experience balance impairments. ActivFOAM, which was developed for balance exercises, was the exercise prototype that got the most positive feedback and results. Balance impairments were the most reported symptoms immediately after the stroke in our survey. Reflecting on these findings, the development of ActivFOAM is highly relevant. The high prevalence of balance impairments and potential consequences of falls support the idea of developing a technical application to encourage and support home-based balance exercises.

5.2.3 Health and social services in the community

According to clinical guidelines, community-dwelling stroke survivors should have access to outpatient and home-based rehabilitation services (SIGN, 2010; Teasell et al., 2020). Our results showed that was the most used health service 1-2 years after the stroke, with 34.2% of the participants reporting use of in the last month prior to answering the survey. This is in line with the CERISE European study which presented data from four European countries; United Kingdom, Switzerland, Germany and Belgium where was the most used outpatient service beside from medical care from general practitioners (Schupp et al., 2012). Still, the authors concluded that community services need to be better documented to facilitate a more precise comparison on the effectiveness of rehabilitation programmes and aftercare. In Iceland, for outpatient stroke survivors is available in private clinics and stroke survivors´ homes. Speech and language therapy and occupational therapy are provided less and are partly based on the availability of therapists (Icelandic Health Insurance, n.d.). Patients need a referral from their general practitioner to be able to attend outpatient therapy of any kind. At the same time, it depends on the availability of therapists and stroke survivors´ motivation if they will receive therapy of any kind. Home and ambulant nursing are available upon request. Stroke survivors´ use of community services has not been documented, but the results of our survey give good insight into services used.

In our study, there was no difference between the age-groups on use of physiotherapy services, which is different from the results of the CERISE study that showed stroke survivors older than 70 years old were less likely to receive outpatient services than the younger individuals (Schupp et al, 2012). However, the use of social domestic services and adult day-care was more in the oldest group than in the two younger age-groups which indicates worse functioning among the oldest individuals. These results emphasize that rehabilitation professionals need to be aware of the fact that more older individuals survive a stroke and they need rehabilitation services to maximize their functioning (Hubbard et al., 2017). On the other hand, there is a lack of knowledge on use of health and social services in the chronic phase of stroke and more up-to-date information is hard to find.

5.3 Technical applications

Technical applications may be used by stroke survivors in community rehabilitation to assist in maintaining functioning by encouraging therapeutic exercise and daily physical activity. The use of technical applications through smart devices is increasing in rehabilitation among community-dwelling stroke survivors (Paul et al., 2016; Chen et al., 2019; Koh & Hoenig, 2020) and facilitates participation after stroke (Marwaa et al., 2019).

5.3.1 ActivABLES

ActivABLES is a technical application that was developed for community-dwelling stroke survivors to promote therapeutic exercise and daily physical activity. The MRC framework (Craig et al., 2008) provided the guidance for development of ActivABLES, which is a complex intervention with different outcomes including balance, function of upper extremities and walking. It is important to follow a relevant framework when developing successful interventions and MRC has been used for developing complex interventions for stroke survivors (Guidetti et al., 2020). Including future users in the development of complex interventions is also highly valuable (Richardson et al., 2016). Community-dwelling stroke survivors, caregivers and rehabilitation professionals participated from the very beginning of the development process by giving feedback and comments on the ideas and development of the prototypes. Using a human-centred approach and co-design is highly important, with the potential future users participating in every step of the process of developing. In addition, a key element was involving the context of potential future situations in the community where the stroke survivors will use ActivABLES in their own homes.

5.3.1.1 Prototypes of ActivABLES

In the development of ActivABLES, we emphasized the importance of stroke survivors´ being able to use ActivABLES at home. This is in line with what other researches have pointed out, namely that stroke survivors and caregivers have been calling for more follow-up services in the home including more opportunities for therapeutic exercise and physical activity (Krishnan et al., 2017; Hjelle et al., 2017). The participants in our feasibility study also called for resources to use for home-based therapeutic exercise and daily physical activity. The ActivABLES prototypes are small and do not require a big space for use, which is different from many other technical applications, like Wii and Kinect, where a television or a bigger screen is needed. ActivABLES also offers activities aiming for different functional outcomes and does not solely focus on one single exercise or activity, which is often the case with technical applications. The results of the survey also support the idea of ActivABLES where participants mentioned a need for more . Although ActivABLES is not meant to replace rehabilitation services, it has potential to be a good asset for rehabilitation professionals in supporting and empowering the stroke survivors to engage in home-based therapeutic exercise and physical activity. Thus, using ActivABLES can potentially further induce motor learning with specific exercises and repetitions.

5.3.1.2 Feasibility of ActivABLES

The feasibility of ActivABLES was evaluated in terms of acceptability, demand, implementation and practicality. It was encouraging for us to experience the enthusiasm of the participants who were willing to give their time and effort to make the most of ActivABLES. As was concluded from the feasibility study, it is important to have wide range of exercises to avoid tediousness. The stroke survivors who participated in the feasibility study were very excited in the beginning and positive towards using ActivABLES. At the end of the study, many described the importance of variety in exercise and having someone supervising the use of ActivABLES.

ActivABLES was found to be feasible for stroke survivors to use for therapeutic exercise and daily physical activity in homes. The expressed functional improvements of the participants that were reported in the interviews and the higher score of the functional measures after the four-week use support the feasibility of ActivABLES. Most of the participants were quite sedentary prior to the four-week use, although they were having on an individual or group basis at least once a week. Therefore the improvements may not solely be related to the use of ActivABLES, although it seems to have made them more aware of being physically active. The novelty of having a technical application like ActivABLES in their homes seemed to encourage the participants and they were enthusiastic to follow instructions on the use.

Caregivers were included in the feasibility study. They were taught how to use the prototypes and given instructions on supporting and encouraging the stroke survivors to use the prototypes. The stroke survivors had relatively good functioning, which is necessary for individuals to be community-dwelling, and they were quite independent with using ActivABLES in a safe way. Although the stroke survivors did not need much assistance from the caregivers during the four-week use of ActivABLES, the stroke survivors reported a need for supervision. This indicates that professional supervision was needed to support progression of the exercises and discuss the proceedings. Caregivers can give support, but, at the same time, they do not have expertise in exercise and may lack the knowledge and incentive to dedicate themselves to exercise in addition to the well-known burden of being caregivers of stroke survivors. Their role needs to be specific, mostly with the technical process, but in addition a professional supervision is needed.

Although ActivABLES gave promising results, these applications need more developing. In the feasibility study, the participants were most satisfied with ActivFOAM to exercise balance. However, more variety is needed in the exercises and the games used with ActivFOAM. The application for walking, WalkingSTARR, worked well as a step counter and visual feedback but the games within the application were found to appeal more to kids and younger people. The tools for hand- and arm-exercises, ActivBALL and ActivSTICKS, need to be further developed to approach different ways of methods and feedback while exercising as was initially aimed at. The lights, ActivLAMP and ActivTREE, seemed to appeal to the participants. According to the MRC framework (Craig et al, 2008), the next step is to go back into the *development phase* to increase variety in exercise and construct more solid prototypes. Then, further feasibility and pilot studies will be needed with larger samples of community-dwelling stroke survivors.

ActivABLES has potential to be used by different groups of people who might have balance impairments, impaired hand- and arm-function or need encouragement for walking, but further research is needed. ActivABLES might also be used in a different setting, like in hospitals or nursing homes, but further research is needed. Finally, although the use of technical applications in community rehabilitation might not improve functioning more than traditional rehabilitation, the progress is highly comparable. Use of technology could also be more cost-effective and lessen the need for professional involvement. It will also make rehabilitation services more accessible for individuals who live in rural settings and where access to rehabilitation professions is limited or during pandemics when physical distancing is important.

5.3.2 Smart devices

The results from our survey show that participants of all ages have access to some kind of smart device, which provides good opportunities to approach community-dwelling stroke survivors with different technical rehabilitation interventions in their own urban and rural homes. This good access is also highly relevant during COVID times where physical distancing is the main issue (Sheth et al., 2020; Koh & Hoenig, 2020). This access of smart devices is in line with results from a study on Canadian community-dwelling stroke survivors (Edgar et al., 2017). About one-third of the participants in our survey reported they could potentially use smart devices in rehabilitation. Other studies have confirmed that stroke survivors of all ages are interested in using smart devices for rehabilitation, especially those who have an experience of using smart devices (Kerr et al., 2018; Bird et al., 2018; Pugliese et al., 2019). In a study from Canada, 91% of participating stroke survivors (mean age 67.6 years) reported use of the internet and 71% on a daily basis (Edgar et al., 2017).

In our survey, over a quarter of the oldest participants (≥75 years old) and almost three quarters of the younger-old (65-74 years old) used smart devices on a regular basis. Moreover, almost half of the oldest participants and 85% of the younger-old had access to smart devices, which increases the potential for future use. International studies on use of smart devices in the older population of community-dwelling stroke survivors were not found. The stroke survivors in the oldest age-group were born prior to the year 1944 and have experienced enormous changes in the society, including learning to use technical devices like computers, tablets and smart phones. This generation might need more adjustment to this new world of technology than younger generations who are kind of raised up in this technical environment. Despite potential generational differences, older people´s access to smart devices and willingness to use them indicates that rehabilitation professionals must not exclude older people from using technical applications in community rehabilitation. Older adults are willing to learn to use technology in different areas and want to be independent with the use (Astell et al., 2020). Based on this, developing simple technical applications for use in community rehabilitation and exploring the feasibility of such interventions is urgent.

5.3.3 Motivation for exercise and physical activity

The results from the BREQ-2 was used to measure self-determination and non-self-determination for exercise. When compared to other patients group, the self-determination among the stroke survivors was similar to cardiac patients (Sweet et al., 2014), little higher than breast cancer survivors (Milne et al., 2008) and little lower than people with mental illness (Vancampfort et al., 2015). According to the SDT, the self-determination is considered to be more important for individuals and their motivation to exercise than the non-self-determination (Teixeira et al., 2012). In our survey, there was no difference found between the age-groups in self-determination, which indicates that the older population has similar motivation for exercise and may be motivated to change their behaviour and engage in more exercise and physical activity. We have not found studies that have used BREQ-2 in different age-groups.

In our survey, the majority of participants (67.5%) reported physical activity at least three times per week, but less than half (47.4%) fulfilled the instructions on physical activity five times per week. The participants in the feasibility study reported less physical activity. Most of them reported seeing a physical therapist at a clinic a couple of times a week but were otherwise physically inactive until their next session. ActivABLES is an application for physical therapists to prescribe home-based therapeutic exercise and daily for stroke survivors, in addition to their treatment at the clinics, and can encourage the stroke survivor to be more active. ActivABLES can also motivate community-dwelling stroke survivors to continue with home-based therapeutic exercise and engage in physical activity without constant supervision of professionals. For that reason, means to motivate stroke survivors to engage in therapeutic exercise and physical activity are highly important. Community-dwelling stroke survivors are found to be highly inactive physically (English et al., 2014; Fini et al., 2017).

5.4 Methodological considerations

5.4.1 Participants in the survey

The response rate of the survey was 56.2%, which is considered to be good for a mailed population-based survey (Safdar et al., 2016). Although the participants were slightly older than the non-participants, we conclude that the results reflect the status of community-dwelling stroke survivors based on the response rate. The majority of those who gave reasons for not responding to the survey reported good recovery or no interest in answering, while fewer reported dependency and cognitive impairments.

It is interesting to see that only 62.3% of the participants reported a hemiparesis in one of the extremities as a symptom immediately after the stroke. According to the literature, 88% of all individuals admitted with a stroke show sign of hemiparesis (Bonita & Beaglehole, 1988). This difference in prevalence may be the fact that our survey focused on community-dwelling stroke survivors, possibly indicating that those who experience hemiparesis immediately after the stroke may have more severe symptoms, which led them to death, or made them unable to continue living in the be community and more likely to be living in a nursing facilities.

Despite the fact that our survey was a national sample, it is small compared to other national samples due to the small population of Iceland. Therefore, we emphasized to reach all community-dwelling stroke survivors who had experienced a stroke in a one year time period. To avoid sampling bias, we decided to get access to a total sample of stroke survivors from hospital registries, based on diagnosis of stroke. At the same time, some misdiagnosis in registers are well-known (Burns et al., 2011) meaning we might have missed some participants. We may also have missed some potential participants due to wrong address or failure in delivery. Little more than one-third of the participants received some help with completing the survey, which may have prompted responses that were desirable to the proxy as opposed to an accurate self-report from the participant. To avoid response bias, the participants were encouraged to engage in answering the questions based on their current situation with the emphasis of no answers being wrong. Anonymity should also have encouraged participants to give honest answers and avoid socially desired answers, although they were aware of the fact that their names were connected to a code. Still, recall bias is common in surveys since they often require participants to recall memories from the past. In our survey these questions were not many since our aim was to describe the current situation. The two standardized measures were put at the end of the survey to address question order bias. Thus, the participants were allowed to get familiar with the survey and give some more personal/relevant information prior to answering the more complicated measures.

5.4.2 Participants in ActivABLES

The samples in the ActivABLES project were purposive, which is necessary when developing resources for specific group of individuals, in our case, for stroke survivors. Therefore, the participants in the feasibility study might have been more interested and enthusiastic to use technical applications than the general population of community-dwelling stroke survivors and their caregivers. However, our samples included a range of younger and older stroke survivors, as well as both men and women, which indicates that ActivABLES is feasible for individuals of all ages.

5.4.3 Measures

The data in this thesis is based largely on self-reports and qualitative interviews, which are inherently subjective and rooted in the personality and experience of the participants, both the stroke survivors and their caregivers. Additionally in the ActivABLES project, standardized functional measures were conducted to describe and evaluate functioning of stroke survivors participating in the process of developing ActivABLES. The psychometric properties of the Icelandic version of ABC have been tested (Arnadottir et al., 2010), but not of the SIS and BREQ-2, which were chosen based on their content and face validity (Taherdoost, 2018) for Icelandic culture. They were translated and reconstructed into Icelandic using the translation/back-translation method to support the use of the measures within Icelandic culture (Behling & Law, 2000). SIS is a stroke specific measure which supports the choice of this measure. BREQ-2 on the other hand has not been used in studies of stroke survivors. Some missing data was noticed in both of these measures, indicating that participants might have found questions difficult to answer.

5.5 Interpretation

The majority of community-dwelling stroke survivors belong to the heterogenous group of individuals 65 years and older. Our results indicate that it is not sufficient to explore functioning and need for rehabilitation of this population in two different age-groups with the age-cut at 65 years of age. Moreover, it is necessary to take into the account the different functioning and social role of the older individuals which are irrelevant to the stroke incidence itself. Rehabilitation in the chronic state of stroke is of vital importance and can be a life-long process for stroke survivors. The healthcare system is unable to provide sufficient life-long services on a daily basis. Technical applications, like ActivABLES, which was found feasible, have potential to be useful for community-dwelling stroke survivors for home-based therapeutic exercise and daily physical activity. Even though rehabilitation professionals may supervise use of technical applications, it may promote efficient use of staff and cost, but further studies are needed.

6 Conclusions

This thesis describes functioning and contextual factors of community-dwelling stroke survivors in Iceland using the international language of ICF and how stroke survivors can use a technical application for health-promotive physical activities by using smart devices. Most individuals who experience a stroke are older than 65 years old. Our results emphasize the need for more age-specific studies of community-dwelling stroke survivors where more attention is paid to the older populations and the heterogeneity among them. Many of the technical interventions used in community rehabilitation are based on interactive technical applications and use of smart devices. Our survey results on contextual factors show, for example, that stroke survivors of all ages have good access to smart devices, which gives potential for participation and opens up for home-based rehabilitation using these applications. ActivABLES was found feasible to motivate and promote home-based therapeutic exercise and physical activity among community-dwelling stroke survivors and the results show how this form of an interactive technical application can be used by stroke survivors in their homes. For future research it is important to pay attention to the older population and the fact that rehabilitation for community-dwelling stroke survivors is not “one fit for all”. A notice must be taken of the heterogeneity among stroke survivors who have reached the age of 65 years and are considered “*old”*. It is a group of individuals whose age-span is wide and can cover 30-40 years. At the same time, the “baby-boomers” have reached or are approaching the older age and they have lived through the technical age which makes them highly competent in use of technical application in community rehabilitation. Therefore, further studies on technical applications in rehabilitation among community-dwelling stroke survivors of all ages are highly recommended.

References

Adamson, J., Beswick, A., & Ebrahim, S. (2004). Is stroke the most common cause of disability? *Journal of Stroke and Cerebrovascular Diseases, 13*(4), 171-177. https://doi.org/10.1016/j.jstrokecerebrovasdis.2004.06.003

Alankus, G., Lazar, A., May, M., & Kelleher, C. (2010, April). *Towards customizable games for stroke rehabilitation.* Paper presented at the Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, 2113-2122. https://doi.org/10.1145/1753326.1753649

Andrew, N. E., Kilkenny, M., Naylor, R., Purvis, T., Lalor, E., Moloczij, N., & Cadilhac, D. A. (2014). Understanding long-term unmet needs in Australian survivors of stroke. *International Journal of Stroke, 9*(A100), 106-112. https://doi.org/ 10.1111/ijs.12325

Arnadottir, S. A., Lundin-Olsson, L., Gunnarsdottir, E. D., & Fisher, A. G. (2010). Application of Rasch analysis to examine psychometric aspects of the Activities-Specific Balance Confidence Scale when used in a new cultural context. *Archives of Physical Medicine and Rehabilitation, 91*(1), 156-163. https://doi.org/10.1016/j.apmr.2009.09.010

Astell, A. J., McGrath, C., & Dove, E. (2020). “That’s for old so and so’s!”: does identity influence older adults’ technology adoption decisions? *Ageing & Society, 40*(7), 1550-1576. https://doi.org/10.1017/S0144686X19000230

Ayerbe, L., Ayis, S., Wolfe, C. D., & Rudd, A. G. (2013). Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. *The British Journal of Psychiatry, 202*(1), 14-21. https://doi.org/10.1192/bjp.bp.111.107664

Behling, O., & Law, K. S. (2000). *Translating questionnaires and other research instruments: problems and solutions*. Thousand Oaks, CA: Sage.

Béjot, Y., Daubail, B., & Giroud, M. (2016). Epidemiology of stroke and transient ischemic attacks: current knowledge and perspectives. *Revue Neurologique, 172*(1), 59-68. https://doi.org/10.1016/j.neurol.2015.07.013

Berg, K., Wood-Dauphinee, S., & Williams, J. (1995). The Balance Scale: reliability assessment with elderly residents and patients with an acute stroke. *Scandinavian Journal of Rehabilitation Medicine, 27*(1), 27-36.

Berg, K. O., Wood-Dauphinee, S. L., Williams, J. I., & Maki, B. (1992). Measuring balance in the elderly: validation of an instrument. *Canadian Journal of Public Health, 83*(Suppl 2), S7-S11.

Bettger, J. P., McCoy, L., Smith, E. E., Fonarow, G. C., Schwamm, L. H., & Peterson, E. D. (2015). Contemporary trends and predictors of postacute service use and routine discharge home after stroke. *Journal of the American Heart Association, 4*(2), e001038. https://doi.org/10.1161/JAHA.114.001038

Bickenbach, J., Cieza, A., Rauch, A., & Stucki, G. (2012). *ICF core sets: manual for clinical practice.* Göttingen, Germany: Hogrefe Publishing.

Bird, M.-L., Eng, J. J., & Sakakibara, B. M. (2018). Predicting interest to use mobile-device telerehabilitation (mRehab) by baby-boomers with stroke. *AIMS Medical Science, 5*(4), 337-347. https://doi.org/10.3934/medsci.2018.4.337

Bleijenberg, N., Janneke, M., Trappenburg, J. C., Ettema, R. G., Sino, C. G., Heim, N., Hafsteinsdóttir, T. B., Richards, D. A., & Schuurmans, M. J. (2018). Increasing value and reducing waste by optimizing the development of complex interventions: enriching the development phase of the Medical Research Council (MRC) Framework. *International Journal of Nursing Studies, 79*, 86-93. https://doi.org/10.1016/j.ijnurstu.2017.12.001

Blum, L., & Korner-Bitensky, N. (2008). Usefulness of the Berg Balance Scale in stroke rehabilitation: a systematic review. *Physical Therapy, 88*(5), 559-566. https://doi.org/10.2522/ptj.20070205

Bonita, R., & Beaglehole, R. (1988). Recovery of motor function after stroke. *Stroke, 19*(12), 1497-1500. https://doi.org/10.1161/01.STR.19.12.1497

Botner, E. M., Miller, W. C., & Eng, J. J. (2005). Measurement properties of the Activities-specific Balance Confidence Scale among individuals with stroke. *Disability and Rehabilitation, 27*(4), 156-163. https://doi.org/10.1080/09638280400008982

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., Bakken, S., Kaplan, C. P., Squiers, L., Fabrizio, C., & Fernandez, M. (2009). How we design feasibility studies. *American journal of preventive medicine, 36*(5), 452-457. https://doi.org/10.1016/j.amepre.2009.02.002

Bower, K. J., Louie, J., Landesrocha, Y., Seedy, P., Gorelik, A., & Bernhardt, J. (2015). Clinical feasibility of interactive motion-controlled games for stroke rehabilitation. *Journal of Neuroengineering and Rehabilitation, 12*. https://doi.org/10.1186/s12984-015-0057-x

Bruce, J., Ralhan, S., Sheridan, R., Westacott, K., Withers, E., Finnegan, S., Davison J., Martin, F. C., & Lamb, S. E. (2017). The design and development of a complex multifactorial falls assessment intervention for falls prevention: the Prevention of Falls Injury Trial (PreFIT). *BMC Geriatrics, 17*(1), 116. https://doi.org/10.1186/s12877-017-0492-6

Burns, E. M., Rigby, E., Mamidanna, R., Bottle, A., Aylin, P., Ziprin, P., & Faiz, O. D. (2011). Systematic review of discharge coding accuracy. *Journal of Public Health, 34*(1), 138-148. https://doi.org/10.1093/pubmed/fdr054

Carod-Artal, F. J., Coral, L. F., Trizotto, D. S., & Moreira, C. M. (2009). Self- and proxy-report agreement on the Stroke Impact Scale. *Stroke, 40*(10), 3308-3314. https://doi.org/10.1161/STROKEAHA.109.558031

Caspersen, C. J., Powell, K. E., & Christenson, G. M. (1985). Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. *Public Health Reports, 100*(2), 126-131.

Chen, Y., Abel, K. T., Janecek, J. T., Chen, Y., Zheng, K., & Cramer, S. C. (2019). Home-based technologies for stroke rehabilitation: a systematic review. *International Journal of Medical Informatics, 123*, 11-22. https://doi.org/10.1016/j.ijmedinf.2018.12.001

Cheok, G., Tan, D., Low, A., & Hewitt, J. (2015). Is Nintendo Wii an effective intervention for individuals with stroke? A systematic review and meta-analysis. *Journal of the American Medical Directors Association, 16*(11), 923-932. https://doi.org/10.1016/j.jamda.2015.06.010

Cieza, A., Brockow, T., Ewert, T., Amman, E., Kollerits, B., Chatterji, S., Ustün, T. B., & Stucki, G. (2002). Linking health-status measurements to the International Classification of Functioning, Disability and Health. *Journal of Rehabilitation Medicine, 34*(5), 205-210. https://doi.org/10.1080/165019702760279189

Cieza, A., Fayed, N., Bickenbach, J., & Prodinger, B. (2019). Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. *Disability and Rehabilitation, 41*(5), 574-583. https://doi.org/10.3109/09638288.2016.1145258

Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Ustün, T. B., & Stucki, G. (2005). ICF Linking Rules: an update based on lessons learned. *Journal of Rehabilitation Medicine, 37*(4), 212-218. https://doi.org/10.1080/16501970510040263

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal,* 337, a1655. https://doi.org/10.1136/bmj.a1655

Csuka, M., & McCarty, D. J. (1985). Simple method for measurement of lower extremity muscle strength. *The American Journal of Medicine, 78*(1), 77-81. https://doi.org/10.1016/0002-9343(85)90465-6

Cumming, T. B., & Mead, G. (2017). Classifying post-stroke fatigue: optimal cut-off on the Fatigue Assessment Scale. *Journal of Psychosomatic Research, 103*, 147-149. https://doi.org/10.1016/j.jpsychores.2017.10.016

Cumming, T. B., Packer, M., Kramer, S. F., & English, C. (2016). The prevalence of fatigue after stroke: a systematic review and meta-analysis. *International Journal of Stroke, 11*(9), 968-977.

Deci, E. L., & Ryan, R. M. (2004). *Handbook of Self-determination Research*: University of Rochester Press. ISBN 9781580461566

de Graaf, J. A., van Mierlo, M. L., Post, M. W. M., Achterberg, W. P., Kappelle, L. J., & Visser-Meily, J. M. A. (2018). Long-term restrictions in participation in stroke survivors under and over 70 years of age. *Disability and Rehabilitation, 40*(6), 637-645. https://doi.org/10.1080/09638288.2016.1271466

Dempsey, P. C., Biddle, S. J. H., Buman, M. P., Chastin, S., Ekelund, U., Friedenreich, C. M., Katzmarzyk, P. T., Leitzmann, M. F., Stamatakis, E., van der Ploeg, H. P., Willumsen, J., & Bull, F. (2020). New global guidelines on sedentary behaviour and health for adults: broadening the behavioural targets. *International Journal of Behavioral Nutrition and Physical activity, 17*(1), 151. https://doi.org/10.1186/s12966-020-01044-0

Ding, D., Lawson, K. D., Kolbe-Alexander, T. L., Finkelstein, E. A., Katzmarzyk, P. T., van Mechelen, W., & Pratt, M. (2016). The economic burden of physical inactivity: a global analysis of major non-communicable diseases. *The Lancet, 388*(10051), 1311-1324. https://doi.org/10.1016/S01406736(16)30383-X

Dongen, L., Hafsteindottir, T., Parker, E., Bjartmarz, I., Hjaltadottir, I., & Jonsdottir, H. (2021). Stroke survivors' experiences with exercising at home and rebuilding life in the community: a qualitative study. *Nursing Open 00,* 1-11. https://doi.org/10.1002/nop2.788

Doyle, P. J., McNeil, M. R., Bost, J. E., Ross, K. B., Wambaugh, J. L., Hula, W. D., & Mikolic, J. M. (2007). The Burden of Stroke Scale (BOSS) provided valid, reliable, and responsive score estimates of functioning and well-being during the first year of recovery from stroke. *Quality of Life Research, 16*(8), 1389-1398. https://doi.org/10.1007/s11136-007-9247-8

Duncan, P. W., Horner, R. D., Reker, D. M., Samsa, G. P., Hoenig, H., Hamilton, B., LaClair, B. J., & Dudley, T. K. (2002). Adherence to postacute rehabilitation guidelines is associated with functional recovery in stroke. *Stroke, 33*(1), 167-177. https://doi.org/10.1161/hs0102.101014

Duncan, P. W., Wallace, D., Lai, S. M., Johnson, D., Embretson, S., & Laster, L. J. (1999). The Stroke Impact Scale version 2.0: evaluation of reliability, validity, and sensitivity to change. *Stroke, 30*(10), 2131-2140. https://doi.org/10.1161/01.STR.30.10.2131

Edgar, M. C., Monsees, S., Rhebergen, J., Waring, J., Van der Star, T., Eng, J. J., & Sakakibara, B. M. (2017). Telerehabilitation in stroke recovery: a survey on access and willingness to use low-cost consumer technologies. *Telemedicine and e-Health, 23*(5), 421-429. https://doi.org/10.1089/tmj.2016.0129

Edwards, B., & O'connell, B. (2003). Internal consistency and validity of the Stroke Impact Scale 2.0 (SIS 2.0) and SIS-16 in an Australian sample. *Quality of Life Research, 12*(8), 1127-1135. https://doi.org/10.1023/A:1026109920478

Edwardson, C. L., Winkler, E. A., Bodicoat, D. H., Yates, T., Davies, M. J., Dunstan, D. W., & Healy, G. N. (2017). Considerations when using the activPAL monitor in field-based research with adult populations. *Journal of Sport and Health Science, 6*(2), 162-178. https://doi.org/10.1016/j.jshs.2016.02.002

English, C., Healy, G. N., Coates, A., Lewis, L. K., Olds, T., & Bernhardt, J. (2016). Sitting time and physical activity after stroke: Physical ability is only part of the story. *Topics in Stroke Rehabilitation, 23*(1), 36-42. https://doi.org/10.1179/1945511915Y.0000000009

English, C., Manns, P. J., Tucak, C., & Bernhardt, J. (2014). Physical activity and sedentary behaviors in people with stroke living in the community: a systematic review. *Physical Therapy, 94*(2), 185-196. https://doi.org/10.2522/ptj.20130175

Feigin, V. L., Forouzanfar, M. H., Krishnamurthi, R., Mensah, G. A., Connor, M., Bennett, D. A., Moran, A. E., Sacco, R. L., Anderson, L., Truelsen, T., O´Donnell, M., Venketasubramanian, N., Barker-Collo, S., Lawes, C. M., Wang, W., Shinohara, Y., Witt, E., Ezzati, M., Naghavi, M., & Murray, C. (2014). Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet, 383*(9913), 245-254. https://doi.org/10.1016/s0140-6736(13)61953-4

Feldman, R. S., Hupp, S., & Jewell, J. (2019). *Development Across the Life Span*. Essex, England: Pearson.

Field, M. J., Gebruers, N., Shanmuga Sundaram, T., Nicholson, S., & Mead, G. (2013). Physical activity after stroke: a systematic review and meta-analysis. *International Scholarly Research Notices, 2013.* http://doi.org/10.1155/2013/464176

Fini, N. A., Holland, A. E., Keating, J., Simek, J., & Bernhardt, J. (2017). How physically active are people following stroke? Systematic review and quantitative synthesis. *Physical Therapy, 97*(7), 707-717. https://doi.org/10.1093/ptj/pzx038

Flansbjer, U.-B., Blom, J., & Brogårdh, C. (2012). The reproducibility of Berg Balance Scale and the Single-Leg Stance in chronic stroke and the relationship cetween the two tests. *Physical Medicine and Rehabilitation, 4*(3), 165-170. https://doi.org/10.1016/j.pmrj.2011.11.004

Flansbjer, U. B., Holmbäck, A. M., Downham, D., Patten, C., & Lexell, J. (2005). Reliability of gait performance tests in men and women with hemiparesis after stroke. *Journal of Rehabilitation Medicine, 37*(2), 75-82. https://doi.org/10.1080/16501970410017215

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). “Mini-mental state”: a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189-198.

Francois, S., Borgermans, L., Van Casteren, V., Vanthomme, K., & Devroey, D. (2014). Availability of informal caregivers in surviving stroke patients in Belgium. *Scandinavian Journal of Caring Sciences, 28*(4), 683-688. https://doi.org/10.1111/scs.12093

Galvin, R., Cusack, T., & Stokes, E. (2009). To what extent are family members and friends involved in physiotherapy and the delivery of exercises to people with stroke? *Disability and Rehabilitation, 31*(11), 898-905. https://doi.org/10.1080/09638280802356369

Gaynor, E. J., Geoghegan, S. E., & O'Neill, D. (2014). Ageism in stroke rehabilitation studies. *Age and Ageing, 43*(3), 429-431. https://doi.org/10.1093/ageing/afu026

George, M. G., Tong, X., & Bowman, B. A. (2017). Prevalence of cardiovascular risk factors and strokes in younger adults. *JAMA Neurology, 74*(6), 695-703 https://doi.org/10.1001/jamaneurol.2017.0020

Geyh, S., Cieza, A., Schouten, J., Dickson, H., Frommelt, P., Omar, Z., Kostanjsek, N., Ring, H., & Stucki, G. (2004). ICF core sets for stroke. *Journal of Rehabilitation Medicine, 36*(0), 135-141. https://doi.org/10.1080/16501960410016776

Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Blaha, M. J., Dai, S., Ford, E. S., Fox, C. S., Franco, S., Fullerton, H. J., Gillespie, C., Hailpern, S. M., Heit, J. A., Howard, V. J., Huffman, M. D., Judd, S. E., Kissela, B. M., Kittner, S. J., . . . & Turner, M. B. (2014). Heart disease and stroke statistics--2014 update: a report from the American Heart Association. *Circulation, 129*(3), e28-e292. https://doi.org/10.1161/01.cir.0000441139.02102.80

Grimby, G., Willén, C., Engardt, M., & Sunnerhagen, K. S. (2010). Stroke. In S. CJ (Ed.), *Physical activity in the prevention and treatment of disease* (pp. 611–621). Östersund: Swedish: National Institute of Public Health.

Guidetti, S., Eriksson, G., von Koch, L., Johansson, U., & Tham, K. (2020). Activities in daily Living: the development of a new client-centred ADL intervention for persons with stroke. *Scandinavian Journal of Occupational Therapy*, 1-12. https://doi.org/10.1080/11038128.2020.1849392

Guidetti, S., Gustavsson, M., Tham, K., Andersson, M., Fors, U., & Ytterberg, C. (2020). F@ce: a team-based, person-centred intervention for rehabilitation after stroke supported by information and communication technology – a feasibility study. *BMC Neurology, 20*(1), 387. https://doi.org/10.1186/s12883-020-01968-x

Hackett, M. L., & Pickles, K. (2014). Part I: frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. *International Journal of Stroke, 9*(8), 1017-1025. https://doi.org/10.1111/ijs.12357

Hafsteinsdóttir, T. B., Rensink, M., & Schuurmans, M. (2014). Clinimetric Properties of the Timed Up and Go Test for Patients With Stroke: a Systematic Review. *Topics in stroke rehabilitation, 21*(3), 197-210. https://doi.org/10.1310/tsr2103-197

Hafsteinsdóttir, T. B., Vergunst, M., Lindeman, E., & Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient Education and Counseling, 85*(1), 14-25. https://doi.org/10.1016/j.pec.2010.07.046

Hebert, D., Lindsay, M. P., McIntyre, A., Kirton, A., Rumney, P. G., Bagg, S., Bayley, M., Dowlatshahi, Dukelow, S., Garnhum, M., Glasser, E., Halabi, M., Kang, E., MacKay-Lyons, M., Martion, R., Rochette, A., Rowe, S., Salback, N., Semenko, B., . . . & Teasell, R. (2016). Canadian stroke best practice recommendations: stroke rehabilitation practice guidelines, update 2015. *International Journal of Stroke, 11*(4), 459-484. https://doi.org/10.1177/1747493016643553

Held, J. P., Ferrer, B., Mainetti, R., Steblin, A., Hertler, B., Moreno-Conde, A., Dueñas, A., Pajaro, M., Parra-Calderón, C. L., Vargiu, E., Zarco, M. J., Barrera, M., Echevarria, C., Jódar-Sánchez, F., Luft, A. R. & Borghese, N. A. (2018). Autonomous rehabilitation at stroke patients home for balance and gait: safety, usability and compliance of a virtual reality system. *European Journal of Physical and Rehabilitation Medicine, 54*(4), 545-553. https://doi.org/10.23736/S1973-9087.17.04802-X

Hilmarsson, A., Kjartansson, O., & Olafsson, E. (2013). Incidence of first stroke: a population study in Iceland. *Stroke, 44*(6), 1714-1716. https://doi.org/10.1161/strokeaha.111.000222

Hjelle, K. M., Alvsvåg, H., & Førland, O. (2017). The relatives' voice: How do relatives experience participation in reablement? A qualitative study. *Journal of Multidisciplinary Healthcare, 10*, 1. https://doi.org/10.2147/JMDH.S122385

Holloway, I., & Galvin, K. (2016). *Quallitative research in nursing and healthcare* (4th edition ed.). West Sussex: Wiley Blackwell.

Hooyman, N. R., & Asuman Kiyak, H. (2014a). Productive aging: Paid and nonpaid roles and activities. In *Social gerontology. A multidisciplinary perspective* (9th ed.). Boston MA: Pearson Education Limited.

Hooyman, N. R., & Asuman Kiyak, H. (2014b). Social policies to address social problems. In *Social gerontology. A multidisciplinary perspective* (9th ed.). Boston MA: Pearson Education Limited.

Hoyle, M., Gustafsson, L., Meredith, P., & Ownsworth, T. (2012). Participation after stroke: Do we understand all the components and relationships as categorised in the ICF? *Brain Impairment, 13*(1), 4. https://doi.org/10.1017/BrImp.2012.9

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. https://doi.org/10.1177/1049732305276687

Hubbard, I. J., Wass, S., & Pepper, E. (2017). Stroke in older survivors of ischemic stroke: standard care or something different? *Geriatrics, 2*(2), 18. https://doi.org/10.3390/geriatrics2020018

Icelandic Health Insurance. (n.d., Accessed on March 10th 2021.). Retrieved from https://www.sjukra.is/english/social-insurance-in-iceland/

Ingledew, D. K., Markland, D., & Ferguson, E. (2009). Three levels of exercise motivation. *Applied Psychology: Health and Well-being, 1*(3), 336-355. https://doi.org/10.1111/j.1758-0854.2009.01015.x

James Lind Alliance Priority Setting Partnerships (2020). Life after Stroke Top 10. Retrieved from https://www.jla.nihr.ac.uk/priority-setting-partnerships/life-after-stroke/top-10-priorities/

Jellema, S., van der Sande, R., van Hees, S., Zajec, J., Steultjens, E. M., & Nijhuis-van der Sanden, M. W. (2016). Role of environmental factors on resuming valued activities poststroke: a systematic review of qualitative and quantitative findings. *Archives of Physical Medicine and Rehabilitation, 97*(6), 991-1002. e1001. https://doi.org/10.1016/j.apmr.2016.01.015

Jönsson, A.-C., Delavaran, H., Iwarsson, S., Ståhl, A., Norrving, B., & Lindgren, A. (2014). Functional status and patient-reported outcome 10 years after stroke: the Lund Stroke Register. *Stroke, 45*(6), 1784-1790. https://doi.org/10.1161/STROKEAHA.114.005164

Kerr, A., Smith, M., Reid, L., & Baillie, L. (2018). Adoption of stroke rehabilitation technologies by the user community: qualitative study. *JMIR Rehabilitation and Assistive Technologies, 5*(2), e15. https://doi.org/10.2196/rehab.9219

Kleim, J. A., & Jones, T. A. (2008). Principles of experience-dependent neural plasticity: implications for rehabilitation after brain damage. *Journal of Speech, Language, and Hearing Research, 51*(1). https://doi.org/10.1044/1092-4388(2008/018)

Koh, G. C.-H., & Hoenig, H. (2020). How should the rehabilitation community prepare for 2019-nCoV? *Archives of Physical Medicine and Rehabilitation*. https://doi.org/10.1016/j.apmr.2020.03.003

Krishnan, S., Pappadis, M. R., Weller, S. C., Stearnes, M., Kumar, A., Ottenbacher, K. J., & Reistetter, T. A. (2017). Needs of stroke survivors as perceived by their caregivers: a scoping review. *American journal of physical medicine & rehabilitation, 96*(7), 487-505. https://doi.org/10.1097/PHM.0000000000000717

Kyoungwon, S., Jieun, K., Hokyoung, R., & Seongho, J. (2014). 'RehabMasterTM': a Pervasive Rehabilitation. Platform for Stroke Patients and Their Caregivers. In A. Holzinger, M. Ziefle, & C. Röcker (Eds.), *Pervasive Health* (pp. 131-155). London: Springer.

Landerman, L. R., Land, K. C., & Pieper, C. F. (1997). An empirical evaluation of the predictive mean matching method for imputing missing values. *Sociological Methods & Research, 26*(1), 3-33. https://doi.org/10.1177/0049124197026001001

Langhorne, P., Bernhardt, J., & Kwakkel, G. (2011). Stroke rehabilitation. *The Lancet, 377*(9778), 1693-1702. https://doi.org/10.1016/S01406736(11)60325-5

Laver, K. E., Adey-Wakeling, Z., Crotty, M., Lannin, N. A., George, S., & Sherrington, C. (2020). Telerehabilitation services for stroke. *The Cochrane Library*. https://doi.org/10.1002/14651858.CD010255.pub3

Laver, K. E., Lange, B., George, S., Deutsch, J. E., Saposnik, G., & Crotty, M. (2017). Virtual reality for stroke rehabilitation. *The Cochrane Library*. https://doi.org/10.1002/14651858.CD008349.pub4

Lee, M. J., Yoon, S., Kang, J. J., Kim, J., Kim, J. M., & Han, J. Y. (2018). Efficacy and safety of caregiver-mediated exercise in post-stroke rehabilitation. *Annals of Rehabilitation Medicine, 42*(3), 406. https://doi.org/10.5535/arm.2018.42.3.406

Lerdal, A. (2014). Fatigue Severity Scale. In A. C. Michalos (Ed.), *Encyclopedia of Quality of Life and Well-Being Research* (pp. 2218-2221). Dordrecht: Springer Netherlands.

Lima, C. A., Ricci, N. A., Nogueira, E. C., & Perracini, M. R. (2018). The Berg Balance Scale as a clinical screening tool to predict fall risk in older adults: a systematic review. *Physiotherapy, 104*(4), 383-394. https://doi.org/10.1016/j.physio.2018.02.002

Lindsay, P., Furie, K. L., Davis, S. M., Donnan, G. A., & Norrving, B. (2014). World Stroke Organization global stroke services guidelines and action plan. *International Journal of Stroke, 9*(A100), 4-13. https://doi.org/10.1111/ijs.12371

Lohse, K. R., Hilderman, C. G. E., Cheung, K. L., Tatla, S., & Van der Loos, H. F. M. (2014). Virtual reality therapy for adults post-stroke: a systematic review and meta-analysis exploring virtual environments and commercial games in therapy. *PLOS ONE, 9*(3), e93318. https://doi.org/10.1371/journal.pone.0093318

Lutz, B. J., & Camicia, M. (2016). Supporting the needs of stroke caregivers across the care continuum. *Journal of Clinical Outcomes Management, 23*(12), 557-566.

MacFarlane, A., Galvin, R., O'Sullivan, M., McInerney, C., Meagher, E., Burke, D., & LeMaster, J. W. (2017). Participatory methods for research prioritization in primary care: an analysis of the World Café approach in Ireland and the USA. *Family Practice, 34*(3), 278-284. https://doi.org/10.1093/fampra/cmw104

Mackenzie, A., & Greenwood, N. (2012). Positive experiences of caregiving in stroke: a systematic review. *Disability and Rehabilitation, 34*(17), 1413-1422. https://doi.org/10.3109/09638288.2011.650307

Maclean, N., Pound, P., Wolfe, C., & Rudd, A. (2000). Qualitative analysis of stroke patients' motivation for rehabilitation. *British Medical Journal, 321*(7268), 1051-1054. https://doi.org/10.1136/bmj.321.7268.1051

Maguire M. (2001). Methods to support human-centred design. *International Journal of Human-Computer Studies, 55*, 587–634. https://doi.org/10.1006/ijhc.2001.0503

Markland, D. (2009). Exercise motivation measurement: The Behavioural Regulation Exercise Questionnaire. Retrieved from http://pages.bangor.ac.uk/~pes004/exercise_motivation/scales.htm

Markland, D., & Tobin, V. (2004). A modification to the Behavioural Regulation in Exercise Questionnaire to include an assessment of amotivation. *Journal of Sport and Exercise Psychology, 26*(2), 191-196. https://doi.org/10.1123/jsep.26.2.191

Marwaa, M. N., Ytterberg, C., & Guidetti, S. (2019). Significant others' perspectives on person-centred information and communication technology in stroke rehabilitation – A grounded theory study. *Disability and Rehabilitation*, 1-8. https://doi.org/10.1080/09638288.2018.1555614

Mathias, S., Nayak, U., & Isaacs, B. (1986). Balance in elderly patients: the" get-up and go" test. *Archives of Physical Medicine and Rehabilitation, 67*(6), 387-389.

Mathiowetz, V., Volland, G., Kashman, N., & Weber, K. (1985). Adult norms for the Box and Block Test of manual dexterity. *American Journal of Occupational Therapy, 39*(6), 386-391. https://doi.org/10.5014/ajot.39.6.386

Mathisen, S., Larsen, J., & Kurz, M. (2017). The prognosis of stroke survivors primarily discharged to their homes. *Acta Neurologica Scandinavica, 136*(4), 338-344. https://doi.org/10.1111/ane.12731

Mawson, S., Nasr, N., Parker, J., Davies, R., Zheng, H., & Mountain, G. (2016). A Personalized self-management rehabilitation system with an intelligent shoe for stroke survivors: a realist evaluation. *JMIR Rehabilitation and Assistive Technologies, 3*(1), e1. https://doi.org/10.2196/rehab.5079

McKevitt, C., Fudge, N., Redfern, J., Sheldenkar, A., Crichton, S., Rudd, A. R., Forster, A., Young, J., Nazareth, I., Silver, L. E., Rothwell P. M., & Wolfe C. D. A. (2011). Self-reported long-term needs after stroke. *Stroke, 42*(5), 1398-1403. https://doi.org/10.1161/STROKEAHA.110.598839

Miller, E. L., Murray, L., Richards, L., Zorowitz, R. D., Bakas, T., Clark, P., & Billinger, S. A. (2010). Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. *Stroke, 41*(10), 2402-2448. https://doi.org/10.1161/STR.0b013e3181e7512b

Miller, K. K., Porter, R. E., DeBaun-Sprague, E., Van Puymbroeck, M., & Schmid, A. A. (2017). Exercise after stroke: patient adherence and beliefs after discharge from rehabilitation. *Topics in Stroke Rehabilitation, 24*(2), 142-148. https://doi.org/10.1080/10749357.2016.1200292

Milne, H. M., Wallman, K. E., Gordon, S., & Courneya, K. S. (2008). Impact of a combined resistance and aerobic exercise program on motivational variables in breast cancer survivors: a randomized controlled trial. *Annals of Behavioral Medicine, 36*(2), 158-166. https://doi.org/10.1007/s1216000890592

Minet, L. R., Peterson, E., von Koch, L., & Ytterberg, C. (2015). Occurrence and predictors of falls in people with stroke: six-year prospective study. *Stroke, 46*(9), 2688-2690. https://doi.org/10.1161/STROKEAHA.115.010496

Mirza-Babaei, P., Kamkarhaghighi, M., Filho, F., & Gerlin, K. (2014). *Opportunities in Game-Based Stroke Rehabilitation*. In *2014 IEEE Games Media Entertainment* (pp. 1-4). IEEE. https://doi.org/10.1109/GEM.2014.7118436

Mohan, K. M., Wolfe, C. D. A., Rudd, A. G., Heuschmann, P. U., Kolominsky-Rabas, P. L., & Grieve, A. P. (2011). Risk and cumulative risk of stroke recurrence. *Stroke, 42*(5), 1489-1494. https://doi.org/10.1161/STROKEAHA.110.602615

Morris, J. H., Oliver, T., Kroll, T., Joice, S., & Williams, B. (2017). Physical activity participation in community dwelling stroke survivors: synergy and dissonance between motivation and capability. A qualitative study. *Physiotherapy, 103*(3), 311-321. https://doi.org/10.1016/j.physio.2016.05.001

Nicholson, S., Sniehotta, F. F., van Wijck, F., Greig, C. A., Johnston, M., McMurdo, M. E., . . . Mead, G. E. (2013). A systematic review of perceived barriers and motivators to physical activity after stroke. *International Journal of Stroke, 8*(5), 357-364. https://doi.org/10.1111/j.1747-4949.2012.00880.x

Nicholson, S., Sniehotta, F. F., van Wijck, F., Greig, C. A., Johnston, M., McMurdo, M. E., Dennis, M., & Mead, G. E. (2013). A systematic review of perceived barriers and motivators to physical activity after stroke. *International Journal of Stroke, 8*(5), 357-364.https://doi.org/10.1111/j.17474949.2012.00880.x

Obradovic, M., Lal, A., & Liedgens, H. (2013). Validity and responsiveness of EuroQol-5 dimension (EQ-5D) versus Short Form-6 dimension (SF-6D) questionnaire in chronic pain. *Health and Quality of Life Outcomes, 11*(1), 110. https://doi.org/10.1186/1477-7525-11-110

Orimo, H., Ito, H., Suzuki, T., Araki, A., Hosoi, T., & Sawabe, M. (2006). Reviewing the definition of “elderly”. *Geriatrics & Gerontology International, 6*. https://doi.org/10.1111/j.1447-0594.2006.00341.x

Ouchi, Y., Rakugi, H., Arai, H., Akishita, M., Ito, H., Toba, K., & Kai, I. (2017). Redefining the elderly as aged 75 years and older: proposal from the Joint Committee of Japan Gerontological Society and the Japan Geriatrics Society. *Geriatrics & Gerontology International 17*(7), 1045-1047. https://doi.org/10.1111/ggi.13118

Paul, L., Wyke, S., Brewster, S., Sattar, N., Gill, J. M., Alexander, G., Rafferty, D., McFadyen, A. K., Ramsay, A. & Dybus, A. (2016). Increasing physical activity in stroke survivors using STARFISH, an interactive mobile phone application: a pilot study. *Topics in Stroke Rehabilitation, 23*(3), 170-177. https://doi.org/10.1080/10749357.2015.1122266

Perneger, T. V. (1998). What's wrong with Bonferroni adjustments. *British Medical Journal, 316*(7139), 1236-1238.https://doi.org/10.1136/bmj.316.7139.1236

Pilipiec, P., Groot, W., & Pavlova, M. (2020). The effect of an increase of the retirement age on the health, well-being, and labor force participation of older workers: a systematic literature review. *Journal of Population Ageing*. https://doi.org/10.1007/s12062-020-09280-9

Platz, T., Pinkowski, C., van Wijck, F., Kim, I.-H., di Bella, P., & Johnson, G. (2005). Reliability and validity of arm function assessment with standardized guidelines for the Fugl-Meyer Test, Action Research Arm Test and Box and Block Test: a multicentre study. *Clinical rehabilitation, 19*(4), 404-411. https://doi.org/10.1191/0269215505cr832oa

Podsiadlo, D., & Richardson, S. (1991). The timed “Up & Go”: a test of basic functional mobility for frail elderly persons. *Journal of the American geriatrics Society, 39*(2), 142-148. https://doi.org/10.1111/j.15325415.1991.tb01616.x

Pollock, A., Baer, G., Campbell, C., Choo, P. L., Forster, A., Morris, J., Pomeroy, V. M., & Langhorne, P. (2014). Physical rehabilitation approaches for the recovery of function and mobility after stroke. *Stroke, 45*(10), e202-e202. https://doi.org/10.1161/STROKEAHA.114.006275

Pollock, A., St George, B., Fenton, M., & Firkins, L. (2014). Top 10 research priorities relating to life after stroke - Consensus from stroke survivors, caregivers, and health professionals. *International Journal of Stroke, 9*, 313-320. https://doi.org/10.1111/j.1747-4949.2012.00942.x

Pollock, C., Eng, J., & Garland, S. (2011). Clinical measurement of walking balance in people post stroke: a systematic review. *Clinical Rehabilitation, 25*(8), 693-708. https://doi.org/10.1177/0269215510397394

Poltawski, L., Boddy, K., Forster, A., Goodwin, V. A., Pavey, A. C., & Dean, S. (2015). Motivators for uptake and maintenance of exercise: perceptions of long-term stroke survivors and implications for design of exercise programmes. *Disability and Rehabilitation, 37*(9), 795-801. https://doi.org/10.3109/09638288.2014.946154

Powell, L. E., & Myers, A. M. (1995). The Activities-specific Balance Confidence (ABC) Scale. *The Journals of Gerontology: Series A, 50A*(1), M28-M34. https://doi.org/10.1093/gerona/50A.1.M28

Pugliese, M., Ramsay, T., Shamloul, R., Mallet, K., Zakutney, L., Corbett, D., Dukelow, S., Stotts, G., Shamy, M., Wilson, K., Guerinet, J., & Dowlatshahi D. (2019). RecoverNow: a mobile tablet-based therapy platform for early stroke rehabilitation. *PLOS ONE, 14*(1), e0210725. https://doi.org/10.1371/journal.pone.0210725

Putrino, D., Zanders, H., Hamilton, T., Rykman, A., Lee, P., & Edwards, D. J. (2017). Patient engagement is related to impairment reduction during digital game-based therapy in stroke. *Games for Health Journal, 6*(5), 295-302. https://doi.org/10.1089/g4h.2016.0108

Pyae, A., Luimula, M., & Smed, J. (2014, October). Understanding stroke patients' motivation for motivation-driven rehabilitative game design. In *International Internet of Things Summit* (pp. 99-111). Springer, Cham.

Rassmus-Gröhn, K., Magnusson, C., Rydeman, B., Randall, G., & Belson, S. (2017). Conjuring up new technology - using magic objects in co-ideation with stroke survivors. *Studies in Health Technology and Informatics, 242*, 429-436. https://doi.org/10.3233

Rensink, M., Schuurmans, M., Lindeman, E., & Hafsteinsdottir, T. (2009). Task-oriented training in rehabilitation after stroke: systematic review. *Journal of Advanced Nursing, 65*(4), 737-754.https://doi.org/10.1111/j.13652648.2008.04925.x

Richards, D. A., & Hallberg, I. R. (2015). *Complex Interventions in Health: An Overview of Research Methods.* London and New York: Routledge.

Richardson, M., Campbell, N., Allen, L., Meyer, M., & Teasell, R. (2016). The Stroke Impact Scale: performance as a quality of life measure in a community-based stroke rehabilitation setting. *Disability and Rehabilitation, 38*(14), 1425-1430. https://doi.org/10.3109/09638288.2015.1102337

Rintala, A., Päivärinne, V., Hakala, S., Paltamaa, J., Heinonen, A., Karvanen, J., & Sjögren, T. (2019). Effectiveness of technology-based distance physical rehabilitation interventions for improving physical functioning in stroke: a systematic review and meta-analysis of randomized controlled trials. *Archives of Physical Medicine and Rehabilitation, 100*(7), 1339-1358. https://doi.org/10.1016/j.apmr.2018.11.007

Robert G. Robinson, & Ricardo E. Jorge. (2016). Post-Stroke Depression: a Review. *American Journal of Psychiatry, 173*(3), 221-231. https://doi.org/10.1176/appi.ajp.2015.15030363

Roger, V. L., Go, A. S., Lloyd-Jones, D. M., Benjamin, E. J., Berry, J. D., Borden, W. B., Bravata, D. M., Dai, S., Ford, E. S., Fox, C. S., Fullerton, H. J., Gillespie, C., Hailpern, S. M., Heit, J. A., Howard, V. J., Kissela, B. M., Kittner, S. J., Lackland, D. T., Lichtman, J. H. … & Turner, M. B. (2012). Heart disease and stroke statistics--2012 update: a report from the American Heart Association. *Circulation, 125*(1), e2-e220.

Sacco, R. L., Kasner, S. E., Broderick, J. P., Caplan, L. R., Connors, J. J., Culebras, A., Elkind, M. S. V., George, M. G., Hamdan, A. D., Higashida, R. T., Hoh, B. L., Janis, L. S., Kase, C. S., Kleindorfer, D. O., Lee, J., Moseley, M. E., Peterson, E. D., Turan, T. N., Valderrama, A. L., & Vinters, H. V. (2013). An updated definition of stroke for the 21st century. *Stroke, 44*(7), 2064-2089. https://doi.org/10.1161/STR.0b013e318296aeca

Safdar, N., Abbo, L. M., Knobloch, M. J., & Seo, S. K. (2016). Research methods in healthcare epidemiology: survey and qualitative research. *Infection Control and Hospital Epidemiology, 37*(11), 1272. https://doi.org/10.1017/ice.2016.171

Salbach, N. M., Mayo, N. E., Hanley, J. A., Richards, C. L., & Wood-Dauphinee, S. (2006). Psychometric evaluation of the original and Canadian French version of the Activities-Specific Balance Confidence Scale among people with stroke. *Archives of Physical Medicine and Rehabilitation, 87*(12), 1597-1604. https://doi.org/10.1016/j.apmr.2006.08.336

Samuelsson, C. M., Hansson, P.-O., & Persson, C. U. (2019). Early prediction of falls after stroke: a 12-month follow-up of 490 patients in The Fall Study of Gothenburg (FallsGOT). *Clinical Rehabilitation, 33*(4), 773-783. https://doi.org/10.1177/0269215518819701

Sarfo, F. S., Ulasavets, U., Opare-Sem, O. K., & Ovbiagele, B. (2018). Tele-rehabilitation after stroke: an updated systematic review of the literature. *Journal of Stroke and Cerebrovascular Diseases, 27*(9), 2306-2318. https://doi.org/10.1016/j.jstrokecerebrovasdis.2018.05.013

Saunders, D. H., Sanderson, M., Brazzelli, M., Greig, C. A., & Mead, G. E. (2013). Physical fitness training for stroke patients. *Cochrane Library.* https://doi.org/10.1002/14651858.CD003316.pub5

Saywell, N., Taylor, N., Rodgers, E., Skinner, L., & Boocock, M. (2017). Play-based interventions improve physical function for people with adult-acquired brain injury: a systematic review and meta-analysis of randomised controlled trials. *Clinical Rehabilitation, 31*(2), 145-157. https://doi.org/10.1177/0269215516631384

Schaechter, J. D. (2004). Motor rehabilitation and brain plasticity after hemiparetic stroke. *Progress in Neurobiology, 73*(1), 61-72. https://doi.org/10.1016/j.pneurobio.2004.04.001

Schmid, A. A., Van Puymbroeck, M., Altenburger, P. A., Dierks, T. A., Miller, K. K., Damush, T. M., & Williams, L. S. (2012). Balance and balance self-efficacy are associated with activity and participation after stroke: a cross-sectional study in people with chronic stroke. *Archives of Physical Medicine and Rehabilitation, 93*(6), 1101-1107. https://doi.org/10.1016/j.apmr.2012.01.020

Schnitzer, S., von dem Knesebeck, O., Kohler, M., Peschke, D., Kuhlmey, A., & Schenk, L. (2015). How does age affect the care dependency risk one year after stroke? A study based on claims data from a German health insurance fund. *BMC Geriatrics, 15*(1), 135. https://doi.org/10.1186/s12877015-0130-0

Schupp, W., Komaratat, N., & Steib, S. (2012). Running a Complementary Stroke Rehabilitation and Aftercare Program: Experiences of Four European Centres. In *Physical Therapy Perspectives in the 21st Century-Challenges and Possibilities*: IntechOpen.

Seo, K., Kim, J., Ryu, H., & Jang, S. (2014). ‘RehabMasterTM’: A pervasive rehabilitation platform for stroke patients and their caregivers. In A. Holzinger, M. Ziefle, & C. Röcker (Eds.), *Pervasive Health: State-of-the-art and Beyond*. London: Springer Science & Business Media.

Sheth, S. A., Wu, T.-C., Sharrief, A., Ankrom, C., Grotta, J. C., Fisher, M., & Savitz, S. I. (2020). Early lessons from world war COVID: reinventing our stroke systems of care. *Stroke, 51*, 2268-2272. https://doi.org/10.1161/strokeaha.120.030154

Shumway-Cook, A., & Woollacott, M. H. (2017). *Motor control: Translating research into clinical practice* (5th edition ed.). Philadelpha PA: Wolters Kluwer.

SIGN, Scottish Intercollegiate Guidelines Network (2010). *Management of patients with stroke: rehabilitation, prevention and management of complications, and discharge planning. A national clincial guideline*. ISBN 978 1 905813 63 6. Retrieved from https://www.sign.ac.uk/media/1056/sign118.pdf

Silva, P. F. S., Quintino, L. F., Franco, J., & Faria, C. D. C. M. (2014). Measurement properties and feasibility of clinical tests to assess sit-to-stand/stand-to-sit tasks in subjects with neurological disease: a systematic review. *Brazilian journal of physical therapy, 18*, 99-110. https://doi.org/10.1590/S1413-35552012005000155

Stein, J., Borg-Jensen, P., Sicklick, A., Rodstein, B. M., Hedeman, R., Bettger, J. P., Hemmitt, R., Silver, B. M., Thode, H. C., & Magdon-Ismail, Z. (2020). Are Stroke Survivors Discharged to the Recommended Postacute Setting? *Archives of Physical Medicine and Rehabilitation, 101*(7), 1190-1198. https://doi.org/10.1016/j.apmr.2020.03.006

Sweet, S. N., Fortier, M. S., Strachan, S. M., Blanchard, C. M., & Boulay, P. (2014). Testing a longitudinal integrated self-efficacy and self-determination theory model for physical activity post-cardiac rehabilitation. *Health Psychology Research, 2*(1). https://doi.org/10.4081/hpr.2014.1008

Taherdoost, H. (2018). Validity and reliability of the research instrument; how to test the validation of a questionnaire survey in a research. *International Journal of Academic Research in Management, 5*(3), 28-36. http://doi.org/10.2139/ssrn.3205040

Taylor, N. F., Dodd, K. J., Shields, N., & Bruder, A. (2007). Therapeutic exercise in physiotherapy practice is beneficial: a summary of systematic reviews 2002–2005. *Australian Journal of Physiotherapy, 53*(1), 7-16. https://doi.org/10.1016/S0004-9514(07)70057-0

Teasell, R., Fernandez, M., McIntyre, A., & Mehta, S. (2014). Rethinking the continuum of stroke rehabilitation. *Archives of Physical Medicine and Rehabilitation, 95*(4), 595-596. https://doi.org/10.1016/j.apmr.2013.11.014

Teasell, R., Meyer, M. J., McClure, A., Pan, C., Murie-Fernandez, M., Foley, N., & Salter, K. (2009). Stroke rehabilitation: an international perspective. *Topics in Stroke Rehabilitation, 16*(1), 44-56. https://doi.org/10.1310/tsr160144

Teasell, R., Salbach, N. M., Foley, N., Mountain, A., Cameron, J. I., Jong, A., Acerra, N. E., Bastasi, D., Carter, S. L., Fung, J., Halabi, M., Iruthayarajah, J., Harris, J., Kim, E., Noland, A., Pooyania, S., Rochette, A., Stack, B. D., Symcox, E., . . . & Lindsay M. P. (2020). Canadian stroke best practice recommendations: rehabilitation, recovery, and community participation following stroke. Part one: rehabilitation and recovery following stroke; Update 2019. *International Journal of Stroke, 15*(7), 763-788. https://doi.org/10.1177/1747493019897843

Teixeira, P. J., Carraça, E. V., Markland, D., Silva, M. N., & Ryan, R. M. (2012). Exercise, physical activity, and self-determination theory: a systematic review. *International Journal of Behavioral Nutrition and Physical Activity, 9*(1), 1-30. https://doi.org/10.1186/1479-5868-9-78

Thomas, L. H., French, B., Coupe, J., McMahon, N., Connell, L., Harrison, J., Sutton, C. J., Tishkovskaya S., & Watkins, C. L. (2017). Repetitive task training for improving functional ability after stroke: a major update of a Cochrane review. *Stroke, 48*(4), e102-e103. https://doi.org/10.1161/STROKEAHA.117.016503

Tistad, M., Tham, K., von Koch, L., & Ytterberg, C. (2012). Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: an explorative observational study. *BMC Neurology, 12*(1), 40. https://doi.org/10.1186/1471-2377-12-40

Törnbom, K., Persson, H., Lundälv, J., & Sunnerhagen, K. (2017). The impact of physical function on participation in the first year post-stroke. *Acta Neurologica Scandinavia, 135*(6), 649-655. https://doi.org/10.1111/ane.12661

Tyson, S. F., Hanley, M., Chillala, J., Selley, A., & Tallis, R. C. (2006). Balance Disability After Stroke. *Physical Therapy, 86*(1), 30-38. https://doi.org10.1093/ptj/86.1.30

Van Der Zee, C. H., Visser-Meily, J. M., Lindeman, E., Jaap Kappelle, L., & Post, M. W. (2013). Participation in the chronic phase of stroke. *Topics in Stroke Rehabilitation, 20*(1), 52-61. https://doi.org/10.1310/tsr2001-52

Vancampfort, D., De Hert, M., Vansteenkiste, M., De Herdt, A., Scheewe, T. W., Soundy, A., Stubbs, B., & Probst, M. (2013). The importance of self-determined motivation towards physical activity in patients with schizophrenia. *Psychiatry Research, 210*(3), 812-818. https://doi.org/10.1016/j.psychres.2013.10.004

Vancampfort, D., Stubbs, B., Venigalla, S. K., & Probst, M. (2015). Adopting and maintaining physical activity behaviours in people with severe mental illness: the importance of autonomous motivation. *Preventive Medicine, 81*, 216-220. https://doi.org/10.1016/j.ypmed.2015.09.006

Veerbeek, J. M., van Wegen, E., van Peppen, R., van der Wees, P. J., Hendriks, E., Rietberg, M., & Kwakkel, G. (2014). What is the evidence for physical therapy poststroke? A systematic review and meta-analysis. *PLOS ONE, 9*(2), e87987. https://doi.org/10.1371/journal.pone.0087987

Vloothuis, J. D., Mulder, M., Nijland, R. H., Goedhart, Q. S., Konijnenbelt, M., Mulder, H., Hertogh C. M., van Tulder, M., van Wegen, E. E., & Kwakkel, G. (2019). Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): a randomized controlled trial. *PLOS ONE, 14*(4), e0214241. https://doi.org/10.1371/journal.pone.0214241

Vloothuis, J. D., Mulder, M., Veerbeek, J. M., Konijnenbelt, M., Visser-Meily, J. M., Ket, J. C., Kwakkel, G. & van Wegen, E. E. (2016). Caregiver-mediated exercises for improving outcomes after stroke. *Cochrane Library.* https://doi.org/10.1002/14651858.CD011058.pub2

Wafa, H. A., Wolfe, C. D. A., Emmett, E., Roth, G. A., Johnson, C. O., & Wang, Y. (2020). Burden of stroke in Europe. *Stroke, 51*(8), 2418-2427. https://doi.org/10.1161/STROKEAHA.120.029606

Walsh, M., Galvin, R., Loughnane, C., Macey, C., & Horgan, N. F. (2015). Community re-integration and long-term need in the first five years after stroke: Results from a national survey. *Disability and Rehabilitation, 37*(20), 1834-1838. https://doi.org/10.3109/09638288.2014.981302

Walsh, M. E., Galvin, R., Williams, D. J., Harbison, J. A., Murphy, S., Collins, R., McCabe, D. J. H., Crowe, N., & Horgan, N. F. (2018). Falls-Related EvEnts in the first year after StrokE in Ireland: results of the multi-centre prospective FREESE cohort study. *European Stroke Journal, 3*(3), 246-253. https://doi.org/10.1177/2396987318764961

Warlow, C., Sudlow, C., Dennis, M., Wardlaw, J., & Sandercock, P. (2003). Stroke. *The Lancet, 362*(9391), 1211-1224. https://doi.org/10.1016/S01406736(03)14544-8

WHO. (2001). *International classification of functioning, disability, and health: ICF*. Geneva: World Health Organization.

WHO. (2002). *Towards a common language for Functioning, Disability and Health:ICF*. Geneva: WHO.

WHO. (2013). *How to use the ICF: a practical manual for using the International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO.

Wilson, P. M., Sabiston, C. M., Mack, D. E., & Blanchard, C. M. (2012). On the nature and function of scoring protocols used in exercise motivation research: an empirical study of the behavioral regulation in exercise questionnaire. *Psychology of Sport and Exercice, 13*(5), 614-622. https://doi.org/10.1016/j.psychsport.2012.03.009

Winstein, C. J., Stein, J., Arena, R., Bates, B., Cherney, L. R., Cramer, S. C., Deruyter, F., Eng, J. J., Fisher, B., Harvey, R. L., Lang, C. E., MacKay-Lyons, M., Ottenbacher, K. J., Pugh, S., Reeves, M. J., Richards, L. G., Stiers, W., & Zorowitz, R. D. (2016). Guidelines for Adult Stroke Rehabilitation and Recovery. *A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association, 47*(6), e98-e169. https://doi.org/10.1161/str.0000000000000098

Wolf, T. J., Brey, J. K., Baum, C., & Connor, L. T. (2012). Activity participation differences between younger and older individuals with stroke. *Brain Impairment, 13*(1), 16-23.

Xu, T., Clemson, L., O'Loughlin, K., Lannin, N. A., Dean, C., & Koh, G. (2018). Risk factors for falls in community stroke survivors: a systematic review and meta-analysis. *Archives of Physical Medicine and Rehabilitation, 99*(3), 563-573.e565. https://doi.org/10.1016/j.apmr.2017.06.032

Yang, C.-C., & Hsu, Y.-L. (2010). A review of accelerometry-based wearable motion detectors for physical activity monitoring. *Sensors, 10*(8), 7772-7788. https://doi.org/10.3390/s100807772

Paper I

Age differences in Functioning and contextual factors in community-dwelling stroke survivors: A national cross-sectional survey

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Abstract

Background: The heterogeneous group of community-dwelling stroke survivors across a wide age-span and different disabilities needs diverse rehabilitation that is tailored to the needs of the individuals. Therefore, it is important to gain a thorough understanding of the functioning and contextual factors and to examine further how older age affects this population. Our study aimed to map functioning and contextual factors among community-dwelling stroke survivors, based on the International Classification of Functioning, Disability and Health (ICF), and to explore if these factors differ among older-old (75 years and older), younger-old (65-74 years), and young (18-65 years) stroke survivors.

Methods: A cross-sectional population-based national survey among community-dwelling stroke survivors, 1-2 years after their first stroke. Potential participants were approached through hospital registries. The survey had 56.2% response rate. Participants (N=114, 50% men), 27 to 94 years old (71.6±12.9 years), were categorized as: older-old (n=51), younger-old (n=34) and young (n=29). They answered questions on health, functioning and contextual factors, the Stroke Impact Scale (SIS) and the Behavioural Regulation Exercise Questionnaire-2.

Results: The responses reflected ICF´s personal and environmental factors as well as body function, activities, and participation. Comparisons between age-groups revealed that the oldest participants reported more anxiety and depression and used more walking devices and fewer smart devices than individuals in both the younger-old and young groups. In the SIS, the oldest participants had lower scores than both younger groups in the domains of activities of daily living and mobility.

Conclusion: These findings provide important information on needs and opportunities in community-based intervention for stroke-survivors, and reveal that this population has good access to smart devices which can be used in community rehabilitation. Moreover, our results support the need for analysis in subgroups of age among the heterogenous group of older individuals in this population.

Key words:

Stroke rehabilitation, Independent living, Age distribution, Patient Reported Outcome Measures, Disability evaluation, Biopsychosocial Models

Introduction

Stroke is one of the primary causes of chronic disability in the Western world [1]. The incidence of stroke increases with age [1], and despite the fact that stroke can happen at any age, 75% of all strokes are among adults older than 65 years of age [2]. After hospitalization and/or inpatient rehabilitation, the majority of stroke survivors are discharged home where they may need appropriate rehabilitation to maximize their functioning [3-5]. For effective rehabilitation interventions, it is crucial to understand the complex underlying factors that create rehabilitation needs and contribute to positive outcomes in rehabilitation. Many recent studies have focused on innovative technical interventions and smart devices to provide rehabilitation to community-dwelling stroke survivors [6] and during the ongoing Covid-19 pandemic, there has been a surge in the implementation of telerehabilitation for these clients, which includes use of smart devices [7]. Therefore, it is important to recognise the access and use smart devices in different age groups as well as the age-related differences in the recovery post-stroke among community-dwelling stroke survivors. Moreover, the theoretical framework from the World Health Organization, International Classification of Functioning, Disability and Health (ICF) [8] is useful to map and recognise various factors in surveys and identify the opportunities for rehabilitation interventions [9].

Among these underlying factors are age-related changes in physical, cognitive, personal and psychosocial function affect the health and functioning of each individual [10]. Therefore, older community-dwelling stroke survivors may be more challenged than younger ones with impairments after stroke in addition to age-related disability. In addition, older stroke survivors might be less willing to use modern telerehabilitation due to attitudes towards technology and computer anxiety [11]. Despite that, stroke survivors are often presented as one group in studies, regardless of age [3,12-17]. Given the high incidence of stroke in the older population, heterogeneity among people who have reached the age of 65 years, and the worldwide emphasis on aging in place, only a limited number of studies have attempted to gain a deeper understanding of older age on community-dwelling stroke survivors [18-20]. Some studies have used the cut-off age of 65 years to compare stroke survivors, and only revealed minor differences in functioning between the age-groups [21-22], indicating the need to improve the consideration of age in more subgroups. These studies may not have captured the important variations in functioning and contextual factors among the heterogeneous group of stroke survivors older than 65 years old.

Applying gerontological theory in stroke research may be a useful approach for older age categorization in the stroke literature. Within gerontological research, the classic definition of *old* has been 65 years, the age when individuals can retire [23] and collect social security benefits [24]. On the other hand, there has been a call for changing this definition of old to 75 years of age based on increased life expectancy, functional independence and more employment of older people [25-27]. Research on stroke may benefit from exploring how the definition of old age being 75 years of age fits the population of older stroke survivors, and whether either cut-off point (75 or 65 years) is helpful in creating meaningful older age categories among stroke survivors who are healthy enough to be community-dwelling. Based on this, the group aged 75 years and older could be categorized as old and reflect people who are expected to have substantial age-related changes in functioning and social roles; the group aged 65-74 years old could be categorized as younger-old and reflect people who are approaching older age with potential age-related changes in social roles and functioning; and those who are younger than 65 years could be categorized as young and middle-aged and reflect those who are expected to be following their career and engaged with family life.

The heterogeneous group of community-dwelling stroke survivors across a wide age-span and different disabilities needs diverse rehabilitation that is tailored to the needs of the individuals, as well as support from the community to optimize their quality of life after stroke. Therefore, it is important to gain a thorough understanding of the functioning and contextual factors and to examine further how older age affects this population. Our study aimed to: 1) map the functioning and contextual factors among community-dwelling stroke survivors one to two years after their first stroke, based on the different components of the ICF [8], and 2) to explore if functioning and contextual factors of this population differ among old (75 years and older), younger-old (65-74 years), and young and middle-aged stroke survivors (18-65 years).

Methods

Study design and participants

A cross-sectional population-based survey was mailed to eligible community-dwelling adult stroke survivors who had been diagnosed with their first stroke one to two years earlier. Potential participants were identified through registries from the two main hospitals in Iceland, which gave the opportunity to approach the whole population diagnosed with stroke in one year. To be defined as eligible the following inclusion criteria were used: Admission to one of the two hospitals within a 12-month period (April 1st 2016 – March 31st 2017) with the diagnosis of stroke (ICD10 I60-I64) for the first time, and at least 18 years old when diagnosed. Exclusion criteria were: Diagnosis of dementia (ICD10 F00-F03) prior to the time of the study, living in a nursing home, not having an Icelandic national insurance number and living abroad. The STROBE standardized reporting guidelines [28] were followed to standardize the conduct and reporting of the study.

The survey

We used the ICF Linking Rules [29-31] to link all survey items to the ICF and they covered all the ICF components except for *body structure* (Fig 1).

Fig 1. Linking of the questions in the survey to the components of the ICF framework

The use of ICF and standardized questionnaires allows our study to be compared effectively with international studies. The survey included 28 questions and two standardized instruments: the Stroke Impact Scale (SIS) [32] and the Behavioural Regulation Exercise Questionnaire 2 (BREQ-2) [33]. The SIS is an ICF-based stroke-specific health status measure which assesses perceived recovery along with eight domains of functioning: strength, memory and thinking, emotions, communication, activities of daily living (ADL)/instrumental activities of daily living (IADL), mobility, hand function, participation and perceived recovery [32]. Each SIS-domain includes a different number of questions (range 4-10). A total score for each domain can be calculated if participant responds to at least half of the questions, otherwise it is assigned as missing [34]. The total score for each SIS-domain range from 0 to 100 where zero is *an inability to complete the items* and 100 means *no difficulties experienced at all*. For perceived recovery zero equals *no recovery* and 100 *full recovery*. A composite physical domain can be created by summing the score from the domains for strength, hand function, mobility and ADL/IADL [34]. The SIS has shown good psychometric properties including validity [35-36], inter-rater/intra-rater reliability [37], test-retest reliability [34, 38], and internal consistency [34]. It has also been tested for use as a mailed questionnaire showing high internal consistency [39]. The SIS has recently been translated into Icelandic using a translation/back-translation method [40]. The BREQ-2 assesses the motivation for exercise and includes 19 statements about engagement in exercise, scoring on a five-point Likert scale (0=not true for me, 4=very true for me). The BREQ-2 has five subscales: 1) amotivation, 2) external regulation, 3) introjected regulation, 4) identified regulation and 5) intrinsic regulation [33]. In line with the self-determined theory, *identified* and *intrinsic regulation* address self-determination (score range 0-32) while *amotivation, external regulation* and *introjected regulation* address non-self-determination (score range 0-44) [41]. Higher scoring of self-determination is positively linked with adaptive health behaviour but higher scoring of non-self-determination indicates the opposite [42]. The psychometric properties of the BREQ-2 have been investigated in samples of healthy people [33, 43] as well as in different patient groups [44-45]. To date, no data is available on psychometric properties when used for stroke survivors but the content and format supports its relevance within that group. Apart from the standardized instruments, a few of the questions were from existing instruments: a question on history of falls from the Prevention of Falls and Injury Trial [46], questions on fatigue and energy from the Fatigue Assessment Scale [47] and Fatigue Severity Scale [48] and a question on pain from EuroQol-5D [49].

The survey was self-reported but participants notified us by marking in an appropriate box if they received assistance. This assistance was allowed to optimize the participation rate and accuracy of responses among individuals with some writing, vision and/or minor communicative problems. The survey was pilot-tested on four community-dwelling stroke survivors (47-78 years old) who answered the final draft of the survey and gave feedback concerning clearer wording and options for answers.

Procedure

The survey, along with an information letter and a stamped envelope for return, was sent to the eligible participants. As described in the information letter, participation was interpreted as giving informed consent. If eligible stroke survivors had not responded within three weeks, a researcher (SAO) followed up with a phone call. In the phone call the person was encouraged to take part and was offered assistance. Participants who refused to take part were politely asked to share the reason with the researcher.

The study was conducted according to the ethical principles of the Declaration of Helsinki and approvals were obtained from the Icelandic Data Protection Authorities and the Icelandic National Bioethics Committee (VSNb2017110024/03.01).

Statistical methods

The R-statistical software was used for data analysis, the level of significance was set at $P<0.05$ and no corrections were made for multiple statistical tests. Imputation was used for missing data in the BREQ-2, using predictive mean matching [50], and the process completed with the statistical package ´mice´ in *R, statistical software* with random seed=500. Age in years was used to create an ordinal variable with three categories; 75 years and older (≥75), 65-74 years and younger than 65 years (<65). Descriptive analysis included mean and standard deviation for the age variable, medians and range for other continuous data, and frequencies and proportions based on valid answers for the categorical variables. T-tests were used to compare participants and non-participants. For subgroup analysis by age and genders, analysis of variance (ANOVA) was used for continuous data and Fisher´s exact tests for categorical variables. A post hoc text, TukeyHSD, was used for comparing possible age-group pairings.

Results

Participants

A total of 454 individuals (men 53.1%) were admitted and diagnosed with a stroke (ICD10 I60-I64) within the pre-defined 12-month period (see flowchart in Fig 2). Eighty-six individuals had died (18.9%) but most stroke survivors were excluded due to a previous diagnosis of stroke (n=82, 18.1%). Eligible participants were 203 (men 51.7%) and 114 participated (men 50%), resulting in a 56.2% response rate.

Fig 2. Flowchart of inclusion of participants

The participants were slightly older than the non-participants (mean age 71.6 ±12.9 years versus 62.1±13.5 years; *P*=0.050) and came from similar residential areas (*P*=0.717), with a comparable proportion of men and women (*P*=0.691). Of the 78 individuals who received a phone call to facilitate their participation, 31 responded to the survey and 30 gave the following reasons for not participating: good/full recovery (n=11), not interested (n=7), difficult to remember the past (n=6) and dependent on others (n=6). Forty-one (36.0%) individuals received assistance with completing the survey, with more participants being ≥75 years old (*P*=0.007) than younger than 65 years old, but with no difference between the genders (*P*=0.329).

The majority of participants (n=74, 66.1%) reported having had an ischemic stroke, with no differences between age-groups (*P*=0.735) or gender (*P*=0.183). Eighteen (15.8%) had had a haemorrhagic stroke, with no difference between the age-groups (*P*=0.052) but more women (n=13, 23.6%) than men (n=5, 8.8%) (*P*=0.032). Twenty participants (17.9%) stated they were unaware of the type of stroke they had had, with more participants older than 75 years old than younger than 65 years old (*P*=0.003) but no difference between the genders (*P*=0.685).

Mapping of the ICF components

Personal factors

The mapping of personal factors is presented in Table 1. The mean age of the participants was 71.6±12.9 years, with the median being 73 years (range 27-94 years). Fifty-one participants (44.7%) were ≥75 years old (men 45.1%), 34 (29.8%) were 65-74 years old (men 50%) and 29 (25.4%) were younger than 65 years old (men 58.6%), with no difference between the genders in any of the age-groups (*P*=0.519).

A difference was found among all three age-groups in the number of comorbidities, where the oldest individuals (≥75 years) had the most comorbidities and the youngest (<65 years) reported having the fewest. Cardiovascular diseases was the most common in all age-groups with no difference between the age-groups (*P*=0.067). The oldest individuals had more anxiety and depression than those in the younger age-groups (<65 years old *P*=0.043, 65-74 years *P*=0.028). A difference between the genders was only found in education, where men had a higher level of education (*P*<0.001), lower prevalence of arthritis (*P*=0.023) and fewer impairments in urinary function (*P*=0.041) than women.

Table 1. Personal factors

	Mean (SD) or N (%[a])				
	All (N=114)	75-94 years (n=51)	65-74 years (n=34)	27-64 years (n=29)	p-value[b]
Demography					
Age	71.6 (12.9)				
Men	57 (50.0%)	23 (45.1%)	17 (50.0%)	17 (58.6%)	0.519
No postsecondary education	67 (58.8%)	31 (60.8%)	25 (73.5%)	11 (37.9%)	0.016[d]
Main symptoms after the stroke[c]					
Balance impairments	70 (61.4%)	31 (60.8%)	26 (76.5%)	13 (44.8%)	0.038[d]
Aphasia	41 (36.0%)	17 (33.3%)	16 (47.1%)	8 (27.6%)	0.248
Memory impairments	37 (32.5%)	18 (35.3%)	11 (32.4%)	8 (27.6%)	0.789
Paresis/paralysis right UE	31 (27.2%)	16 (31.4%)	9 (26.5%)	6 (20.7%)	0.638
Paresis/paralysis left LE	30 (26.3%)	14 (27.5%)	12 (35.3%)	4 (13.8%)	0.134
Paresis/paralysis left UE	29 (25.4%)	11 (21.6%)	11 (32.4%)	7 (24.1%)	0.555
Apraxia	24 (21.1%)	12 (23.5%)	9 (26.5%)	3 (10.3%)	0.237
Paresis/paralysis right LE	21 (18.4%)	7 (13.7%)	7 (20.6%)	7 (24.1%)	0.479
Problems with swallowing	18 (15.8%)	9 (17.6%)	7 (20.6%)	2 (6.9%)	0.277
Neglect	14 (12.3%)	6 (11.8%)	6 (17.6%)	2 (6.9%)	0.469
Visual disturbances	6 (5.3%)	1 (2.0%)	3 (8.8%)	2 (6.9%)	0.322
Face numbness/paralysis	5 (4.4%)	2 (3.9%)	1 (2.9%)	2 (6.9%)	0.719
Headache	5 (4.4%)	0 (0%)	3 (8.8%)	2 (6.9%)	0.088
Falls in the last 12 months					
Experienced one or more fall	34 (29.8%)	18 (35.3%)	12 (35.3%)	4 (13.8%)	0.013[e]
Had fractures from falls	8 (7.0%)	4 (7.8%)	2 (5.9%)	2 (6.9%)	0.383
Comorbidities					
Number of comorbidities	1.5 (1.2)	2.0 (1.2)	1.4 (1.2)	0.8 (0.8)	< 0.001[f]
Cardiovascular disease	58 (50.9%)	32 (62.7%)	13 (38.2%)	13 (44.8%)	0.067
Osteo-/Rheumatoid Arthritis	28 (24.6%)	15 (29.4%)	11 (32.4%)	2 (6.9%)	0.024[d]
Impaired urinary function	24 (21.1%)	19 (37.3%)	5 (14.7%)	0 (0%)	< 0.001[f]
Anxiety/depression	18 (15.8%)	16 (31.4%)	1 (2.9%)	1 (3.4%)	< 0.001[g]
Diabetes	14 (12.3%)	6 (11.8%)	7 (20.6%)	1 (3.4%)	0.140
Cancer	13 (11.4%)	6 (11.8%)	5 (14.7%)	2 (6.9%)	0.647
Osteoporosis	9 (7.9%)	6 (11.8%)	1 (2.9%)	2 (6.9%)	0.366
Myalgia	5 (4.4%)	2 (3.9%)	0 (0%)	3 (10.3%)	0.120
COPD	4 (3.5%)	1 (2.0%)	3 (8.8%)	0 (0%)	0.200

Abbreviations: UE=Upper extremity, LE=Lower extremity, No=Number, COPD=Chronic obstructive pulmonary disease

[a]Proportions are based on valid data for each variable.
[b]Fisher´s Exact Test the categorical variables and Linear Model ANOVA for the continuous variable of number of comorbidities.
[c]The main symptoms after stroke were linked to personal factors as a lived experience, since the results reflected the current situation of participants, 1-2 years after stroke.
[d]Difference between <65 years old and 65-74 years old.
[e]Difference between <65 years old and both older groups.
[f]Difference between all three groups.
[g]Difference between ≥75 years old and both younger groups.

Environmental factors

The mapping of environmental factors is presented in Table 2. The oldest individuals (≥75 years) had more walking devices (<65 years old *P*=0.007, 65-74 years old *P*=0.020) and more security buzzers (<65 years old *P*=0.001, 65-74 years old *P*<0.001) than those in the younger age-groups. The majority of participants had access to smart devices, with computers being the most common. The oldest individuals had less access to computers (<65 years old *P*=0.004, 65-74 years old *P*=0.002) and smart phones (<65 years old *P*<0.001, 65-74 years old *P*<0.001) than those in the younger age-groups. No differences were found between the genders in any of the environmental factors studied.

Table 2. Survey items linked to the ICF component of environmental factors

	N (%[a])				
Environmental factors	**All (N=114)**	**75-94 years (n=51)**	**65-74 years (n=34)**	**27-65 years (n=29)**	**p-value[b]**
Residence, housing and pension					
Live in capital area (e215)	76 (66.7%)	41 (80.4%)	16 (47.1%)	19 (65.5%)	0.007[e]
Live alone (e398)	32 (28.1%)	21 (41.2%)	7 (20.6%)	4 (13.8%)	0.017[f]
Had to change housing after stroke (e155)	2 (1.8%)	1 (2.0%)	1 (2.9%)	0 (0%)	1.000
Good access in home (e155)	107 (93.9%)	46 (90.2%)	34 (100%)	27 (93.1%)	0.208
State pension[c] (e570)	77 (67.5%)	50 (98%)	26 (76.5%)	1 (3.4%)	< 0.001[g]
Invalidity pension[d] (e570)	10 (8.8%)	0 (0%)	0 (0%)	10 (34.5%)	< 0.001[h]
Access to assistive and smart devices					
Walking devices (e120)	33 (28.9%)	24 (47.1%)	6 (17.6%)	3 (10.3%)	< 0.001[i]
Wheelchairs (e120)	5 (4.4%)	1 (2.0%)	2 (5.9%)	2 (6.9%)	0.519
Other assistive devices (e115)	14 (12.3%)	7 (13.7%)	3 (8.8%)	4 (13.8%)	0.497
Buzzer (e115)	33 (28.9%)	28 (54.9%)	3 (8.8%)	2 (6.9%)	< 0.001[i]

Laptop or computer (e130)	78 (68.4%)	24 (47.1%)	29 (85.3%)	25 (86.2%)	< 0.001[i]
Smartphone (e130)	69 (60.5%)	17 (33.3%)	28 (82.4%)	24 (82.8%)	< 0.001[i]
Tablet (e130)	50 (43.9%)	14 (27.5%)	16 (47.1%)	20 (69.0%)	0.001[f]
Health care and social services					
Inpatient rehabilitation after stroke (e580)	96 (84.2%)	42 (82.4%)	29 (85.3%)	25 (86.2%)	1.000
Services during last month (e5)	52 (45.6%)	32 (62.7)	14 (41.2%)	6 (20.7%)	0.001[f]
Physical therapy (e580)	39 (34.2%)	22 (43.1%)	12 (35.3%)	5 (17.2%)	0.054
Occupational therapy (e580)	1 (0.9%)	0 (0%)	1 (2.9%)	0 (0%)	0.553
Speech therapy (e580)	1 (0.9%)	1 (2.0%)	0 (0%)	0 (0%)	1.000
Home nursing (e580)	8 (7.0%)	5 (9.8%)	2 (5.9%)	1 (3.4%)	0.648
Ambulant nursing(e580)	1 (0.9%)	0 (0%)	1 (2.9%)	0 (0%)	0.533
Social domestic (e575)	16 (14.0%)	13 (25.5%)	1 (2.9%)	2 (6.9%)	0.006[i]
Adult day care (e580)	5 (4.4%)	5 (9.8%)	0 (0%)	0 (0%)	0.056[i]
Transportation services(e575)	7 (6.1%)	6 (11.8%)	0 (0%)	1 (3.4%)	0.071
Fulfilled needs (n=50) (e580)	33 (28.9%)	19 (37.3%)	9 (26.5%)	5 (17.2%)	1.000

[a]Proportions are based on valid data for each variable.
[b]Fisher´s Exact Test for categorical variables.
[c]State pension can be received at the age of 65.
[d]Personal Independence Payment can be received at the age of 18-66.
[e]Difference between ≥75 years old and 65-74 years old.
[f]Difference between ≥75 years old and <65 years old.
[g]Difference between all three groups.
[h]Difference between <65 years old and both older groups.
[i]Difference between ≥75 years old and both younger groups.

Body function

Motivation for exercise, which was assessed with BREQ-2, showed more self-determination than non-self-determination in all age-groups. No difference was found in self-motivation between the age-groups but the oldest age-group reported more non-self-determination than the youngest group (*P=0.034).* No differences were in found in other categories of body function between the age-groups or genders (Table 3).

Table 3 Survey items linked to the ICF component of body function

	Mean (SD) or N (%[a])				
Body function	**All (N=114)**	**75-94 years (n=51)**	**65-74 years (n=34)**	**27-64 years (n=29)**	**p-value**
BREQ-2 for motivation of exercise (b130)					

Table 3 Survey items linked to the ICF component of body function

Body function	Mean (SD) or N (%[a]) All (N=114)	75-94 years (n=51)	65-74 years (n=34)	27-64 years (n=29)	p-value
Self-determination	4.8 (2.4)	4.9 (2.3)	4.8 (2.3)	4.6 (2.8)	0.786[b]
Non-self-determination	3.0 (2.1)	3.3 (2.2)	3.3 (2.0)	2.1 (2.0)	0.028[b,d]
I get tired very quickly (b455)					0.189[c]
Never or seldom	25 (23.6%)	8 (16.3%)	8 (25.8%)	9 (34.6%)	
Sometimes, most often or always	81 (76.4%)	41 (83.7%)	23 (74.2%)	17 (65.4%)	
Fatigue is among my most disabling symptoms (b455)					0.262[c]
Never or seldom	40 (43.0%)	14 (34.1%)	13 (46.4%)	13 (54.2%)	
Sometimes, most often or always	53 (57.0%)	27 (65.9%)	15 (53.6%)	11 (45.8%)	
I have enough energy for everyday life (b130)					0.787[c]
Never or seldom	16 (15.4%)	8 (18.2%)	4 (12.5%)	4 (14.3%)	
Sometimes, most often or always	88 (84.6%)	36 (81.8%)	28 (87.5%)	24 (85.7%)	
Statements on pain today (b280)					0.808[c]
No or slight pain	80 (75.5%)	33 (71.7%)	26 (78.8%)	21 (77.8%)	
Moderate, severe or extreme pain	26 (24.5%)	13 (28.3%)	7 (21.2%)	6 (22.2%)	

[a]Proportions are based on valid data for each variable.
[b]Linear Model ANOVA.
[c]Fisher´s Exact Test for categorical variables.
[d]Difference between ≥75 years old and <65 years old.

Activities and participation

The mapping of activities and participation is presented in Table 4. The majority of participants (70.2%) drove a car with fewer individuals in the oldest group than in both younger groups (<65 years old P=0.023, 65-74 years old P=0.012). They also depended more on others for transportation than those younger than 65 years old (P=0.031). Compared to both younger groups, the oldest individuals used computers less (<65 years old P<0.001, 65-74 years old P<0.001) and smart phones (<65 years old P<0.001, 65-74 years old P=0.001).

Men were working more full-time (P=0.029) and part-time (P=0.020) than women, and women depended more on others for transportation (P<0.001) than men. No differences were found between the genders in other factors studied within the components of activities and participation.

Table 4. Survey items linked to the ICF component of activities and participation

	N (%[a])				
Activities and participation	**All (N=114)**	**75-94 years (n=51)**	**65-74 years (n=34)**	**27-64 years (n=29)**	**p-value[b]**
Employment status					
Working full-time (d850)	17 (14.9%)	1 (2.0%)	3 (8.8%)	13 (44.8%)	< 0.001[d]
Working part-time (d850)	9 (7.9%)	0 (0%)	5 (14.7%)	4 (13.8%)	0.005
Volunteering (d855)	5 (4.4%)	2 (3.9%)	2 (5.9%)	1 (3.4%)	1.000
Transportation					
Drive a car (d475)	80 (70.2%)	29 (56.9%)	27 (79.4%)	24 (82.8%)	0.023[e]
Depend on others[c] (d470)	27 (23.7%)	18 (35.3%)	7 (20.6%)	2 (6.9%)	0.019[e]
Use public transport (d470)	9 (7.9%)	6 (11.8%)	1 (2.9%)	2 (6.9%)	0.366
Use of smart devices					
Regular use of a laptop or computer (d369)	62 (54.4%)	14 (27.5%)	25 (73.5%)	23 (79.3%)	< 0.001[f]
Regular use of a smartphone (d369)	59 (51.8%)	14 (27.5%)	23 (67.6%)	22 (75.9%)	< 0.001[f]
Regular use of a tablet (d369)	38 (33.3%)	9 (17.6%)	14 (41.2%)	15 (51.7%)	0.003[e]
Physical activity or exercise					
At least three times a week (d570)	73 (64.0%)	30 (58.8%)	24 (70.6%)	19 (65.5%)	0.559
At least five times a week (d570)	54 (47.4%)	23 (45.1%)	17 (50.0%)	14 (48.3%)	0.888

[a]Proportions are based on valid data for each variable.
[b]Fisher´s Exact Test for categorical variables.
[c]Includes depending on individuals as well as use of transportation services for disabled.
[d]Difference between <65 years old and both older groups (P<0.05).
[e]Difference between ≥75 years old and <65 years old.
[f]Difference between ≥75 years old and both younger groups.

Stroke Impact Scale

The results from the SIS are presented in Table 5. The highest score was in the communication domain (median=92.9, range 10.7-100) and the lowest score was in the emotion domain (median=63.9, range 30.6-87.5). Differences were found between the age-groups in three domains: ADL/IADL (P=0.002), mobility (P<0.001) and participation (P=0.020) as well as in the composite physical domain (P=0.040). The oldest individuals

(≥75 years) deviated from the two younger age-groups in ADL/IADL (<65 years old $P<0.001$, 65-74 years old $P=0.037$) and mobility (<65 years old $P<0.001$, 65-74 years old $P=0.016$) and from the youngest group (<65 years) in participation- ($P=0.005$) and composite physical domain ($P=0.015$). Women reported worse mobility ($P=0.006$) and hand function ($P=0.025$) than men.

Table 5. Results from Stroke Impact Scale

	Median [Min, Max]				
Domains of Stroke Impact Scale (ICF code)	**All (N=114)**	**75-94 years (n=51)**	**65-74 years (n=34)**	**27-65 years (n=29)**	**p-value[a]**
Strength (b730)	75.0 [18.8, 100]	75.0 [25.0, 100]	65.6 [37.5, 100]	93.8 [18.8, 100]	0.096
Memory and thinking (b114, b140, b144, b160, d230)	85.7 [3.57, 100]	89.3 [3.57, 100]	78.6 [39.3, 100]	89.3 [28.6, 100]	0.403
Emotions (b152)	63.9 [30.6, 87.5]	61.1 [33.3, 86.1]	68.1 [33.3, 87.5]	69.4 [30.6, 86.1]	0.530
Communication (b167, d350, d360)	92.9 [10.7, 100]	92.9 [10.7, 100]	91.1 [14.3, 100]	92.9 [20.0, 100]	0.387
ADL/IADL (b525, b620, d510, d520, d530, d540, d550, d620, d640)	87.5 [27.5, 100]	82.5 [27.5, 100]	90.0 [45.0, 100]	100 [27.5, 100]	0.002[c]
Mobility (d410, d415, d450, d455)	83.3 [11.1, 100]	72.2 [11.1, 100]	83.3 [47.2, 100]	100 [25.0, 100]	<0.001[c]
Hand function (d430, d440, d445)	90.0 [0, 100]	85.0 [5.00, 100]	80.0 [0, 100]	100 [0, 100]	0.167
Participation (d750, d760, d850, d855, d920, d930)	78.1 [9.38, 100]	75.0 [9.38, 100]	75.0 [28.1, 100]	98.4 [40.6, 100]	0.020[d]
Perceived recovery (personal factor)	80.0 [15.0, 100]	77.5 [15.0, 100]	75.0 [35.0, 100]	87.5 [30.0, 100]	0.143
Composite physical domain[b]	78.7 [15.6, 100]	73.8 [27.4, 100]	76.1 [39.9, 100]	93.8 [15.6, 100]	0.040[d]

[a]Linear Model ANOVA
[b]Composite physical domain includes the domains of strength, ADLs/IADLs, mobility, and hand function.
[c]Difference between ≥75 years old and both younger groups.
[d]Difference between ≥75 years old and <65 years old.

Discussion

Our results highlight functioning and contextual factors among community-dwelling stroke survivors one to two years after their first stroke based on the ICF and reveal interesting differences and similarities between the three specific age-groups of stroke survivors.

Although differences were most notable between the oldest (≥75 years old) and the youngest group, (<65 years old), there were some important differences between the two older groups indicating more impairments and showing that more support is needed among the oldest individuals (≥75 years old). At the same time there were some noteworthy similarities between the two younger groups which indicate high functioning of these two age-groups. In line with studies within gerontology, these results support the need for exploring functioning among stroke survivors who are older than 65 years of age in different age-groups.

In our study, the ICF was used to organize the complex pattern of functioning and disability one to two years after stroke and to map contextual factors of community-dwelling stroke survivors. Moreover, we used the linking rules [29-31] to code all the variables from our survey and link them to the appropriate ICF categories, and thereby we transformed our results to the international language of the ICF. Other national surveys have been conducted with different survey items and different time points post-stroke [12,16,17,20,21] and linking their variables to the ICF would improve the potential for international comparisons.

In studies focusing on potential age differences among stroke survivors, the age-groups and analysis fluctuate markedly [4,5,18-21,51], which makes comparisons of results difficult, but in general, worse functioning is associated with higher age. In a study on stroke survivors, 10 years after stroke, increased age was correlated with less functioning and more disability, when four specific age-groups were compared (<65 years, 65-74 years, 75-84 years and ≥75 years) but differences between the groups were not analysed [20]. In a study on participation of stroke survivors younger and older than 70 years old, the older group had significantly more restrictions in participation due to impaired mobility [18]. A study on stroke survivors showed that age was significantly associated with care dependency, and those who were older than 75 years old had more risk of care dependency than stroke survivors 75 years and younger [19].

Use of technical solutions through smart devices is increasing in rehabilitation among community-dwelling stroke survivors [52-55] and facilitates participation after stroke [56]. Studies have shown that they are interested in using smart devices for exercise and physical activity, especially those who have an experience of using smart devices [57,58]. Our results show that participants of all ages have access to some kind of smart device, which provides good opportunities to approach community-dwelling stroke survivors with different rehabilitation interventions in their own urban and rural homes. This good access is also highly relevant during COVID times where physical distancing is the main issue [7]. The oldest participants (≥75 years) used smart devices the least, although over a quarter of them reported regular use of computers and smartphones. At the same time, almost half of them had access to smart devices, which gives potential for future use.

Results from studies on gender differences of stroke survivors are mixed but there are indications that women experience more severe strokes and have worse post-stroke functioning than men [59]. Research also suggests that women may also be less likely to have their health needs fulfilled than men [21]. Although we did not find many differences between the genders, the few differences we found supported the indications on women being worse off compared to men after stroke.

The response rate of our survey was 56.2%, which is considered good for a mailed population-based survey where the potential participants are identified from registries that cover all citizens diagnosed with stroke [60]. In previous surveys on stroke survivors, participants have been recruited from stroke clinics and support groups and showed a wide response rate, in the range 17-78% [16,17,21]. Surveys that recruit individuals from support groups and volunteers tend to have higher response rates than surveys where participants are identified through registries like in our study [21]. Both the sample of the total population and the acceptable participation rate of the survey strengthen the generalizability of the results.

Successful community rehabilitation must be tailored to the individuals needs and directed toward maximizing stroke survivors´ functioning, which is based on potentially complex interactions between stroke survivors´ health condition and contextual factors.
Sixty-five years might not be the ideal cut-off of age, even though it is often used when studying community-dwelling stroke survivors. Moreover, the findings reveal the need to direct the focus of rehabilitation and research towards the heterogeneous group of older stroke survivors in order to discover how to best meet their community requirements.

Limitations

The small sample size, mainly due to the small population of the Icelandic nation, limited the power of the study resulting in possible underestimation of differences between the age-groups. Moreover, the study was powered enough to detect some differences between the age-groups. Nevertheless, the finding should represent well the functioning of community-dwelling stroke survivors in this nation, since the sample is based on hospital registries of the two main hospitals in Iceland where most stroke survivors are admitted. The small sample size also limited the possibilities of multivariate analysis of the data. This should challenge future research to use larger samples to detect further differences between age-groups and to further analyse older as well as younger age-groups of community-dwelling stroke survivors.

About one third of the participants received some help with completing the survey which may have prompted responses that were desirable to the proxy as opposed to an accurate response from the participant. However, this might have given us answers from older participants and/or participants with writing, vision or communicative problems.

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References

1. Feigin VL, Forouzanfar MH, Krishnamurthi R, Mensah GA, Connor M, Bennett DA, et al. Global and regional burden of stroke during 1990-2010: Findings from the Global Burden of Disease Study 2010. Lancet 2014;383(9913):245-54.

2. Katan M, and Luft A. Global burden of stroke. Semin Neurology 2018;38(2):208-11.

3. Mathisen S, Larsen J, and Kurz M. The prognosis of stroke survivors primarily discharged to their homes. Acta Neurol Scand 2017;136(4):338-44.

4. Bettger JP, McCoy L, Smith EE, Fonarow GC, Schwamm LH, and Peterson ED. Contemporary trends and predictors of postacute service use and routine discharge home after stroke. J Am Heart Assoc 2015;4(2):e001038.

5. Francois S, Van Casteren V, Borgermans L, Vanthomme K, and Devroey D. Place of residence after a stroke: Results of the registration by the Belgian Sentinel Network of general practitioners. Rom J Intern Med 2014;52(2):79. PMID: 25338343

6. Rintala A, Päivärinne V, Hakala S, Paltamaa J, Heinonen A, Karvanen J, et al. Effectiveness of technology-based distance physical rehabilitation interventions for improving physical functioning in stroke: A systematic review and meta-analysis of randomized controlled trials. Arch Phys Med Rehabil 2019;100(7):1339-58.

7. Sheth SA, Wu T-C, Sharrief A, Ankrom C, Grotta JC, Fisher M, et al. Early lessons from world war COVID: Reinventing our stroke systems of care. Stroke 2020;51(7):2268-2272.

8. WHO. Towards a common language for Functioning, Disability and Health: ICF. Geneva: WHO; 2002.

9. WHO. How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Geneva: WHO; 2013.

10. Feldman RS, Hupp S, and Jewell J. Development across the life span. 9th ed.Essex, England: Pearson; 2019. ISBN-13: 9780135172971.

11. Astell AJ, McGrath C, and Dove E. "That's for old so and so's!": Does identity influence older adults' technology adoption decisions? Ageing Soc 2020;40(7):1550-76.

12. Tistad M, Tham K, von Koch L, and Ytterberg C. Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: An explorative observational study. BMC Neurol 2012;12(1):40.

13. Törnbom K, Persson H, Lundälv J, and Sunnerhagen K. The impact of physical function on participation in the first year post-stroke. Acta Neurol Scand 2017;135(6):649-55.

14. Minet LR, Peterson E, von Koch L, and Ytterberg C. Occurrence and predictors of falls in people with stroke: Six-year prospective study. Stroke 2015;46(9):2688-90.

15. Samuelsson CM, Hansson P-O, and Persson CU. Early prediction of falls after stroke: A 12-month follow-up of 490 patients in The Fall Study of Gothenburg (FallsGOT). Clin Rehabil 2019;33(4):773-83.

16. Walsh M, Galvin R, Loughnane C, Macey C, and Horgan, NF. Community re-integration and long-term need in the first five years after stroke: Results from a national survey. Disabil Rehabil 2015;37(20):1834-8.

17. McKevitt C, Fudge N, Redfern J, Sheldenkar A, Crichton S, Rudd AR, et al. Self-reported long-term needs after stroke. Stroke 2011;42(5):1398-403.

18. de Graaf JA, van Mierlo ML, Post MW, Achterberg WP, Kappelle LJ, and Visser-Meily JMA. Long-term restrictions in participation in stroke survivors under and over 70 years of age. Disabil Rehabil 2018;40(6):637-45.

19. Schnitzer S, von dem Knesebeck O, Kohler M, Peschke D, Kuhlmey A, and Schenk L. How does age affect the care dependency risk one year after stroke? A study based on claims data from a German health insurance fund. BMC Geriatr 2015;15(1):135.

20. Jönsson A-C, Delavaran H, Iwarsson S, Ståhl A, Norrving B, and Lindgren A. Functional status and patient-reported outcome 10 years after stroke: The Lund Stroke Register. Stroke 2014;45(6):1784-90.

21. Andrew NE, Kilkenny M, Naylor R, Purvis T, Lalor E, Moloczij N, et al. Understanding long-term unmet needs in Australian survivors of stroke. Int J Stroke 2014;9:106-12.

22. Palmcrantz S, Widén Holmqvist L, Tistad M, and Ytterberg C. Differences between younger and older individuals in their use of care and rehabilitation but not in self-perceived global recovery 1 year after stroke. J Neurol Sci 2012;321(1-2):29-34.

23. Hooyman NR and Asuman Kiyak H. Productive aging: Paid and nonpaid roles and activities. In: Hooyman NR & Asuman Kiyak H, editors. Social gerontology A multidisciplinary perspective. 9th ed. Boston MA: Pearson Education Limited; 2014. p 463-524. ISBN-13: 978-0205763139

24. Hooyman NR and Asuman Kiyak H. Social policies to address social problems. In: Hooyman NR & Asuman Kiyak H, editors. Social gerontology A multidisciplinary perspective. 9th ed. Boston MA: Pearson Education Limited; 2014. p 659-700. ISBN-13: 978-0205763139

25. Orimo H, Ito H, Suzuki T, Araki A, Hosoi T, and Sawabe M. Reviewing the definition of “elderly”. Geriatr Gerontol Int 2006;6.

26. Ouchi Y, Rakugi H, Arai H, Akishita M, Ito H, Toba K, et al. Redefining the elderly as aged 75 years and older: Proposal from the Joint Committee of Japan Gerontological Society and the Japan Geriatrics Society. Geriatr Gerontol Int 2017;17(7):1045-7.

27. Pilipiec P, Groot W, and Pavlova M. The effect of an increase of the retirement age on the health, well-being, and labor force participation of older workers: A systematic literature review. JPA 2020.

28. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, and Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for reporting observational studies. Preventive Medicine 2007;45(4):247-51.

29. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, et al. Linking health-status measurements to the International Classification of Functioning, Disability and Health. J Rehab Med 2002;34(5):205-10.

30. Stucki G. ICF Linking Rules: An update based on lessons learned. J Rehabil Med 2005;37(4):212-8.

31. Cieza A, Fayed N, Bickenbach J, and Prodinger B. Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. Disabil Rehab 2019;41(5):574-83.

32. Duncan PW, Bode RK, Lai SM, and Perera S. Rasch analysis of a new stroke-specific outcome scale: The Stroke Impact Scale. Arch Phys Med Rehabil 2003;84(7):950-63

33. Markland D, and Tobin V. A modification to the Behavioural Regulation in Exercise Questionnaire to include an assessment of amotivation. J Sport Exercise Psychol 2004;26(2):191-6.

34. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, and Laster LJ. The Stroke Impact Scale version 2.0: evaluation of reliability, validity, and sensitivity to change. Stroke 1999;30(10):2131-40.

35. Doyle PJ, McNeil MR, Bost JE, Ross KB, Wambaugh JL, Hula WD, et al. The Burden of Stroke Scale (BOSS) provided valid, reliable, and responsive score estimates of functioning and well-being during the first year of recovery from stroke. Qual Life Res 2007;16(8):1389-98.

36. Duncan PW, Horner RD, Reker DM, Samsa, GP, Hoenig H, Hamilton B, et al. Adherence to postacute rehabilitation guidelines is associated with functional recovery in stroke. Stroke 2002;33(1):167-77.

37. Carod-Artal FJ, Coral LF, Trizotto DS, and Moreira CM. Self-and proxy-report agreement on the Stroke Impact Scale. Stroke 2009;40(10):3308-14.

38. Edwards B, and O'connell B. Internal consistency and validity of the Stroke Impact Scale 2.0 (SIS 2.0) and SIS-16 in an Australian sample. Qual Life Res 2003;12(8):1127-35.

39. Richardson M, Campbell N, Allen L, Meyer M, and Teasell R. The Stroke Impact Scale: Performance as a quality of life measure in a community-based stroke rehabilitation setting. Disabil Rehabil 2016;38(14):1425-30.

40. Behling O, and Law KS. Translating questionnaires and other research instruments: Problems and solutions. Sage University Paper Series on Quantitative Applications in the Social Sciences. Thousand Oaks, CA: Sage; 2000. ISBN 0761918248.

41. Sweet SN, Fortier MS, Strachan SM, Blanchard CM, and Boulay P. Testing a longitudinal integrated self-efficacy and self-determination theory model for physical activity post-cardiac rehabilitation. Health Psychol Res 2014;2(1).

42. Wilson PM, Sabiston CM, Mack DE, and Blanchard CM. On the nature and function of scoring protocols used in exercise motivation research: An empirical study of the behavioral regulation in exercise questionnaire. Psychol Sport Exerc 2012;13(5):614-22.

43. Ingledew DK, Markland D, and Ferguson E. Three levels of exercise motivation. Appl Psychol Health Well-being 2009;1(3):336-55.

44. Milne HM, Wallman KE, Gordon S, and Courneya KS. Impact of a combined resistance and aerobic exercise program on motivational variables in breast cancer survivors: A randomized controlled trial. Ann Behav Med 2008;36(2):158-66.

45. Vancampfort D, De Hert M, Vansteenkiste M, De Herdt A, Scheewe TW, Soundy A, et al. The importance of self-determined motivation towards physical activity in patients with schizophrenia. Psychiatry Res 2013;210(3):812-8.

46. Bruce J, Ralhan S, Sheridan R, Westacott K, Withers E, Finnegan S, et al. The design and development of a complex multifactorial falls assessment intervention for falls prevention: The Prevention of Falls Injury Trial (PreFIT). BMC Geriatr 2017;17(1):116.

47. Cumming TB, and Mead G. Classifying post-stroke fatigue: Optimal cut-off on the Fatigue Assessment Scale. J Psychosom Res 2017;103:147-9.

48. Lerdal A. Fatigue Severity Scale. In: Michalos AC, editor. Encyclopedia of Quality of Life and Well-Being Research. Dordrecht: Springer Netherlands; 2014. p 2218-21.

49. Obradovic M, Lal A, and Liedgens H. Validity and responsiveness of EuroQol-5 dimension (EQ-5D) versus Short Form-6 dimension (SF-6D) questionnaire in chronic pain. Health Qual Life Outcomes 2013;11(1):110.

50. Landerman LR, Land KC, and Pieper CF. An empirical evaluation of the predictive mean matching method for imputing missing values. Sociol Methods Res 1997;26(1):3-33.

51. Morris JH, Oliver T, Kroll T, Joice S, and Williams B. Physical activity participation in community dwelling stroke survivors: Synergy and dissonance between motivation and capability. A qualitative study. Physiotherapy 2017;103(3):311-21.

52. Paul L, Wyke S, Brewster S, Sattar N, Gill JM, Alexander G, et al. Increasing physical activity in stroke survivors using STARFISH, an interactive mobile phone application: A pilot study. Top Stroke Rehabil 2016;23(3):170-7.

53. Chen Y, Abel KT, Janecek JT, Chen Y, Zheng K, and Cramer SC. Home-based technologies for stroke rehabilitation: A systematic review. Int J Med Info 2019;123:11-22.

54. Koh GC-H, and Hoenig H. How should the rehabilitation community prepare for 2019-nCoV? Arch Phys Med Rehab 2020.

55. Olafsdottir SA, Jonsdottir H, Bjartmarz I, Magnusson C, Caltenco H, Kytö M, et al. Feasibility of ActivABLES to promote home-based exercise and physical activity of community-dwelling stroke survivors with support from caregivers: A mixed methods study. BMC Health Serv Res 2020;20(1):1-17.

56. Marwaa MN, Ytterberg C, and Guidetti S. Significant others' perspectives on person-centred information and communication technology in stroke rehabilitation – A grounded theory study. Disabil Rehabil 2019:1-8.

57. Kerr A, Smith M, Reid L, and Baillie L. Adoption of stroke rehabilitation technologies by the user community: Qualitative study. JRAT 2018;5(2):e15.

58. Bird M-L, Eng JJ, and Sakakibara BM. Predicting interest to use mobile-device telerehabilitation (mRehab) by baby-boomers with stroke. AIMS Med Sci 2018;5(4):337-47.

59. Girijala RL, Sohrabji F, and Bush RL. Sex differences in stroke: Review of current knowledge and evidence. Vasc Med 2017;22(2):135-45.

60. Safdar N, Abbo LM, Knobloch MJ, and Seo SK. Research methods in healthcare epidemiology: Survey and qualitative research. Infect Control Hosp Epidemiol 2016;37(11):1272.

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TECHNICAL ADVANCE Open Access

Developing ActivABLES for community-dwelling stroke survivors using the Medical Research Council framework for complex interventions

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Abstract

Background: Novel technical solutions are called for to promote home-based exercise among community-dwelling stroke survivors supported by their caregivers. Lack of resources and knowledge about how to accomplish it, has been demonstrated. The objective of this study is to describe in detail the development of ActivABLES, a technical intervention to promote home-based exercise and physical activity engagement of community-dwelling stroke survivors with support from their caregivers.

Methods: The technical development process of ActivABLES was guided by the Medical Research Council (MRC) framework for development and evaluation of complex interventions as well as by principles of human-centred design and co-design. The main steps included: (1) Synthesis of evidence supporting the inclusion of balance exercises, mobility and walking exercises and exercises for the upper arm; (2) Implementation of initial user studies with qualitative data collection from individual interviews with stroke survivors, and focus group interviews with caregivers and health professionals; (3) Preliminary testing of eight prototypes with seven stroke survivors and their caregivers.

Results: After the preliminary testing of eight prototypes, four prototypes were not further developed whereas four prototypes were modified further. In addition, two new prototypes were developed, leaving six prototypes for further modification: 1) ActivFOAM for balance exercises, 2) WalkingSTARR to facilitate walking, 3) ActivBALL for hand exercises, 4) ActivSTICKS for upper arm exercises, and 5) ActivLAMP and 6) ActivTREE which both give visual feedback on progress of daily exercise and physical activities. ActivFOAM, ActivBALL and ActivSTICKS are all connected to a tablet where exercise instructions are given. All the exercise prototypes can be connected to ActivLAMP and ActivTREE to give feedback on how much exercise the user has done. Settings can be individualised and recommended daily time and/or repetition can easily be changed as the user progresses to higher activity levels.

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Conclusions: The development process of ActivABLES was guided by the principles of human-centred design, with iterative testing of future users, and by the MRC framework of complex intervention, with a repeated process of development and testing. This process resulted in six prototypes which are available for feasibility testing among a small group of community-dwelling stroke survivors.

Keywords: Stroke survivors, Home-based exercise, Technical intervention

Background

The global incidence of stroke is increasing while the mortality rate is decreasing [1–3]. In 1990–2016, global age-standardized mortality decreased by 36.2%, leaving more people with chronic disability [3]. The impact of a stroke depends on the lesion location and the size of the affected area in the brain [4]. Studies have reported a decrease in functional outcome, an increase of functional dependence, and a lower quality of life after stroke [4, 5]. The symptoms can be relatively mild, and the stroke survivor may be independent in activities of daily living (ADLs). On the other hand, symptoms can be so severe that the stroke survivor is dependent on others for ADLs. Additionally, about one-third of stroke survivors present with depression, which significantly impacts patients' well-being, recovery as well as their rehabilitation [6].

Various clinical practice guidelines [7–9] and systematic reviews [10–13] have summarised the evidence of positive effects of task-oriented exercise on the various outcomes of patients with stroke. Studies have shown that 30–60 min of training per day, five to seven days per week, is effective [11]. Continuation of exercise after a period of in-patient rehabilitation is important to optimise functional level [10, 12, 14, 15] and exercise and physical activity should be a lifelong process for stroke survivors [16]. Strong evidence exists for physical therapy interventions favouring intensive highly repetitive, task-oriented and task-specific exercise in all phases after stroke [12, 17]. However, community-dwelling stroke survivors only receive a limited amount of outpatient exercise and physical activity after inpatient rehabilitation. In four European countries, physical therapy was the most frequently used follow-up health service after inpatient rehabilitation, apart from medical care provided by a general practitioner [18]. Physical therapy services may only be available for a limited amount of time per week, which does not fulfil the need for daily exercise and physical activity. Therefore, community-dwelling stroke survivors need to be motivated to continue with home-based exercise and engage in physical activity without the constant supervision of professionals. For that reason, finding ways to motivate stroke survivors to engage in home-based exercise and physical activity is highly important.

Stroke survivors often have little motivation and confidence to continue with home-based exercise on their own after hospitalisation or inpatient rehabilitation [19, 20]. Lack of motivation and understanding about how to incorporate daily activities into an exercise plan, have been reported as reasons for limited unsupervised exercise adherence of stroke survivors [21]. A systematic review synthesised the evidence from six studies, exploring perceived barriers and motivators to physical activity after stroke, and showed that lack of motivation was a barrier to physical activity, in addition to environmental factors and health concerns [20]. Another systematic review focused on the designing of rehabilitation games and explored stroke survivors' motivation in rehabilitation. Factors positively influencing stroke survivors' level of motivation included social and emotional support from family members, the patient-therapist relationship, goal setting and music [22]. When designing ways to promote exercise and facilitate physical activity, it is important to understand what factors can motivate and hinder stroke survivors in exercise and physical activity.

The literature shows that informal caregivers (hereafter referred to as caregivers), who are often family members, express willingness and are often able to support stroke survivors with home-based exercise, resulting in the stroke survivors acquiring improved physical and mental function [12, 23–25]. Still, they often lack knowledge about what and how to do it and need more professional support and/or supervision to feel secure supporting the family member after stroke [26, 27]. Therefore, it is important to find ways and resources to support them in encouraging home-based exercise and increased physical activity for the stroke survivors.

Studies have reported good adherence of community-dwelling stroke survivors to exercise and perform physical activity when using technical applications in their homes to support these activities [28–30]. Technical interventions and applications that can be used for exercise and physical activity are increasingly being researched for different groups, including stroke survivors. Tangible interaction offers significant potential benefits, creating tangible user interfaces (TUIs) that are easy to handle for persons with cognitive or motor impairments [31]. Moreover, there are indications that the use of technology can motivate stroke survivors to engage in home-based exercise and physical activity [32], and motivational feedback seems to be the most important factor in technical solutions [33]. Technical interventions can offer repetitive and challenging exercises which are necessary for brain plasticity and motor learning [34]. The results from reviews of use of technical interventions have shown functional improvements [35, 36]. Some studies have investigated exercise in virtual reality [28, 35, 37, 38] and the use of video games, such as Nintendo Wii [36, 39–41] and Microsoft Kinect [42, 43] on which motion-controlled games may be played [22, 29, 32]. Games played through technical applications can motivate stroke survivors to participate in home-based exercise [35, 44, 45] and they are effective in improving balance and independence [46]. A systematic review showed that it is important that stroke rehabilitation games combine mental support, motivation and accessible interfaces in order to have a positive impact on participation in exercise and physical activity. Empowering stroke survivors to take charge of their own rehabilitation was important to initiate playing games and exercising [32].

The purpose of this paper is to report on the development of ActivABLES, a modular technical intervention built of multiple exchangeable components, to allow its thorough review and replication. The aim of the ActivABLES intervention is to motivate and support community-dwelling stroke survivors with home-based exercise to increase physical activity with support from their caregivers, and under the supervision of a physical therapist or other rehabilitation professionals. Our research question is: How can a tangible intervention, aiming to increase exercise and physical activity for community-dwelling stroke survivors, be developed with the involvement of future users?

Methods

The design was based on the Medical Research Council Framework (MRC), human-centred design and co-design. A three-step procedure was used for the development of ActivABLES which included: (1) identifying the evidence and outcomes where we used the findings from earlier systematic reviews, (2) implementation of an initial user study and iterative tests which included qualitative individual and focus group interviews with stroke survivors, caregivers and professionals, and (3) preliminary testing where each prototype was tested in the home of seven stroke survivors for a few hours. The study was approved by the National Ethics Committee of Iceland (Ref. VSNb2015110001/03.01), the Regional Ethics Committee in Lund, Sweden (dnr 2015/678) and the City of Helsinki, Finland (HEL 2016–002570). The study was conducted between September 2015 and March 2018 in accordance with the principles of the Declaration of Helsinki, and all participants signed an informed consent for participation.

The Medical Research Council framework

The MRC framework for development of complex interventions was used to guide the development of the ActivABLES as a healthcare intervention. The MRC framework defines interventions that contain several interacting components as complex interventions and provides guidance for their development [47] (Fig. 1). The framework describes the process of development, which includes four phases; (i) Development, (ii) Feasibility and piloting, (iii) Evaluation and (iv) Implementation. These phases do not have a linear sequence and each one can affect the others. In this paper, we report on the first phase of the framework which includes the development of ActivABLES. We used the first two phases of the framework. The Criteria for Reporting the Development and Evaluation of Complex Interventions in Healthcare (CReDECI 2) was used to report the phases of the development process [48].

Human-centred design and co-design

The technical development process of ActivABLES was guided by the principles of human-centred design (HCD)

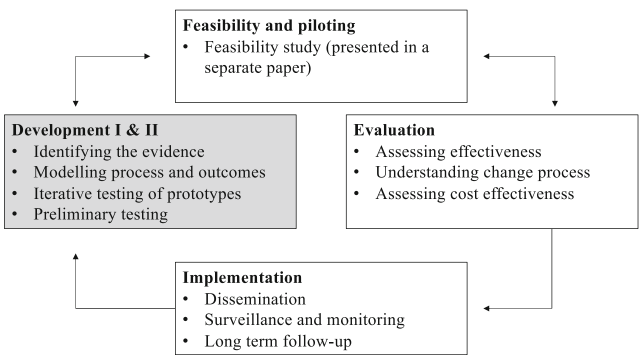


Fig. 1 Medical Research Council framework for ActivABLES

(ISO 9241-210:2010) and methods of co-design. HCD is a management framework that develops solutions by involving the human perspective in all steps of the problem-solving process [49]. Co-design assumes that individuals of equal cognitive and physical abilities participate in the development process [50]. This design is often used when interactive technologies are being developed. During the development process and prior to the feasibility study conducted in Iceland, small technical tests were performed iteratively in Sweden and Finland. These tests involved stroke survivors, caregivers and health professionals, and included the testing of several aspects of the prototypes, such as user interface, usability, etc. The technical and design process has been described in previous papers: the initial studies and user requirements [51], the balance part of the technical system [52], the development of the arm/hand tools [53] and the app design [54].

The ActivABLES team

The ActivABLES research team includes multi-disciplinary researchers from (i) Iceland: five nurse scientists (TBH, HJ, IB, IH, EP) and two physical therapist scientists (SAO, SAA) with extensive experience in stroke rehabilitation and research; (ii) Sweden: two design sciences engineers (CM, HC); and (iii) Finland: three computer scientists (DM, MK, LM) and one computer scientist student (WB), all with experience in the development of technical interventions in healthcare. Throughout the development process, the team had bi-weekly Skype meetings and six cross-country meetings where the research team discussed the progress of the development and the research work (Fig. 2).

Development process of ActivABLES

The development of ActivABLES involved the three following steps (Fig. 2):

Step 1. Identifying the evidence and outcomes

We identified the evidence base for effective exercise interventions and important outcomes for stroke survivors. The findings of systematic reviews showed the importance of augmenting exercise and physical activities among stroke survivors [10, 15, 55]. Physical inactivity and sedentary behaviour are significant considerations at all stages after stroke (acute, subacute and chronic) and seem to increase from the subacute state to the chronic stage [56, 57]. Many stroke survivors do not continue with training and become physically inactive following inpatient rehabilitation [55, 57], often due to depression or lack of motivation [20, 22].

The following evidence from systematic reviews was used to identify the outcome measures for the ActivABLES intervention:

- Balance: Balance impairments are very common in stroke survivors, affect general mobility and walking ability [58], and increase the risk for falls. Studies have shown that 33–48% of stroke survivors fall at least once within the first year after their stroke [59]. Balance exercises can result in improved

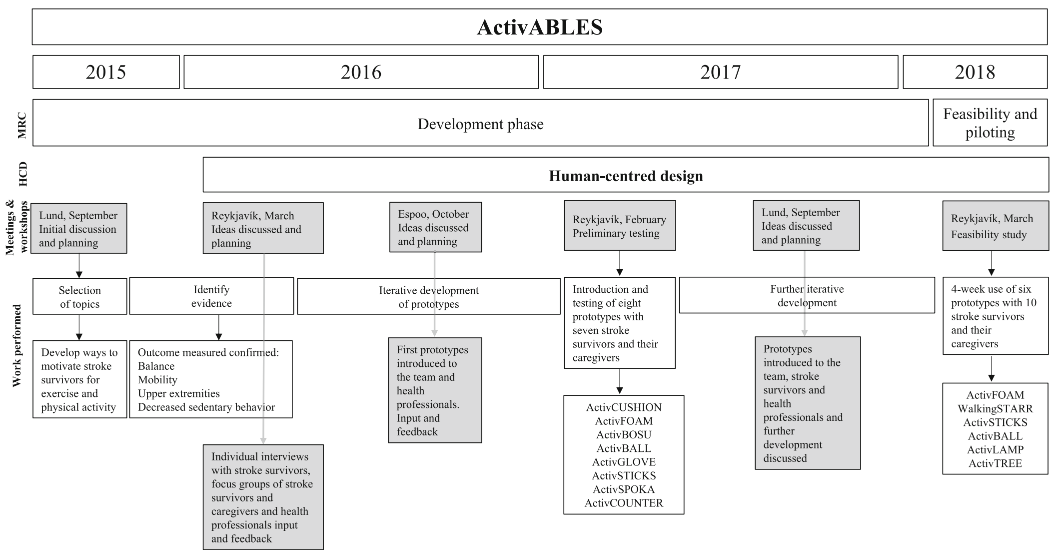


Fig. 2 Timeline and process of the development of ActivABLES

function in all post-stroke phases [12, 25]. There is strong evidence that balance can be improved with exercise, including using technical applications [25]. Balance exercises with visual or auditory feedback can have significant effects on improving the balance of chronic stroke survivors, especially those with mild to moderate impairments [12].

- Mobility: Mobility is defined as “the ability to move in one’s environment with ease and without restriction” [60] and includes the ability to stand up/sit down and walk. There is strong evidence that gait exercise significantly improves the mobility of stroke survivors in all phases after stroke [12, 25]. Task-oriented exercise and visual and auditory feedback are especially recommended as key factors for improving mobility [61].
- Upper extremity: Impairments of the upper extremities are common in stroke survivors and can cause difficulties in different activities of daily living such as eating, dressing and washing [62]. Various reviews have emphasised the importance of exercise for the upper extremities, especially for stroke survivors with mild to moderate impairments, and they can benefit from exercise emphasising task-specific repetitions, which is a key factor in motor learning [12, 17, 25, 34].
- Motivation: Motivation for exercise and physical activity is often lacking after a stroke [20] and about one-third of stroke survivors deal with depression, which can affect motivation [6]. Motivational interventions, including internet-based programmes and reinforcement strategies, can increase adherence to exercise [63]. Feedback can motivate stroke survivors to engage in exercise and physical activity, and both visual and audio feedback can motivate stroke survivors to continue with exercise. Support from caregivers and health professionals is also important [20, 64].

Step 2. Initial user study and iterative tests

We involved stroke survivors with a mild to moderate level of physical disability (Modified Rankin Scale 2–4), informal caregivers, rehabilitation professionals and other stakeholders in the whole development process to gain their feedback on the development. An initial user study was conducted in Iceland. This included a qualitative focus group interview and 10 individual interviews with stroke survivors. The qualitative interviews were thematically analysed according to Brown & Clark (2006), resulting in three identified themes: managing the challenges of impairment, long-term challenges of everyday life and framing exercise within the context of everyday life. These findings emphasised the importance of exploring innovative ways of using technology to empower stroke survivors to tackle challenges and be responsible in their daily activities, and to motivate them to engage in home-based exercise and physical activity. The results of this study will be published in a separate paper (Hafsteinsdottir et al. 2020/work in progress). In addition, ideas and prototypes were introduced and discussed with stroke survivors, caregivers and professionals at the on-site team meetings, and iterative tests were performed in Sweden and Finland to test the design and technical systems of the prototypes [51–54]. Workshops were also held for stroke survivors, caregivers and rehabilitation professionals during the development process, where different prototypes were presented to solicit feedback and input on usability.

Step 3. Preliminary testing of prototypes

In the context of development according to the MRC framework, a preliminary testing of eight ActivABLES prototypes was conducted in February 2017 (Fig. 2). This preliminary testing aimed to investigate how the prototypes could be used by stroke survivors in their home environment, and to gain feedback on the development and feasibility of ActivABLES prototypes. The testing took place in the stroke survivors’ homes and lasted for 1–2 h. Each prototype was tested until the stroke survivors had tried all the exercise and activity possibilities each prototype included. Observations were made, and participant-researcher interactions were video-recorded. During the observations, we asked questions and received feedback on each prototype and one of the researchers filled in a form with comments on each prototype (Additional file 1: Appendix I). These comments were used to improve and further develop the prototypes, along with input from the technical team. Following the testing, the researchers conducted semi-structured interviews separately with each stroke survivor and his/her caregiver, using interview guides (Additional file 1: Appendix II). Additional questions were asked to gain feedback concerning experiences, meaning, technical elements of the prototype (background, light, sound, objects etc.).

A purposive sample included seven community-dwelling stroke survivors ≥18 years, with a mild to moderate level of physical disability (Modified Rankin Scale 2–4) and their caregivers. The age range of the stroke survivors (four women and three men) participating was 31–76 years and their strokes had occurred from 9 months to 22 years previously. Functional outcome measures were carried out to provide a thorough description of the stroke survivors participating (Table 1). Six caregivers participated, three men and three women, in the age range of 53–75 years. All of them were spouses of the stroke survivors, four were employed and two were retired.

Eight ActivABLES prototypes were introduced in the preliminary testing, namely: ActivCUSHION, ActivFOAM, ActivBOSU, ActivBALL, ActivGLOVE,

Table 1 Characteristics of the participants in the preliminary testing

Stroke survivors	Age	Time since stroke	Side of hemiparesis	Walking device inside	BBS[a]	BBT[b]	ABC[c]
SS-1	31	19 months	left	no	56	x	76.3
SS-2	60	4 years	left	no	37	x	38.1
SS-3	62	9 months	left	no	47	x	51.4
SS-4	63	22 years	left	no	43	x	66
SS-5	66	2 years	right	no	33	53	65
SS-6	72	4 years	left	yes. a cane	43	6	73.1
SS-7	76	9 years	left	yes, a cane	37	12	29.4

SS stroke survivor
[a]Berg Balance Scale, score 0-56 where lower score indicates more balance impairments
[b]Box and Block Test, number of blocks moved between boxes in one minute. X presents those who were not able to use their affected hand
[c]Activities-Specific Balance Confidence Scale assesses self-efficacy in different activities, score 0-100 where 0 represents no confidence and 100 represents complete confidence

ActivSTICKS, ActivSPOKA and ActivLAMP. The findings of the preliminary testing showed that four prototypes were found to be relevant for further development for community-dwelling stroke survivors with mild to moderate impairments: ActivFOAM, ActivBALL, ActivSTICKS and ActivLAMP. During the preliminary testing, the stroke survivors and their caregivers indicated that there was a need for an application to stimulate and detect more general activity like walking. This result was further supported by a workshop carried out in the EU project STARR at the Stroke Organisation in Bromsgrove, UK [65]. Therefore, as a joint effort with this EU project, WalkingSTARR was developed, which is an application for the iPhone with a step-counter and games to encourage walking. In addition, ActivTREE was developed as an application providing feedback on more than one exercise/physical activity (Table 2).

ActivCUSHION and ActivBOSU were not considered to be appropriate for community-dwelling stroke survivors with slight to moderate symptoms. ActivCUSHION is a thin cushion that can be put on a seat and then the stroke survivor sits on it. Pressure sensors pick up the weight and give individually tailored visual and sound feedback on posture while seated and for example warning if the stroke survivor is leaning more towards one side. It was not challenging enough for the stroke survivors who participated since they generally had good sitting balance. Still, the stroke survivors and researchers agreed that stroke survivors with impaired sitting balance could benefit from using it. ActivBOSU is a half ball, with an unstable base, and can be used for balance and posture exercise. It was considered to be too difficult and not safe to use for balance exercise at home, since it is quite challenging to stand on the soft and unstable surface of ActivBOSU and doing so would increase the risk of falling while doing the exercises. However, it was deemed to be fitting for supervised use by stroke survivors with good active balance. ActivSPOKA is a little lamp which lights up to remind the stroke survivor to exercise and/or to give feedback when the daily recommended exercises and physical activity are finished. Due to similarities and redundancies with ActivLAMP it was excluded from further development. ActivGLOVE gave promising results, with possibilities of extension and flexion extension movements of the fingers, but it was too difficult for the stroke survivors to put it on and further design was needed to make it more suitable. Therefore, four of the prototypes were excluded after the preliminary testing: ActivCUSHION, ActivBOSU, ActivSPOKA and ActivGLOVE (Table 3).

The data from the interviews with the stroke survivors and their caregivers were analysed individually using thematic analysis (Brown and Clark, 2006). Two themes were identified for each group: *Importance of feedback and encouragement* and *Integration of exercise into activities of daily living* (Fig. 3) for the stroke survivors and *Importance of feedback and encouragement* and *Lack of resources to assist with exercise* for the caregivers (Fig. 4). Based on these findings, the prototypes were further developed and adapted to the needs of the stroke survivors and their caregivers. The idea of ActivABLES was to give stroke survivors and their caregivers resources to use for exercise and physical activity. The prototypes were made small to make them easy to use in homes and accessible in daily life. As requested, some form of feedback mechanism was included into all of the prototypes.

Results

The development process resulted in the six following prototypes relevant for community-dwelling stroke survivors with slight to moderate impairments: ActivFOAM, WalkingSTARR, ActivBALL, ActivSTICKS which are exercise prototypes and ActivLAMP and ActivTREE which give visual feedback on the amount of exercise done.

ActivFOAM is a soft balance mat with pressure sensors that give individually tailored visual and sound

Table 2 Prototypes of ActivABLES

	Preliminary testing	Feedback during observations	Revisions of the prototype
ActivFOAM 	The foam was connected to a tablet where the users could see how their weight was distributed on the mat, get audio feedback and play one game (The bomb). The user could see on the screen when weight was shifted from 1 foot to the other.	"It is very convenient to stand on this and see how I am standing. It gives you comments on how you are standing".	Two games were added as ways to practice balance. Also, there were possibilities to use different music to encourage weight shifting and stepping one the mat.
WalkingSTARR 	Not yet developed.		After the preliminary testing it was decided to develop an iPhone application to encourage walking.
ActivBALL 	The ball was introduced as a mouse for a computer when browsing Google Street View, and online magazines and for basic internet browsers, and to play basic games such as Tic-Tac-Toe. It could also be used as a tool for squeezing (or do other exercises for the hand/wrist) to "earn" a series from television/Netflix.	"I think it could work as a mouse - it would be a more suitable movement [for the hand]".	Due to lack of time, it was not possible to develop these possibilities further prior to the feasibility study. Therefore, the exercises were repetitive movements with the recommended number of daily exercises seen on the tablet. A counter for the exercises was visible on the tablet.
ActivSTICKS 	The sticks were introduced as a tool to use to browse Google Street View. The idea was to have a double-arm tool to use for "wandering around" on Google streets.	The users found it difficult to handle the sticks. Although the idea was new to the users, it was decided to develop it further.	Due to lack of time, it was not possible to develop these possibilities further prior to the feasibility study. Therefore, the exercises were repetitive movements with the recommended number of daily exercises seen on the tablet. A counter for the exercises was visible on the tablet.
ActivLAMP 	The light gave feedback on how long the users had been exercising.	"I think it is rewarding to see the light strip become progressively more lit up".	ActivLAMP was further developed into a single light strip in a stained glass cylinder that lit up as the user used one ActivABLES tool.
ActivTREE 	Not yet developed.	"It would be good to have something that gives an overview of the exercises"	After the preliminary testing, it was decided that it was necessary to provide feedback on multiple activities at the same time.

feedback on weight shifting and centre of mass while standing [52]. The mat is connected to a tablet which is positioned in front of the user (Fig. 5). Three interactive games and different types of audio feedback can be selected from the tablet and used for exercising:

(i) *Pong* for reactive balance, where the user moves a paddle by shifting the amount of weight on each foot to hit a ball which comes at different speeds from an unknown direction (Fig. 6). The user has to shift more weight to the other foot to make the paddle move. The size of the paddle can be adjusted: smaller paddles make the game more difficult. The user collects a point each time he/she hits the ball.

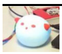
(ii) *Escape* for proactive balance where the user moves a ball, by putting more weight onto 1 foot to avoid barriers which are in the way (Fig. 7). The user collects a point for each barrier he/she escapes.

(iii) *The bomb* for proactive balance, where the user moves a ball in and out of a circle. The ball is moved outside the circle by putting more weight onto 1 foot, as much as the user is able to, and then back into the circle by adjusting the weight onto both feet. The ball needs to be back in the circle before audio feedback indicates a bomb explosion (Fig. 8).

(iv) More possibilities include use of different types of audio feedback like jazz, samba and guitar tones while looking at a screen showing how much weight is being put on each leg.

WalkingSTARR is an iPhone application that includes a step counter which records the daily steps taken and walking time [54]. Daily recommendations for the number of steps to take can be individualised in the app for each user. The idea is to mimic taking the dog out for a

Table 3 Excluded prototypes after the prelimary testing

	Preliminary testing	Feedback during observations	Reason for exclusion
ActivCUSHION 	The thin cushion was put on a chair and could give feedback on weight bearing in sitting, as it was connected to a tablet. The idea of different feedback was discussed.	"I would sit up straight, for example in front of the television or when working by the kitchen table".	We thought that only very few users with mild or moderate impairments would be in need of this kind of tool. Therefore, it was decided not to develop it further at this point. Still, we got some ideas on different feedback, i.e. vibration that would be more private than a light or a sound.
ActivBOSU 	Only one user who had hardly any balance difficulties, was able to try ActivBOSU.		It was decided that ActivBOSU was too difficult for users to use safely in their homes.
ActivGLOVE 	The glove had visual and audio feedback with the purpose to extend the fingers. The finger lit gradually when the finger was extended or played a sound when it was fully extended.	"The glove needs to be a mitten or not for each finger". "It would be a good idea to have a specific sound for the movement of each finger".	It was hard to put the glove on and it was decided another version was needed which would be more open and easier to put on. This version would fit all hand sizes. Further development of the glove turned out to be quite complex and needed extensive expertise. Therefore, it was decided not to develop it further at this point.
ActivSPOKA 	The light gave feedback on how long the users had been exercising.	"I see the purpose of this one, as a reward thing, I also think it's just fun". "You could have it red or green, depending on how you are doing".	Due to similarities and redundancies with ActivLAMP and the greater flexibility of ActivLAMP, ActivSPOKA was not further developed.

walk and the app "barks" randomly during the day to remind the user to go for a walk. The app also includes a few optional tasks which involve having to stop to let the dog pee by a tree and eat food from a bowl. The user needs to point the iPhone in certain directions to find the tree and the bowl, which are visible on the iPhone. These tasks require some motor control where the user has to initiate and stop walking to meet the dog's needs. The user might also have to turn in order to point the iPhone into the right direction. These tasks are supposed to be motivating as the user collects stars when each task is completed. The visual feedback can be seen in Fig. 9 where the ellipse gradually fills up with colour as the daily recommendations are met.

ActivBALL is a soft ball which is intended to improve motor control of the forearm and upper arm, and grip strength. The ball is connected to a tablet which is positioned in front of the user and can be pre-programmed for individually tailored sets of exercises. The ball can be used to exercise the following movements: 1) Forearm pronation and supination (Fig. 10), 2) Dorsiflexion and palmar flexion of the wrist, 3) Flexion and extension of

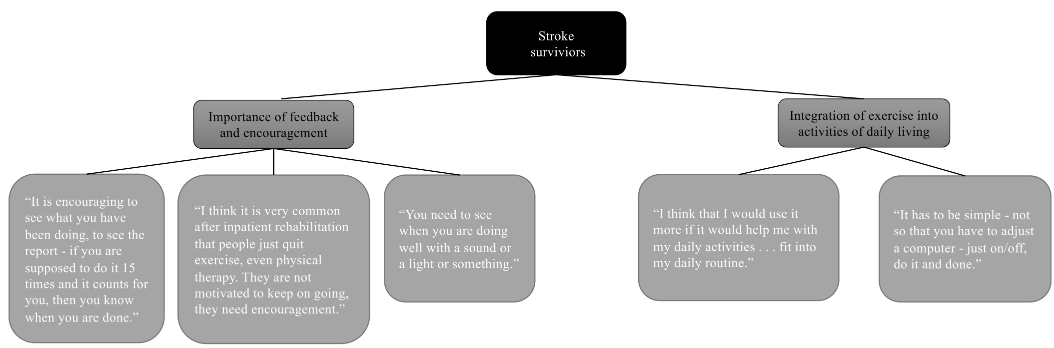


Fig. 3 Thematic analysis of interviews with stroke survivors

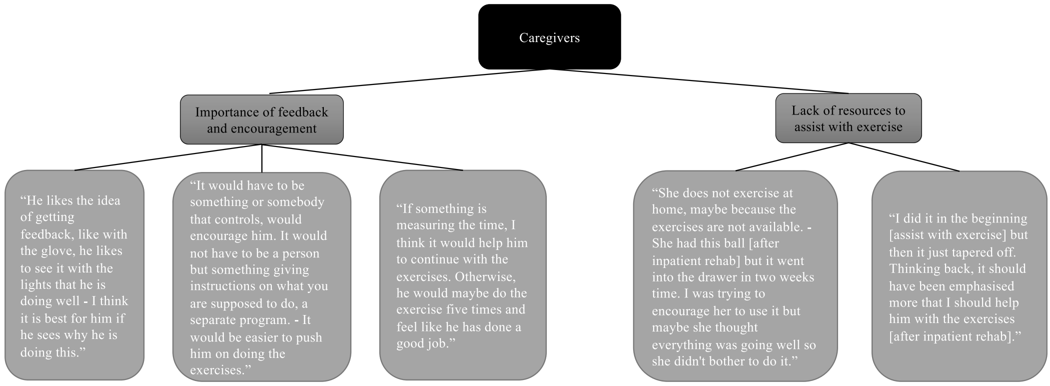


Fig. 4 Thematic analysis of interviews with caregivers

the fingers while squeezing, and 4) External and internal rotation of the shoulder. The range of motion and pressure detected while squeezing can be adjusted for each user. While exercising using ActivBALL, the user follows instructions on the tablet about the number of repetitions and sets, both of which can be individualised for each user.

Fig. 5 Setup for ActivFOAM

ActivSTICKS consists of two plastic sticks which are linked together forming an angle from 0° to 180° [53]. The sticks are connected to a tablet which is positioned in front of the user and can be pre-programmed for individually tailored sets of exercises. The sticks can be used to perform the following movements: 1) Abduction and adduction of the shoulder, 2) Flexion of the shoulder, 3) Elbow flexion and extension along with coordination of the left and right arms while doing "scissors", and 4) Rotation of the upper body (Fig. 11). The range of motion as well as the resistance to the movement can be adjusted for each user. While exercising using ActivSTICKS, the user follows instructions on the tablet about the number of repetitions and sets, both of which can be individualised for each user.

ActivLAMP and ActivTREE give visual feedback on the stroke survivor's daily progress by gradually lighting to indicate the proportion of exercises completed. The more exercises done or steps taken, the more the ActivLAMP/ActivTREE lights up. ActivLAMP and ActivTREE

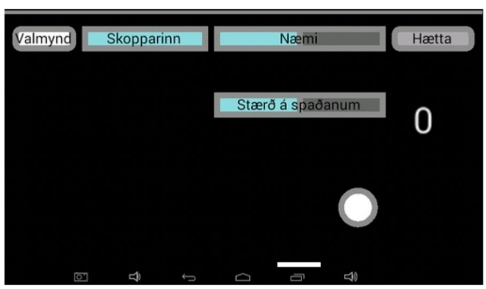


Fig. 6 Screenshot of *Pong*

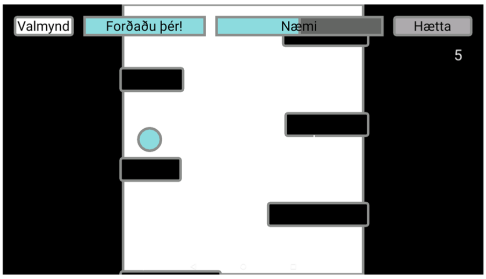


Fig. 7 Screenshot of *Escape*

reset every day at midnight. Settings can be individualised for each user and the recommended use per day and/or number of repetitions can easily be changed as the user further progresses to higher activity levels. A rehabilitation professional gives instructions on which prototype to use and for how long the user should exercise based on a baseline functional assessment and preferences for each stroke survivor.

Discussion

In this paper we provide a detailed report of the three-step development process of ActivABLES for community-dwelling stroke survivors and their caregivers to allow for a thorough review and replication of the process. The development process resulted in six prototypes: four exercise prototypes which are ActivFOAM, WalkingSTARR, ActivBALL and ActivSTICKS, along with ActivLAMP and ActivTREE, which give visual feedback on the amount of exercise done. Three of the exercise prototypes and the two feedback prototypes were connected to a tablet but WalkingSTARR was only developed as an application for iPhone. Digital servers store data about all uses of the prototypes. The tangible prototypes do not take up much space and can easily be used in a small environment, such as a small room. In this respect they are different from

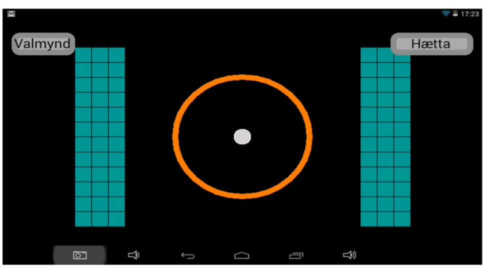


Fig. 8 Screenshot of *Bomb*

Fig. 9 The ellipse fills up with blue in WalkingSTARR

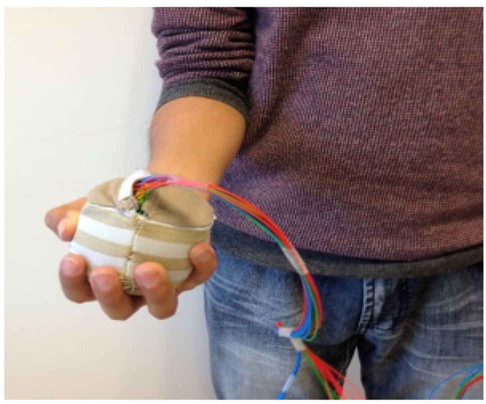


Fig. 10 Using ActivBALL for exercising supination/pronation of the hand

Fig. 11 Using ActivSTICKS for rotation of upper body

many other technical solutions, such as Wii and Kinect, where a television or a bigger screen is needed. ActivABLES also offer different activities aimed at different functional outcomes but do not focus solely on one single exercise or activity. The challenges in each exercise and physical activity can be individualized for each user. ActivABLES is specially developed for community-dwelling stroke survivors, since these stroke survivors and their caregivers have called for more opportunities for exercise and physical activity in their own home [19, 66]. The results of the three steps in the development process support our ideas that ActivABLES is relevant for community-dwelling stroke survivors with mild to moderate symptoms. The evidence found in the literature shows what kind of exercise and physical activity are relevant for community-dwelling stroke survivors. The initial user study gave us an idea about where to put the emphasis in the development, and the iterative technical testing during the development made the prototypes useable in the preliminary testing. The results of the preliminary testing gave positive feedback for further development and preparation for the feasibility study which is presented in another submitted paper (Olafsdottir et al. 2020/work in progress).

Much innovative research and many interventions are ongoing, and they often lack a thorough description, which is important to improve replicability. The CReDECI 2 guidelines for reporting of the development of complex interventions [48] proved useful to report the first and second stages of the development of ActivABLES in order to ensure the quality of transparent reporting of this complex intervention. Also, the MRC framework provides guidance for development, of the ActivABLES intervention as a complex intervention. The reporting of the feasibility testing of the ActivABLES is given in another paper (Olafsdottir et al. 2020/work in progress) and studies on the other phases of the MRC framework, including the evaluation and the implementation, are still to be done (Fig. 1). The design of the study, using a human-centred approach and co-design in which stroke survivors, caregivers and rehabilitation professionals participated, is highly important, with the potential future users involved in every step of the development process. A key element in the process has been to involve not only potential future users, but also the context of potential future situations of use, the stroke survivors' homes.

The six ActivABLES prototypes developed include: ActivFOAM for balance exercise, WalkingSTARR for encouraging walking, ActivBALL for hand exercises, ActivSTICKS for arm exercises and ActivLAMP and ActivTREE for feedback on exercise.

ActivABLES seems to be very suitable for helping caregivers to support the stroke survivors in exercising at home. This is important as studies have shown that caregiver-mediated home-based exercise can give good functional results [23, 67] and can have a positive impact on anxiety and depression of both the stroke survivor and the caregiver [24]. In addition, caregivers are willing to be more involved in the rehabilitation process at home if they have more information and knowledge about how they can support and motivate their stroke survivor to exercise and be more physically active [66, 68, 69].

Other studies using interactive games, similar to games with ActivFOAM, have shown promising results regarding adherence acceptability and safety [29]. ActivABLES aims to motivate users and make home-based exercise and physical activities more fun and less tedious with more variety in exercise and training options for community-dwelling stroke survivors with slight to moderate activity limitations. ActivABLES could be a resource for physical therapists to motivate community-dwelling stroke survivors to engage and continue with home-based exercise and physical activities after inpatient rehabilitation. Further benefits of an intervention like ActivABLES may include less need for inpatient healthcare services and possible earlier discharge from hospital or inpatient rehabilitation, resulting in lower healthcare costs and other economic benefits [24, 70]. More research is needed with larger samples of community-dwelling stroke survivors and caregivers.

The main limitations of this study include technical problems, which are inherent when using experimental prototypes that are primitive and fragile and need to be delicately handled. In the development process, the technicians were involved at all times so they could solve the emerging problems. Another limitation is the small sample of participants. Among the strengths of this study are (i) the use of theoretical underpinnings, as we followed the MRC-model for complex interventions, (ii) the human-centred design which gives the researchers a thorough understanding and inputs from future users, including stroke survivors, caregivers and the multi-disciplinary team working on the idea, and (iii) the evidence-based approach, which brings out knowledge about ways to promote home-based exercise and physical activity of community-dwelling stroke survivors.

ActivABLES has the potential to be a good resource for healthcare professionals and the healthcare system to follow up on community-dwelling stroke survivors. The healthcare system is unable to provide daily support for those who need encouragement and/or support with physical activity. Community-dwelling stroke survivors need to increase their health-promoting physical activity, preferably in their own environment, with support from their caregivers and instructions from rehabilitation professionals. ActivABLES seems to be very suitable to support community-dwelling stroke survivors in exercising at home.

Conclusion

ActivABLES is promising technical equipment aiming to support community-dwelling stroke survivors when engaging in home-based exercise and health-promoting physical activities with support from caregivers. Community-dwelling stroke survivors, caregivers and rehabilitation professionals were involved in the whole development process. ActivABLES integrates Tangible User Interfaces into the everyday activities of community-dwelling stroke survivors to provide feedback to increase motivation and support the continuation of home-based exercise and physical activity. Different feedback options including games, music and lights, are used to increase the motivation of community-dwelling stroke survivors to engage in exercise and physical activity to improve their physical and mental function, increase their walking, and decrease sedentary behaviour, with the ultimate goal of improved participation in society and improved quality of life. Robust and large outcome studies are needed to further investigate the effects of ActivABLES on various outcomes of community-dwelling stroke survivors and caregivers, as well as to examine the cost-effectiveness for the healthcare system.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12913-020-05198-2.

Additional file 1. Appendix I Form for feedback on prototypes during observationsppendix. Appendix II Semi-structured interview guides.

Abbreviations

ADLs: Activities of daily living; CReDECI 2: Criteria for Reporting the Development and Evaluation of Complex Interventions in Healthcare; HCD: Human-centred design; MRC: Medical Research Council; TUI: Tangible user interfaces

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Authors' contributions

THB, HJ and CM designed and coordinated the study and wrote the protocol. IB, EP and IH contributed to the qualitative initial data collection. SAO, IB and TBH conducted the preliminary testing and SAA contributed to the data collection. CM, HC, DM, MK and LM developed the prototypes and iteratively tested the prototypes among stroke survivors. CM is the grant holder for the programme that supported this work. SAO and TBH wrote the first draft of the manuscript, which was critically revised for important intellectual content by all authors. All authors have approved the final version of this manuscript prior to submission. TBH and SAO are the guarantors of the manuscript, and affirm that the manuscript is an honest, accurate, and transparent account of the research being reported; and that no important aspects of the study have been omitted.

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Availability of data and materials

The prototypes developed are kept at Lund University in Sweden and Aalto University in Helsinki. We do not have a publicly open database. Additional anonymised data from the qualitative interviews and focus groups and further results from the preliminary testing are available upon request from the corresponding author.

Ethics approval and consent to participate

Ethical approval for the study was granted by the National Ethics Committee of Iceland (Ref. VSNb2015110001/03.01), the Regional Ethics Committee in Lund, Sweden (dnr 2015/678) and the City of Helsinki, Finland (HEL 2016–002570). All participants signed a consent for participation. All the requirements of the Helsinki Declaration were fulfilled.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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References

1. Béjot Y, Daubail B, Giroud M. Epidemiology of stroke and transient ischemic attacks: current knowledge and perspectives. Rev Neurol. 2016;172:59–68.
2. Kim J, Thayabaranathan T, Donnan GA, et al. Global stroke statistics 2019. Int J Stroke. 2020. https://doi.org/10.1177/1747493020909545.
3. Johnson CO, Nguyen M, Roth GA, et al. Global, regional, and national burden of stroke, 1990-2016: a systematic analysis for the global burden of disease study 2016. Lancet Neurol. 2019;18(5):439–58.
4. Warlow C, Sudlow C, Dennis M, et al. Stroke. Lancet. 2003;362:1211–24.
5. De Wit L, Theuns P, Dejaeger E, et al. Long-term impact of stroke on patients' health-related quality of life. Disabil Rehabil. 2017;39:1435–40.
6. Hackett ML, Pickles K. Part I. Frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. Int J Stroke. 2014;9:1017–25.
7. Lindsay P, Furie KL, Davis SM, et al. World stroke organization global stroke services guidelines and action plan. Int J Stroke. 2014;9:4–13.
8. Hebert D, Lindsay MP, McIntyre A, et al. Canadian stroke best practice recommendations: stroke rehabilitation practice guidelines, update 2015. Int J Stroke. 2016;11:459–84.
9. Winstein CJ, Stein J, Arena R, et al. Guidelines for adult stroke rehabilitation and recovery. A guideline for healthcare professionals from the American Heart Association/American Stroke Association. Stroke. 2016;47:e98–e169.
10. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. Lancet. 2011;377:1693–702.
11. Pollock A, St George B, Fenton M, et al. Top 10 research priorities relating to life after stroke - consensus from stroke survivors, caregivers, and health professionals. Int J Stroke. 2014;9:313–20.
12. Veerbeek JM, van Wegen E, van Peppen R, et al. What is the evidence for physical therapy poststroke? A systematic review and meta-analysis. PLoS One. 2014;9:e87987.
13. Mathiowetz V, Volland G, Kashman N, et al. Adult norms for the box and block test of manual dexterity. Am J Occup Ther. 1985;39:386–91.
14. Saunders DH, Sanderson M, Hayes S, et al. Physical fitness training for stroke patients. Cochrane Database Syst Rev. 2016;3:CD003316.
15. Pollock A, Baer G, Campbell P, et al. Physical rehabilitation approaches for the recovery of function and mobility following stroke. Cochrane Database Syst Rev. 2014;4:CD001920.
16. Teasell R, Fernandez M, McIntyre A, et al. Rethinking the continuum of stroke rehabilitation. Arch Phys Med Rehabil. 2014;95:595–6.
17. Thomas LH, French B, Coupe J, et al. Repetitive task training for improving functional ability after stroke: a major update of a Cochrane review. Stroke. 2017;48:e102–3.
18. Schupp W, Komaratat N, Steib S. Running a complementary stroke rehabilitation and aftercare program: experiences of four European centres. In: Bettany-Saltikov J, Paz-Lourido B, editors. Physical therapy perspectives in the 21st century - challenges and possibilities. Croatia: IntechOpen; 2012. p. 315–36.
19. Krishnan S, Pappadis MR, Weller SC, et al. Needs of stroke survivors as perceived by their caregivers: a scoping review. Am J Phys Med Rehabil. 2017;96:487–505.
20. Nicholson S, Sniehotta FF, van Wijck F, et al. A systematic review of perceived barriers and motivators to physical activity after stroke. Int J Stroke. 2013;8:357–64.
21. Miller KK, Porter RE, DeBaun-Sprague E, et al. Exercise after stroke: patient adherence and beliefs after discharge from rehabilitation. Top Stroke Rehabil. 2017;24:142–8.
22. Pyae A, Luimula M, Smed J. Understanding stroke patients' motivation for motivation-driven rehabilitative game design. Internet of Things. User-Centric IoT; 2015. p. 99–111.
23. Vloothuis JD, Mulder M, Veerbeek JM, et al. Caregiver-mediated exercises for improving outcomes after stroke. Cochrane Database of Syst Rev. 2016;12:CD011058.
24. Vloothuis JDM, Mulder M, Nijland RHM, et al. Caregiver-mediated exercises with e-health support for early supported discharge after STROKE (CARE4STROKE): a randomized controlled trial. PLoS One. 2019;14:e0214241.
25. Teasell R, Cotoi A, Chow J, et al. The stroke rehabilitation evidence-based review: (18th edition): Canadian stroke network; 2018. http://www.ebrsr.com/sites/default/files/documents/v18-SREBR-ExecutiveSummary-2.pdf.
26. Lutz BJ, Camicia M. Supporting the needs of stroke caregivers across the care continuum. J Clin Outcomes Manag. 2016;23:557–66.
27. Hafsteinsdóttir TB, Vergunst M, Lindeman E, et al. Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. Patient Educ Couns. 2011;85:14–25.
28. Held JP, Ferrer B, Mainetti R, et al. Autonomous rehabilitation at stroke patients home for balance and gait: safety, usability and compliance of a virtual reality system. Eur J Phys Rehabil Med. 2018;54:545–53.
29. Bower KJ, Louie J, Landesrocha Y, et al. Clinical feasibility of interactive motion-controlled games for stroke rehabilitation. J Neuroeng Rehabil. 2015;12:63.
30. Putrino D, Zanders H, Hamilton T, et al. Patient engagement is related to impairment reduction during digital game-based therapy in stroke. Games Health J. 2017;6:295–302.
31. McGookin D, Robertson E, Brewster S. Clutching at straws: using tangible interaction to provide non-visual access to graphs. Atlanta: In: Proceedings of the SIGCHI conference on human factors in computing systems; 2010. p. 1715–24. https://doi.org/10.1145/1753326.1753583. Accessed 10 Apr 2010.
32. Mirza-Babaei P, Kamkarhaghighi M, Gerling K. Opportunities in game-based stroke rehabilitation. In: Proceedings of the 2014 IEEE Games Media Entertainment: GEM; 2014 Oct 22. Toronto: IEEE Xplore; 2015. Available from: https://ieeexplore.ieee.org/document/7118436.
33. Mawson S, Nasr N, Parker J, et al. A personalized self-management rehabilitation system with an intelligent shoe for stroke survivors: a realist evaluation. JMIR Rehabil Assist Technol. 2016;3(1):e1.
34. Shumway-Cook A, Woollacott MH. Motor control: translating research into clinical practice. 5th ed. Philadelphia: Wolters Kluwer; 2017.
35. Laver KE, George S, Thomas S, et al. Virtual reality for stroke rehabilitation. Cochrane Database of Syst Rev. 2017;11:CD008349.
36. Cheok G, Tan D, Low A, et al. Is Nintendo Wii an effective intervention for individuals with stroke? A systematic review and meta-analysis. J Am Med Dir Assoc. 2015;16:923–32.
37. Rooij I, van de Port I, Meijer J. Feasibility and effectiveness of virtual reality training on balance and gait recovery early after stroke: a pilot study. Int J Phys Med Rehab. 2017;5:4.
38. Saposnik G, Cohen LG, Mamdani M, et al. Efficacy and safety of non-immersive virtual reality exercising in stroke rehabilitation (EVREST): a randomised, multicentre, single-blind, controlled trial. Lancet Neurol. 2016;15:1019–27.
39. Adie K, Schofield C, Berrow M, et al. Does the use of Nintendo Wii sports™ improve arm function? Trial of Wii™ in stroke: a randomized controlled trial and economics analysis. Clin Rehabil. 2017;31:173–85.
40. Pessoa TM, Coutinho DS, Pereira VM, et al. The Nintendo Wii as a tool for neurocognitive rehabilitation, training and health promotion. Comput Human Behav. 2014;31:384–92.
41. Wingham J, Adie K, Turner D, et al. Participant and caregiver experience of the Nintendo Wii sports™ after stroke: qualitative study of the trial of Wii™ in stroke (TWIST). Clin Rehabil. 2015;29:295–305.
42. Givon Schaham N, Zeilig G, Weingarden H, et al. Game analysis and clinical use of the Xbox-Kinect for stroke rehabilitation. Int J Rehabil Res. 2018;41:323–30.
43. Abreu J, Rebelo S, Paredes H, et al. Assessment of Microsoft Kinect in the monitoring and rehabilitation of stroke patients. In: Rocha Á, Correia A, Adeli H, Reis L, Costanzo S, editors. Recent advances in information systems and technologies: proceedings of the world conference on information systems and technologies: WorldCIST; 2017 Apr 11; Calicia, Spain. Cham: Springer; 2017. p. 167–74.
44. Seo K, Kim J, Ryu H, et al. 'RehabMaster™': a pervasive rehabilitation platform for stroke patients and their caregivers. In: Holzinger A, Ziefle M, Röcker C, editors. Pervasive health. London: Springer; 2014. p. 131–55.

45. Alankus G, Lazar A, May M, et al. Towards customizable games for stroke rehabilitation. Atlanta: In: Proceedings of the SIGCHI conference on human factors in computing systems; 2010. p. 2113–22. https://doi.org/10.1145/1753326.1753649. Accessed 10 Apr 2010.
46. Saywell N, Taylor N, Rodgers E, et al. Play-based interventions improve physical function for people with adult-acquired brain injury: a systematic review and meta-analysis of randomised controlled trials. Clin Rehabil. 2017; 31:145–57.
47. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new medical research council guidance. BMJ. 2008;337: 979–83.
48. Möhler R, Kopke S, Meyer G. Criteria for reporting the development and evaluation of complex interventions in healthcare: revised guideline (CReDECI 2). Trials. 2015;16:204.
49. Maguire M. Methods to support human-centred design. Int J Hum Comput Stud. 2001;55:587–634.
50. Donetto S, Pierri P, Tsianakas V, et al. Experience-based co-design and healthcare improvement: realizing participatory design in the public sector. Design J. 2015;18:227–48.
51. Magnusson C, Caltenco HA, McGookin D, et al. Tangible interaction for stroke survivors: Design recommendations. Yokohama: In: Proceedings of the eleventh international conference on tangible, embedded, and embodied interaction; 2017. p. 597–602. https://doi.org/10.1145/3024969.3025073. Accessed 20 Mar 2017.
52. Magnusson C, Caltenco H, Rassmus-Gröhn K, et al. Universal balance? Stud Health Technol Inform. 2018;256:847–53.
53. Kytö M, McGookin D, Bock W, et al. Designing bimanual tangible interaction for stroke survivors. Stockholm: In: Proceedings of the twelfth international conference on tangible, embedded, and embodied interaction; 2018. p. 245–52. https://doi.org/10.1145/3173225.3173269. Accessed 18 Mar 2018.
54. Magnusson C, Rassmus-Gröhn K, Rydeman B, et al. Walk after stroke: initial development of a step counting game for stroke survivors. In: Proceedings of the 20th international conference on human-computer interaction with mobile devices and services adjunct: MobileHCI 18; 2018 Sep 3; Barcelona, Spain. New York: Association for Computing Machinery; 2018. p. 237–44.
55. English C, Manns PJ, Tucak C, et al. Physical activity and sedentary behaviors in people with stroke living in the community: a systematic review. Phys Ther. 2014;94:185–96.
56. English C, Healy GN, Coates A, et al. Sitting time and physical activity after stroke: physical ability is only part of the story. Top Stroke Rehabil. 2016;23:36–42.
57. Fini NA, Holland AE, Keating J, et al. How physically active are people following stroke? Systematic review and quantitative synthesis. Phys Ther. 2017;97:707–17.
58. Pollock C, Eng J, Garland S. Clinical measurement of walking balance in people post stroke: a systematic review. Clin Rehabil. 2011;25:693–708.
59. Samuelsson CM, Hansson P-O, Persson CU. Early prediction of falls after stroke: a 12-month follow-up of 490 patients in the fall study of Gothenburg (FallsGOT). Clin Rehabil. 2019;33:773–83.
60. "Mobility". In O'Toole M, editor. Miller-Keane encyclopedia and dictionary of medicine, nursing, and allied health, 7th ed. Saunders; 2003. ISBN: 9781455726240.
61. English C, Bowen A, Hébert D, et al. Rehabilitation after stroke: evidence, practice, and new directions. In: Hankey J, Macleod M, Gorelick PB, Chen C, Caprio FZ, Mattle H, editors. editors Warlow's stroke: practical management: Wiley Online Library; 2019. p. 867–77. https://doi.org/10.1002/9781118492390.ch18.
62. Pollock A, Farmer S, Brady M, et al. Interventions for improving upper limb function after stroke. Cochrane Database Syst Rev. 2014;1:CD010820.
63. McGrane N, Galvin R, Cusack T, et al. Addition of motivational interventions to exercise and traditional physiotherapy: a review and meta-analysis. Physiotherapy. 2015;101:1–12.
64. Poltawski L, Boddy K, Forster A, et al. Motivators for uptake and maintenance of exercise: perceptions of long-term stroke survivors and implications for design of exercise programmes. Disabil Rehabil. 2015;37:795–801.
65. Rassmus-Gröhn K, Magnusson C, Rydeman B, et al. Conjuring up new technology – using magic objects in co-ideation with stroke survivors. In: Cudd P, de Witte L, editors. Harnessing the Power of Technology to Improve Lives. Amsterdam: IOS Press BV; p. 429–36.
66. Hjelle KM, Alvsvåg H, Førland O. The relatives' voice: how do relatives experience participation in reablement? A qualitative study. J Multidis Healthc. 2017;10:1.
67. Lee MJ, Yoon S, Kang JJ, et al. Efficacy and safety of caregiver-mediated exercise in post-stroke rehabilitation. Ann of Rehab Med. 2018;42:406–15.
68. Mackenzie A, Greenwood N. Positive experiences of caregiving in stroke: a systematic review. Disabil Rehabil. 2012;34:1413–22.
69. Galvin R, Cusack T, Stokes E. To what extent are family members and friends involved in physiotherapy and the delivery of exercises to people with stroke? Disabil Rehabil. 2009;31:898–905.
70. Langhorne P, Baylan S. Early supported discharge services for people with acute stroke. Cochrane Database Syst Rev. 2017;7:CD000443.

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RESEARCH ARTICLE Open Access

Feasibility of ActivABLES to promote home-based exercise and physical activity of community-dwelling stroke survivors with support from caregivers: A mixed methods study

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Abstract

Background: Technical applications can promote home-based exercise and physical activity of community-dwelling stroke survivors. Caregivers are often able and willing to assist with home-based exercise and physical activity but lack the knowledge and resources to do so. ActivABLES was established to promote home-based exercise and physical activity among community-dwelling stroke survivors, with support from their caregivers. The aim of our study is to investigate the feasibility of ActivABLES in terms of acceptability, demand, implementation and practicality.

Methods: A convergent design of mixed methods research in which quantitative results were combined with personal experiences of a four-week use of ActivABLES by community-dwelling stroke survivors with support from their caregivers. Data collection before, during and after the four-week period included the Berg Balance Scale (BBS), Activities-Specific Balance Confidence Scale (ABC), Timed-Up-and-Go (TUG) and Five Times Sit to Stand Test (5xSST) and data from motion detectors. Semi-structured interviews were conducted with stroke survivors and caregivers after the four-week period. Descriptive statistics were used for quantitative data. Qualitative data was analysed with direct content analysis. Themes were identified related to the domains of feasibility: acceptability, demand, implementation and practicality. Data was integrated by examining any (dis)congruence in the quantitative and qualitative findings.

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Results: Ten stroke survivors aged 55–79 years participated with their informal caregivers. Functional improvements were shown in BBS (+ 2.5), ABC (+ 0.9), TUG (− 4.2) and 5xSST (− 2.7). More physical activity was detected with motion detectors (stand up/sit down + 2, number of steps + 227, standing + 0.3 h, hours sitting/lying − 0.3 h). The qualitative interviews identified themes for each feasibility domain: (i) acceptability: *appreciation, functional improvements, self-initiated activities* and *expressed potential for future stroke survivors*; (2) demand: *reported use, interest in further use* and *need for follow-up;* (3) implementation: *importance of feedback, variety of exercises* and *progression of exercises* and (4) practicality: *need for support* and *technical problems.* The quantitative and qualitative findings converged well with each other and supported the feasibility of ActivABLES.

Conclusions: ActivABLES is feasible and can be a good asset for stroke survivors with slight or moderate disability to use in their homes. Further studies are needed with larger samples.

Background

Stroke is one of the main causes of chronic disability in the Western world [1]. Engaging in ongoing exercise and physical activity is important after stroke to maintain and improve physical function [2, 3] and as a method of secondary prevention of stroke [4]. Therefore, exercise and physical activity need to be a lifelong part of the daily life of community-dwelling stroke survivors. Despite this knowledge, community-dwelling stroke survivors are physically inactive [5] and they sit for long periods of time [6]. Lack of motivation and confidence can diminish stroke survivors' participation in exercise and physical activity after inpatient rehabilitation [7–9], when they need to rely more on themselves and their informal caregivers to continue with exercise and physical activity. At the same time, community-dwelling stroke survivors and their informal caregivers report uncertainty regarding what they can do to maintain and/or improve function at home [10] and might often be in need of practical and emotional support to continue with exercise and physical activity.

In recent years, home-based exercise programmes have been increasingly developed to promote exercise and physical activity among community-dwelling stroke survivors [11–15]. Home-based exercise programmes can result in improved function of stroke survivors, including better balance and more involvement in activities of daily living [16, 17]. Family members and other informal caregivers are able to assist stroke survivors with exercises that are supervised by physical therapists or other members of the rehabilitation team [17–19] and it can be motivating for stroke survivors to do such exercises [20]. Informal caregivers are generally willing to assist with exercise and feel more content if they are able to assist [18, 21]. On the other hand, informal caregivers often lack knowledge and support and they need more education on how they can provide support with exercise and physical activity [22, 23]. Many studies have revealed a need for practical support for stroke survivors and their informal caregivers to help them engage in home-based exercise [10], and recent studies have suggested support could be provided by technical applications [24–27].

Technical applications, such as virtual reality and computer games, can support stroke survivors with home-based exercise [28, 29], encourage them to adhere to the exercises [25, 30–32] and decrease sedentary behaviour [30]. Stroke survivors with mild to moderate residual deficits have been shown to benefit more in terms of functional improvements with use of technical applications than stroke survivors with more severe deficits [31]. Technical applications can offer a variety of repetitive and challenging functional tasks [29, 31] that can encourage plasticity of the brain and enhance motor learning. Stroke survivors are generally willing to use technical applications to assist with home-based exercise [32–34] and many studies have investigated different technical approaches [24, 30, 35, 36]. Virtual reality has been defined as a user-computer interface with real-time simulation and has been shown to increase activity significantly more than conventional therapy [31, 37]. Game-based interventions are thought to be more enjoyable than traditional therapy and have shown to be more effective in improving balance and independence than traditional exercises in stroke survivors [29]. This evidence supports the hypothesis that technical approaches have the potential to be used to promote home-based exercise and physical activity among stroke survivors. Therefore, it is important to continue to develop useable and feasible technical applications for stroke survivors that can be used successfully in their homes.

Based on this background, and as a way to respond to stroke survivors' and informal caregivers' needs for home-based exercise and physical activity, an international collaborative project was established to develop ActivABLES. ActivABLES is a modular technological intervention, comprising multiple exchangeable components, to promote home-based exercise and facilitate physical activity engagement of community-dwelling stroke survivors with support from their informal caregivers. The aim of our study is to investigate the feasibility of ActivABLES for community-dwelling stroke survivors and their informal caregivers (hereafter referred to as caregivers) in terms of acceptability, demand, implementation and practicality of the intervention.

Methods

Design

A feasibility pilot study was conducted using a convergent mixed method design [38], which included concurrent collection of quantitative and qualitative data, as well as independent interpretation of the data and integration to evaluate the feasibility of ActivABLES after a four-week use (Fig. 1). Since ActivABLES includes different tools aiming to improve various outcomes of community-dwelling stroke survivors, the Medical Research Council's (MRC) framework for development and evaluation of complex health interventions was used to guide the development and testing process [39, 40]. Studying feasibility is an important part of the development and evaluation of complex interventions according to the MRC model [39]. Feasibility was evaluated in terms of acceptability, demand, implementation and practicality, which are four components of the feasibility framework presented by Bowen (2009) [41]. Acceptability assesses how the stroke survivors and their caregivers react to ActivABLES and how suitable, satisfying or attractive they think the tools are. Demand looks at how ActivABLES is used by the stroke survivors and how likely it is they will use the tools in the future. Implementation focuses on the execution, type of resources and factors affecting the implementation of ActivABLES and how the tools can be improved. Practicality assesses how ActivABLES is delivered to stroke survivors and how they manage the use of the tools with regard to resources, assistance/support and circumstances [41].

Sample and participants

In our study, we used a purposive sampling of community-dwelling stroke survivors and their caregivers. Participants were approached through inpatient rehabilitation clinics and outpatient physical therapy clinics. We included stroke survivors who met the following criteria: older than 18 years of age; at least 4 months since discharge from hospital or inpatient rehabilitation; with slight or moderate impairment defined by a score of 2–3 on the Modified Rankin Scale [42]; with no severe cognitive deficits defined by the Mini Mental State Examination (> 24) [43]; no severe comorbidities or pre-existing conditions affecting function or ability to speak and understand Icelandic. Also included were informal caregivers (hereafter referred to as caregivers), defined as a family member or a close friend in a good relationship with the stroke survivor, older than 18 years of age, and able to communicate and assist the stroke survivor. All the participating stroke survivors and caregivers received verbal and written information

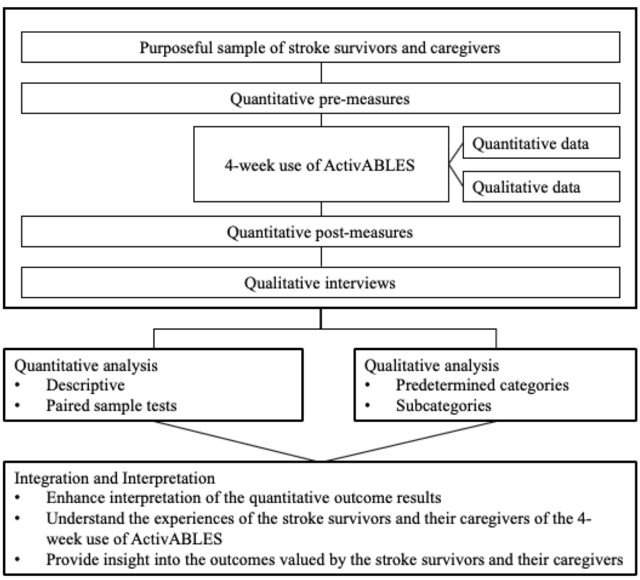

Fig. 1 Diagram of the mixed methods study

about the study, emphasising that participation was voluntary, anonymous and confidential. The participants and the researcher (SAO) signed an informed consent prior to participating in the study.

ActivABLES

The development of ActivABLES used human-centred design (ISO 9241-210:2010) including elements of participatory design/co-design [44]. Thus, prototype designs were tested iteratively in collaboration with community-dwelling stroke survivors and health professionals during the whole development process. The MRC framework for the development and evaluation of complex interventions further guided the development of the ActivABLES as a healthcare intervention. The development process is described in detail in a separate paper [45]. ActivABLES consists of six tools (Table 1): (1) ActivFOAM with interactive games for balance exercises [46]; (2) Walking STARR, an iPhone application which includes a step counter, activity monitoring and games [47]; (3) ActivBALL to exercise motor control of the wrist and shoulder and the grip strength; (4) ActivSTICKS to exercise motor control of the shoulder and upper body [48]; (5) ActivLAMP which gives feedback on daily progress in

Table 1 Prototypes of ActivABLES tested in the feasibility study

	Description	Purpose
ActivFOAM 	A foam balance mat with pressure sensors that gives individually tailored visual and audio feedback on weight shifting and center of mass while standing. The mat is connected to a tablet which is positioned in front of the user. Three games and different forms of audio feedback can be selected from the tablet.	To exercise balance and weight-bearing in a standing position.
Walking STARR 	An application for iPhone which records steps and walking time. The idea is to simulate taking the dog for a walk. Games include having to stop to let the dog pee and eat. Finishing games allows the user to collect stars.	To motivate and provide feedback on progress of walking.
ActivBALL 	A soft ball to exercise motor control of the arm and develop grip strength. The ball is connected to a tablet which is positioned in front of the user and which can be pre-programmed for individually tailored sets of exercises. The range of motion and pressure detected while squeezing can be adjusted for each user. The tablet gives feedback by counting the repetitions. The ball can be used to exercise: 1) forearm pronation/supination, 2) dorsiflexion and palmar flexion of the wrist, 3) external/internal rotation of the shoulder, 4) flexion and extension of the fingers while squeezing.	To exercise the motor control of the hand and forearm
ActivSTICKS 	Two sticks linked together forming an angle from 0° to 180°. The sticks are connected to a tablet which is positioned in front of the user and which can be pre-programmed for individually tailored sets of exercises. The range of motion detected, and resistance can be adjusted for each user. The tablet gives feedback by counting the repetitions. The sticks can be used to exercise: 1) abduction and adduction of the shoulder, 2) flexion of the shoulder, 3) elbow flexion and extension, along with coordination of the left and right arms while doing "scissors", 4) rotation of the upper body.	To exercise the motor control of the shoulder and upper body.
ActivLAMP 	A lamp that that gradually brightens in connection with exercises or physical activities. The lamp is connected to a tablet and can be connected to any of the above exercise tools.	To motivate and provide feedback on progress of exercises or walking.
ActivTREE 	A tree that has three branches that gradually brighten in connection with exercises and physical activities. The tree is connected to a tablet and can be connected to any of the above exercise tools. Each branch represents a different tool and they all share the same trunk.	To motivate and provide feedback on progress of exercises and walking.

one exercise, and (6) ActivTREE which gives feedback on daily progress in up to three exercises. All the ActivABLES tools give an instant feedback in the form of sound and/or light which is intended to strengthen the motivation to exercise.

Data

Quantitative and qualitative data were collected prior to, during and after the four-week use of ActivABLES (Fig. 1). Data from functional measures, questionnaire, motion detectors, digital servers, adherence diaries and semi-structured interviews were used to evaluate the feasibility of ActivABLES.

The mobility and functional progress of the stroke survivors were evaluated before and after the four-week use of ActivABLES using the following measures:

- Static and dynamic balance was measured with the *Berg Balance Scale* (BBS) [49] which consists of 14 static and dynamic activities of varying difficulty. Each item gives a score of 0–4 and the maximum score is 56 which indicates good functional balance. The psychometric properties of the BBS for stroke survivors show good and excellent results [50–53].
- Balance self-efficacy when performing activities was measured with the *Activities-Specific Balance Confidence Scale* (ABC) [54]. ABC is a 16-item self-report measure in which participants rate their balance confidence for performing activities on a scale of 0–100%. The psychometric properties of ABC for stroke survivors show good and excellent results [55, 56].
- General mobility was measured with the *Timed-Up-and-Go* (TUG) [57]. In TUG, the participant stands up from a chair, walks a distance of three meters, turns around, walks back to the chair and sits down. The time required to perform the TUG is recorded using a stopwatch. The psychometric properties of the TUG for stroke survivors show good and excellent results [58, 59].
- Functional lower limb muscle strength was measured with the *Five Times Sit to Stand Test* (5xSST) [60], which measures the time required to perform the 5xSST, using a stopwatch. The psychometric properties of the 5xSST for stroke survivors show good results [61].
- Arm and hand function were measured with the *Box and Block Test* (BBT) [62]. In the BBT, the participant moves as many cubes between boxes as possible in 1 min. The psychometric properties of the BBT for stroke survivors with arm paresis show good and excellent results [63, 64].

Motivation to exercise was measured with the *Behaviour Regulation Exercise Questionnaire 2* (BREQ-2) [65]. The BREQ-2 is a 19-item questionnaire, where each question is answered on a five-point Likert scale ranging from 0 (not true for me) to 4 (very true for me). BREQ-2 was developed to assess exercise behaviour based on the self-determined theory (SDT), which is a popular framework to assess motivation in exercise psychology [66]. In the SDT various forms of motivation represent different ways in which behaviour can be regulated, ranging from completely non-self-determined to completely self-determined regulation. The BREQ-2 has five subscales: (i) amotivation (lack of any intention to engage in exercise), (ii) external regulation (engaging in exercise only to satisfy external pressures or to get externally imposed rewards), (iii) introjected regulation (self-imposed pressures to avoid guilt or maintain self-esteem), (iv) identified regulation (accepting exercise as an important factor to achieve personally valued outcomes) and (v) intrinsic regulation (taking part in exercise for the enjoyment and satisfaction of it) [66]. In line with SDT, amotivation and external and introjected regulation address non-self-determination with scoring of 0–44, while identified and intrinsic regulation address self-determination with scoring of 0–32 [67]. Lower scoring of non-self-determination and higher scoring of self-determination is positively linked with adaptive health behaviour [68] indicating that people are more aware of the outcomes of exercise and feel more committed to it [69]. The psychometric properties of the BREQ-2 have been investigated in a sample of healthy people indicating good construct validity [66, 70, 71] and have been used in different patient groups [67, 72, 73].

The actual use of ActivABLES was evaluated by connecting all the ActivABLES tools to a server which collected digital data on the frequency and length of use of ActivABLES.

Data on sedentary, upright and ambulatory activities were collected with *ActivPAL motion detectors* (PAL Technologies Ltd., Glasgow, UK). The stroke survivors wore the motion detectors around their non-affected thigh for 7 days (24 h) at three different time points; a week prior to the start of the four-week period of ActivABLES, midway through the study and a week after the four-week period. The data generated represents a 24-h summary of time spent in sitting/lying and standing positions and taking steps, number of transitions from sitting to standing and number of steps taken. Motion detectors have been used in many studies to explore physical activity [74, 75] in stroke survivors [76].

The caregivers were asked to filled in the adherence diaries during the four-week use of ActivABLES, which provided both quantitative and qualitative data. The adherence diaries had a format for each of the ActivABLES tool including questions on the frequency and length of use (in minutes), which exercises were done with each tool, the execution of the exercises and the need for support and motivation. A Borg scale [77] was used to assess perceived exertion, which evaluated the intensity of the exercises (0 indicated no exertion and 10 indicated much strain) and experienced execution, which evaluated how they managed using the tools (0 indicated "impossible to use" and 10 indicated "very useable"). In addition, there was an empty place in the diaries where the caregivers were asked to write down their thoughts and comments on their experience of the exercises and the feasibility of using ActivABLES.

Qualitative data was collected with semi-structured interviews [78] which were conducted separately with each stroke survivor and their caregivers after the four-week use of ActivABLES, to gain deeper understanding of how they experienced the feasibility of ActivABLES. The interview guides included questions which focused on the feasibility of ActivABLES in terms of acceptability, demand, implementation and practicality (Table 2).

Procedure

Data was collected over a six-week period, which included a four-week use of ActivABLES (Fig. 2). Two researchers, a physical therapist (PT) (SAO) and a registered nurse (RN) (IB) collected the data in three steps:

Step 1. Pre-test measures

A week prior to the four-week use of ActivABLES (week 1), the two researchers (SAO and IB) visited the stroke survivor and his/her caregiver. Detailed information about the study was given and ActivABLES was introduced to the participants. Demographic and clinical data were collected, including information on time since stroke and the side of hemiparesis. The stroke survivors were also asked about indoor use of walking devices and all participants were asked if they used tablets/computers on a daily basis. Baseline functional measures were carried out, and two self-report questionnaires (ABC and BREQ-2) were left with each stroke survivor to answer with assistance from caregiver if needed. A motion detector was attached to the stroke survivor's affected leg to wear for 7 days.

Table 2 Interview guides for stroke survivors and informal caregivers

Stroke survivors	Informal caregivers
1. Why did you decide to participate in this research?	1. How have the exercise been going over the last 4 weeks? (Ask about all the tools)
2. Did you exercise at home before this research? Why / Why not?	2. Has the stroke survivor been following the exercise protocol through the whole period of 4 weeks? Do you feel his/her motivation has changed over the time? How?
3. What is your overall experience of doing the exercise over last 4 weeks?	3. Did you need to encourage the stroke survivors to exercise using the tools? Over the whole period?
4. Have you been able to follow the exercise program over the period? Did your motivation change over time?	4. Did you need to assist the stroke survivor with the exercises or using the tools? If yes, how? Please describe further?
5. Did you feel the tools encouraged you to continue?	5. Were there exercises/tools that the stroke survivor did liked more or less than others? What was it about the exercises/tools that the stroke survivor liked or disliked?
6. What exercise/tool did you like the most / the least? How/why? Please describe further	6. Were there exercises/tools that the stroke survivor felt were more challenging / less challenging? If yes, please describe further?
7. What exercise/tool did you feel was most challenging / least challenging? How/why? Please describe further	7. Do you think the general physical activity of the stroke survivor has changed over the last 4 weeks? Has he/she been doing something on a daily basis that he/she had not been doing recently? Please describe further.
8. Do you think your general physical activity has changed over last 4 weeks? Have you been doing something more/less on a daily basis than before?	8. Do you think these tools can be useful for the stroke survivor permanently? Why? / Why not?
9. Do you feel like you could continue to use these tools for an unlimited time? Why? / Why not?	9. What is your overall experience of using the tools? – Is there something that needs to be changed?
10. Do you think these tools could be useful in doing exercises at home – to maintain / improve your health? Why? / Why not?	
11. What is your overall experience of using the tools? – Is there something that needs to be changed? – How/why?	

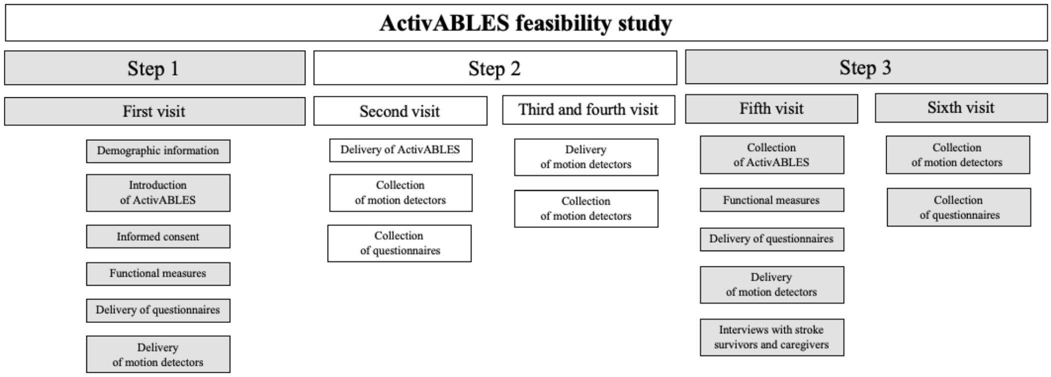

Fig. 2 Procedure of data collection

Step 2. ActivABLES

Together with the stroke survivors and their caregivers, the PT selected relevant ActivABLES tools to be used, based on the pre-tests and the needs of each stroke survivor. Each participant was assigned at least one exercise tool (maximum of three) and one feedback tool (maximum of two). Both researchers, along with technicians, visited each stroke survivor at his/her home with selected ActivABLES tools and delivered an interactive training session on their use along with written guidance on how to use them. The stroke survivors were asked to use the selected ActivABLES tools at least five times per week for 4 weeks. The recommended daily use was determined on an individual basis in agreement with each stroke survivor, ranging from 10 to 30 min. The stroke survivors were encouraged to gradually increase the duration of use, with the aim of exercising for 30 min per day. Caregivers were involved and gave practical and social support which could include assistance with using the tools, thereby ensuring safety and providing encouragement during the four-week period. Researchers provided adherence diaries and gave information to the caregivers on how to fill them in. The participants were encouraged to contact the researchers via phone or email, if problems occurred. One of the researchers visited the participants after approximately 10 days of using ActivABLES (third visit) and attached a motion detector to the stroke survivor to wear for the next 7 days. This was picked up a week later (fourth visit).

Step 3. Post-test measures

After the four-week use of ActivABLES, the researchers visited each stroke survivor (fifth visit) and repeated the functional measures and conducted semi-structured interviews with the stroke survivors and their caregivers about their experiences of using ActivABLES. The PT carried out the functional measures while the RN documented the results of the measures to avoid performance bias. The PT interviewed the stroke survivors while the RN interviewed the caregivers. The interviews were recorded and transcribed verbatim.

Data analysis

Quantitative data, including the demographic data, functional measures, digital data and data from the adherence diaries, were recorded in Excel and transferred into *jamovi software*, version 0.9 (Retrieved from https://www.jamovi.org, 2018). Descriptive statistics were used to analyse quantitative data, including medians and interquartile range for continuous data. Imputation was used to approach missing data in BREQ-2, using predictive mean matching [79]. The data was imputed with the statistical package mice in *R, statistical software* (The R Foundation for Statistical Computing, Vienna, Austria). Qualitative data were analysed using direct content analysis [80] and themes identified from the data based on the four domains of feasibility: acceptability, demand, implementation and practicality as suggested by Bowen et al. (2009) [41]. One researcher (SAO) identified themes according to the domains and discussed these with co-authors until agreement on the content was reached. Quotes related to the identified themes were translated from Icelandic to English. Quantitative and qualitative data were then integrated by looking for common concepts across the data, comparing the data and examining any (dis)congruence in the findings.

Results

Participants

A total of 20 individuals took part in the study, including 10 stroke survivors and 10 caregivers. The stroke survivors were five women and five men, with the median age of 72 years (range 55–79 years), and the time since stroke ranging from 5 months to 30 years. Six stroke survivors had left hemiparesis and four had right hemiparesis. Four stroke survivors used assistive walking devices. Eight stroke survivors went to physical therapy every week. Ten caregivers were included, seven women and three men, who were all family members, with the median age of 69 years (range 28–80 years). Five caregivers were retired, four were employed and one was unemployed due to disability. Six stroke survivors and seven caregivers used a personal tablet/computer on a regular basis (Table 3).

All the stroke survivors were given the ActivFOAM for balance exercises to use for the 4 weeks, two received the ActivSTICKS for exercising the upper arms, and two were given the ActivBALL for exercising the arm and hand. Four stroke survivors received the walking application to record their step counts while walking, six were given the ActivLAMP and five received the ActivTREE for visual feedback.

Quantitative findings

All the stroke survivors took part in the functional pretests but only nine took part in the post- tests since one stroke survivor was hospitalised for some days during the four-week period (Table 4.). Seven stroke survivors, who took part in both pre and post measures of function, improved in two or more measures. The median of the functional measures showed improvements in all tests. The results of BBS changed from 43.5 to 46.0 and scoring of the ABC-Scale improved from 55.5 to 56.4. The participants needed 4.2 s less to finish TUG and were 2.7 s faster to finish 5xSST. The data from the motion detectors showed more physical activity during and after the intervention, with a higher median in the number of standing up/sitting down, and steps and hours standing, and fewer hours spent sitting/lying. The results from the BREQ-2 for motivation to exercise showed higher self-determined motivation than non-self-determined motivation to exercise in both pre and post measures, indicating that the stroke survivors valued the benefits of exercise.

According to the digital servers, seven stroke survivors used ActivABLES for the recommended 5 days a week for the 4 weeks with the median use of 23 days, (range 5–27 days). Four of the adherence diaries were thoroughly filled in, whereas six diaries gave reports for only a limited number of days. The data from the four diaries on the number of days that the tools were used, correlated with the data on the number of days reported on the digital servers. However, more use was reported on the number of minutes spent exercising in the adherence diaries when compared to data on the digital servers. The average daily use per participant reported in the diaries was in the range of 14–48 min, whereas on the servers the average daily use range was nine to 28 min.

The stroke survivors and/or their caregivers called the researcher 19 times in total, to ask for advice and/or report technical difficulties during the four-week period. On nine occasions restarting the tablet was enough to resolve the issue and twice the caregivers were able to take care of some minor configurations. On seven occasions, additional support was needed and two phone calls were to report accidents with one of the tools and a tablet which fell on the floor and broke.

Table 3 Characteristics of all participants

Stroke survivors					Informal caregivers		
age	time since stroke	side of hemiparesis	walking device inside	tablet/computer use on daily basis	age	occupation	tablet/computer use on daily basis
63	23 years	left	no	yes	68	working part-time	yes
55	9 months	right	no	no	28	unemployed	yes
71	15 months	left	yes, a cane	yes	72	retired	no
79	5 months	right	no	yes	79	retired	no
66	26 months	right	no	yes	66	working part-time	yes
74	19 months	left	yes, a cane	no	70	retired	yes
67	8 months	left	no	yes	58	working full-time	yes
73	30 years	left	yes, a crutch	yes	51	working full-time	yes
78	4 years and 3 months	left	yes, a crutch	no	79	retired	yes
72	14 months	right	no	no	80	retired	yes

Table 4 Quantitative measures

	pre-test[a]		halftime of the intervention[a]		post-test[a]		change in score[b]
Berg Balance Scale (0–56)	43.5	(39–47.3)			46.0	(43.0–48.0)	↑ 2.5
ABC-Scale (%)	55.5	(39.1–58.8)			56.4	(46.0–67.2)	↑ 0.9
Timed-Up-and-Go (sec)	20.1	(17.6–21.3)			15.9	(12.5–19.2)	↑ 4.2
Five Times Sit to Stand (sec)	20.9	(17.4–27.0)			18.2	(16.7–20.3)	↑ 2.7
Box and Block Test (no blocks)	33	(31–35)			33	(32–34)	0
Data from motion detectors							
standing up/sitting down (times/day)	47	(32–50)	48	(46–50)	49	(42–56)	↑ 2
number of steps (per day)	1836	(1706–2636)	2469	(1707–3036)	2063	(1724–2998)	↑ 227
standing (hours/day)	2.3	(1.7–3.2)	2.6	(2.0–3.1)	2.6	(1.8–3.1)	↑ 0.3
sitting/lying (hours/day)	21.3	(20.4–22.4)	21.4	(20.8–22)	21.0	(20.6–22.3)	↑ -0.3
Behaviour Regulation Exercise Questionnaire							
non-self-determined motivation (0–44)	9	(8.3–12.8)			8.5	(8.0–9.75)	↑ 0.5
self-determined motivation (0–32)	28	(24.3–29.5)			26	(25.3–26)	↓2.0

[a]median (1st and 3rd quartile)
[b] the arrows indicate if the change is positive (↑) or negative (↓)

Qualitative findings

The feasibility of ActivABLES was described by the participants in terms of four feasibility domains: acceptability, demand, implementation and practicality. Twelve themes emerged from these domains which further explicate the domains and quotes illustrate the themes within each domain (Fig. 3).

Acceptability

Four themes were identified that illustrate the acceptability of ActivABLES: (1) appreciation, (2) functional improvements, (3) self-initiated activities and (4) potential use for future stroke survivors (Fig. 3).

Appreciation Both stroke survivors and caregivers expressed appreciation for being offered an opportunity to take part in the development of ActivABLES to promote home-based exercise and physical activities.

But I think this is really great, I would have liked to get this much sooner...(Stroke survivor)

I think this is an excellent initiative and I just hope that they will be able to refine this and put it into use. (Caregiver)

Functional improvements: Most stroke survivors and their caregivers described improvements in functioning. Few did not notice improvements including the man who was hospitalised and could not use ActivABLES as recommended, as well as those who had stroke long time ago.

I think my walking is better, at least they [in physical therapy] say that my gait has improved. (Stroke survivor)
I don't know if it is because of this but she is doing better when she is walking, she does not use the walker inside anymore, She is walking around so her mobility is getting better. (Caregiver)

Self-initiated activities were identified when participants described activities they had not recently taken part in. They stroke survivors described increased motivation

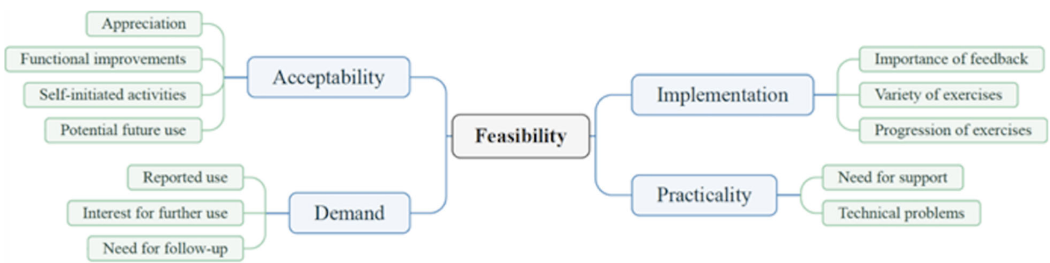

Fig. 3 Themes identified in line with feasibility domains

to engage in self-initiated activities such as walking indoors without using a cane/crutch and washing the floor. They were also more aware of using the affected arm. In addition, the caregivers also described noticing self-initiated activities by the stroke survivors.

Yes, for example [the exercises] motivated me to try to take a shorter stroll without a crutch, and to take the posh-stick as I call it, (my cane) to practice with it. It's obviously at the top of the wish list to walk with a cane. (Stroke survivor)
He gets things himself a lot more, he is not calling for me all the time, he just stands up and goes to the freezer and gets things. In this respect I feel there is a big difference, he is helping himself a lot more. (Caregiver)

Potential use for future stroke survivors All participants described ActivABLES to have potential use for future stroke survivors.

This can do so much more than I expected when I first saw it last year or the year before. I think this ActivABLES has a potential, especially for younger people or people right after the stroke. It is just so important to move around as much as you can with help from professionals. (Stroke survivor)
Absolutely, especially the balance exercises for people who haven't too much paresis or are not so insecure when walking. The ball could also be useful for all stroke survivors, even though you are in wheelchair. (Caregiver)

Demand

Three themes that illustrated demand were identified: (5) *reported use,* (6) *interest in further use* and (7) *need for follow-up* (Fig. 3).

Most stroke survivors and their caregivers described having tried to use ActivABLES at least five times a week over the four-week period, but some said they quit few days earlier due to technical issues, mostly connection issues between the tablet and the tools.

I have been using the tools as conscientiously as I can every single day but maybe for a shorter time than I would have liked some days. (Stroke survivor)
I think he has been doing very well with this, he has dedicated himself to using it and he is interested in it. (Caregiver)

Interest in further use The stroke survivors said they would be interested in further use of ActivABLES themselves. The caregivers also thought "their" stroke survivor would be interested in further use.

It would be good to get a plan of exercises to follow; something like this, for the balance. (Stroke survivor)
Yes, these movements he is doing, he likes it and it seems to be doing him good. (Caregiver)

The need for follow up The stroke survivors and caregivers emphasised the need for follow-up services and said that ActivABLES might have potential as a part of this kind of service if supervised by a rehabilitation professional.

I think that current follow-up services for people like me who have had a stroke are not good enough. - This is kind of a follow-up [like ActivABLES] is lacking. (Stroke survivor)
What she needs is more physical activity; like if somebody would come and take her out for a walk. (Caregiver)

Implementation

Three themes that illustrated implementation were identified from the interviews: (8) the *importance of feedback,* (9) *variety of exercises* and (10) *progression of exercises* (Fig. 3).

Importance of feedback Both stroke survivors and caregivers said that the feedback was very important while doing the exercises. The stroke survivors also mentioned how many points they had scored and their enthusiasm for competing for more points. Having a target to compete for was also described by the caregivers. The visual feedback from ActivTREE and ActivLAMP were helpful in this regard.

I once made it up to 100. [Yes, good for you, well done]. Yes, usually I went up to 20 or 30, then I was finished. But I was so upbeat that day that I went up to 100, I thought it was great. (Stroke survivor)
I believe the feedback is good . . . You know, being able to fill the tree completely. I realise it is so motivating to be able to do that, and to keep going and do a little more, or even better. - He was happy when the right branch of the tree became fully lit. Yes, it made him happy. (Caregiver)

Variety of exercises The stroke survivors thought the exercises lacked variety and would have liked to have more diversity in the types of them. Their caregivers agreed with these sentiments.

The ActivFOAM could have a more diverse list of games, such as Escape. It is sometimes fun, it was particularly fun at the beginning but then it became, like, just boring. (Stroke survivor)
The interest decreased a little, yesterday or the day before yesterday, she talked about it, saying that the variety, it was missing a bit. (Caregiver)

Progression of exercises Some stroke survivors said they had progressed with the exercises and that they made attempts to make them more challenging. In the adherence diaries, the stroke survivors rated the exercises as more difficult at the beginning (5–8 out of 10). During the final days of the study they had become less difficult (1–5 out of 10).

They [the games] should not be too hard, but something that everybody can do as an exercise. And then you could make them more difficult for progression. (Stroke survivor)

Practicality

Two themes that illustrated practicality were identified: (11) *need for support* and (12) *technical problems* (Fig. 3).

Need for support Only few caregivers described occasional encouragement or reminders for doing the exercises. One caregiver said she physically had to assist her husband with the exercises. Others described assisting such as with turning on ActivABLES and/or charging the tablet. The stroke survivors described they were almost independent as regards using ActivABLES and doing the exercise.

I think it might have happened about three times, like "well now, let's hurry up with this" [caregiver said]. Yes, three times or something, but no more. Otherwise she was always just, she called me when she was done to tell me that she was so happy, you see. (Caregiver)

Technical problems There were technical problems in relation to the use of ActivABLES. All participants had a problem at some point in time during the four-week period. Sometimes it was enough to restart the tablet. Those who were familiar with using tablets or computers were aware of that and had already tried that before contacting the researchers. On one occasion, the ActivBALL became dysfunctional after falling accidentally on the floor and it was not possible to fix or replace it. Some participants had a tablet that had the same input for charging and for connecting the ActivFOAM and on one occasion, the tablet fell on the floor and broke while a stroke survivor was plugging in the cables. This happened during the last week of the four-week period. The tablet was still useable, but the crack irritated the user and did affect use of the tablet. Some stroke survivors reported frustration when dealing with the technical issues.

It has challenged my patience, a bit (silence). [Interviewer: Was it mainly due to technical problems or?] Well, just yes, because the devise apparently didn't work completely, despite ones wishes. (Stroke survivor)
There were some technical difficulties and then, just her physical fatigue, physical and mental fatigue caused annoyance and a lack of willingness to do anything (silence) -the exercises. (Caregiver)

Integration of quantitative and qualitative findings

The integration of the quantitative and qualitative data is summarised in Table 5. There was congruence in all components of the feasibility framework both between the quantitative and qualitative data and generally also between the stroke survivors and the caregivers. Both accepted the usability of ActivABLES. The stroke survivors also improved in function and physical activity after the four-week use of ActivABLES. The stroke survivors had tried to use ActivABLES for at least 5 days per week. Participants — stroke survivors and caregivers — were in agreement on the potential of ActivABLES for further use in the homes.

Although technical problems were frequent when using ActivABLES, the stoke survivors only needed minimal assistance from the caregivers.

Discussion

The feasibility of ActivABLES was evaluated in a mixed methods study in terms of acceptability, demand, implementation and practicality among 10 stroke survivors. Quantitative and qualitative results were integrated after data analysis to gain a thorough understanding of the feasibility of ActivABLES [38]. The main findings show that both stroke survivors and caregivers found ActivABLES to be feasible for community-dwelling stroke survivors with slight or moderate impairments to use for exercise and physical activity with support from their caregivers. These results encourage the researchers to proceed with further development of the prototypes.

Acceptability

In our study, the stroke survivors and their caregivers did appreciate the idea of ActivABLES and believed that ActivABLES could be useful and beneficial for themselves as well as for future stroke survivors. Most of the

Table 5 Integration of quantitative and qualitative findings

Feasibility domains	Quantitative results			Qualitative themes	Integration
Acceptability	Measure	Change in median from pre to post		Functional improvements	
	BBS (score)	43.5–46	↑ 2.5	Stroke survivors reported improvements in function. Caregivers reported improvements in function of their stroke survivors.	The quantitative functional measures confirm the experience of the participants of improved function.
	ABC (score)	55.5–56.4	↑ 0.9		
	TUG (sec)	20.1–15.9	↑ 4.2		
	5xSST (sec)	20.9–18.2	↑ 2.7		
	BBT (score)	33–33	0		
	Motion detectors:			Self-initiated activities	
	Standing up /sitting down	47–49	↑ 2	Stroke survivors described increased motivation to engage in self-initiated activities.	The quantitative data from the motion detectors suggest that the stroke survivors were more mobile which might indicate they engaged in more activities.
	Number of steps	1836–2063	↑ 227		
	Standing (hours/day)	2.3–2.6	↑ 0.3		
	Sitting/lying (hours/day)	21.3–21.0	↑ 0.3		
Demand				Reported use	
	Use according to digital servers			Stroke survivors and their caregivers reported use of ActivABLES at least five times a week.	The quantitative data from servers and diaries were congruent with each other while reported use in the interview tended to be more than from the servers and diaries.
	• Seven stroke survivors used ActivABLES for the recommended five days a week.				
	Use according to adherence diaries				
	• Median use 23 days.				
	Measure	Change in mean from pre to post		Interest in further use	
	BREQ-2: Self-determined motivation	28–26	↓ 2.0	Stroke survivors reported interest in further use. Caregivers thought their stroke survivor would be interested in further use.	The quantitative results from BREQ-2 does only partially support the qualitative results on interest in further use.
	Non-self-determ motivation	9–8.5	↑ 0.5		
Implementation				Progression of exercises	
	In the adherence diaries, the stroke survivors rated the exercises as more difficult in the beginning (5–8) and less difficult (1–5) during the last days of use.			Stroke survivors reported they had progressed with the exercises, making them more challenging	In the diaries, the stroke survivors report the exercises as being less difficult, which is convergent with what they reported in the interviews. Progression should lead to at least the same level of difficulty.

stroke survivors showed improvements in functioning although they only used ActivABLES for the limited time of 4 weeks. Still, it is important to note that most of the stroke survivors had physical therapy once or twice a week during the 4 weeks they were using ActivABLES. Therefore, we do not know how much value ActivABLES had as regards their functional progress.

The outcomes used in our study were chosen to reflect physical function trained while using ActivABLES. Those who did worse on these outcomes at baseline improved more than those who had higher score. Training effects of exercise can appear as soon as after 1 week, especially if the person is inactive, but the effects are considerably greater with regular exercise for several months [81]. Although most of the cortical reorganisation in the brain takes place in the first 6 months after a stroke [82], there is a growing evidence on stroke survivors improving their function in the chronic phase of stroke, well beyond the first 6 months [83]. All but one stroke survivor in our study were in the chronic phase of stroke (> 6 months since stroke), and this person was actually the only stroke survivor who did not show improvements in any of the functional measures. The two stroke survivors that had their strokes more than 20 years ago were, however, less interested in using ActivABLES but both indicated they would have liked to have had something like this in the earlier phase of stroke. Still, both of them did improve their function in three of the functional measures.

Increased duration of exercise can improve function in stroke survivors [84, 85] and therefore it is important to motivate stroke survivors to engage in exercise. Most of the stroke survivors in our study met a PT once or twice a week (individual or group session) and most of them remained inactive between the physical therapy sessions. The stroke survivors in our study seemed to be very inactive when compared with community-dwelling stroke survivors in international studies [5, 86] and are far from meeting the guidelines for physical activity [81]. According to a review conducted in 2017 [86], the average number of daily steps among community-dwelling stroke survivors in the chronic phase was 4078, whereas the range of daily steps taken by the stroke survivors in our study was 1706 steps prior to the intervention to 3036 during the intervention. The average time spent walking daily was 30 min in our study but 88 min in the review [86]. In another review, the average number of daily steps of stroke survivors ranged between 1389 and 7379, and hours standing, or walking ranged from 2.7 to 4.5 h per day [5]. In our study, the average daily standing and walking hours were 2.3. Some of these differences could possibly be explained by the fact that different motion detectors were used in the studies [86]. Still, there are indications that the stroke survivors did increase their physical activity after the four-week use of ActivABLES.

Demand

Data on reported use were obtained from the interviews, the digital servers and the adherence diaries, all showing that most of the stroke survivors followed the instructions about the daily use of ActivABLES and used it at least 5 days a week. These results of compliance compare well with the findings of other studies investigating the use of technical applications for home-based exercise [30, 87, 88]. Reported use in our study was different, where the digital servers showed much less use in minutes than reported in the interviews and in the adherence diaries. It is well known in research that people tend to overestimate their physical activity [89]. Still, we believe the reports of use as described in the qualitative findings of the interviews and diaries are reliable because they generally agree with the days and the minutes reported in the diaries. Stroke survivors need to stay physically active to maintain their function, but research has shown they are physically inactive and sit for a prolonged time [5, 86, 90]. According to guidelines for prescribing physical activity to stroke survivors, they should exercise their balance and do some strength and functional exercise one to three times per week and walk or do some aerobic activities for 10–60 min two to five times per week throughout life [81]. The results of BREQ-2 showed that the stroke survivors scored high in self-determination at the beginning. ActivABLES did not change the motivation to exercise which was measured with BREQ-2, although the data demonstrate a tendency in a positive direction towards increased self-determination. A systematic review revealed that different methods and lengths of time were needed to change motivation, depending on how motivated individuals were at each time [91]. There was much missing data in the answers to BREQ-2, which may have affected the outcomes. A larger sample is needed to explain whether ActivABLES can increase motivation for exercise and physical activity.

Implementation

The spontaneous feedback from ActivABLES is thought to be important, both the direct feedback on the tablet for each exercise as well as the feedback for the whole day given by ActivLAMP and ActivTREE. These results are in line with other studies, showing the importance of feedback in terms of personalised goals and activities [25, 92]. At the same time, the stroke survivors found it important to have more variety in game-based exercises to make them both challenging and engaging to them [34, 93]. The results of our study are partly in line with the findings of a meta-analysis from 2018 [35], where interactive games were shown to be effective in improving functional balance of stroke survivors, measured with BBS, but not effective in improving mobility, measured with TUG, like in our study. Enjoyment of exercise motivates stroke survivors to adhere to exercise and physical activity [88] and more variety is likely to increase enjoyment. One stroke survivor in our study was quite active already, aside from ActivABLES use, and followed his activity using an Apple Watch and he did not find a use for the collective feedback given by the ActivLAMP.

Practicality

All participants agreed there was not much need for support or assistance and stroke survivors were generally self-sufficient with the exercise. The caregivers were willing and able to help and were glad to have a resource to use in their homes to increase the physical activities of their loved one. ActivABLES was easy to handle for the stroke survivors with slight or moderated impairments and they generally did not need assistance, except at the very beginning. As can be expected, some participants experienced technical problems which caused some frustrations. This, however, is always an issue when developing technological prototypes due to their more experimental nature, but it emphasises the importance of having tools that are easy to use and are uncomplicated. This might explain why some stroke survivors did not show full compliance with the recommended use of the ActivABLES tools.

Limitations and strengths

Among the limitations of the study are the small sample size and a the lack of a control group which limits the generalisation of the study results. In addition, the participants reported different technical problems when using ActivABLES, which is inherent in a study like this. The tools were technological prototypes, and thus somewhat fragile and vulnerable to minor tumbling. Only four adherence diaries were filled in properly, indicating that more emphasis and/or support from the researchers might have been needed on the importance of documenting the use of the tools properly. The participants may also have become tired of keeping the diaries resulting in less thorough reporting. Moreover, there were missing data in the motion detectors and the self-report questionnaires. Lastly, the researchers who conducted the interviews with participants were known to the participants and may have elicited answers that were desirable rather than an accurate reflection of the actual experience. However, to minimize the risk of bias the researchers emphasised the need for negative as well as positive feedback on using ActivABLES.

Our study had various strengths that need to be emphasised. With an innovative technical intervention like ActivABLES, it is important to have a multidisciplinary team working on the development. Our team was composed of healthcare professionals with much experience in stroke rehabilitation research including physical therapists, nurses as well as engineers and computer scientists who are experts in the field of technical innovation. Theoretical underpinnings through the use of the MRC framework and the human-centred design are highly important since both provide input and feedback from future users, such as stroke survivors, their caregivers and healthcare professionals, to the team. The research team used an evidence-based approach to developing ActivABLES, which provided knowledge about the potential for innovations to motivate and encourage stroke survivors to engage in home-based exercise and physical activity. Comprehensive and robust methods were used to conduct the study to gain a broad and extensive idea of the feasibility of ActivABLES among the participants and strong agreements were found between the findings based on the quantitative and qualitative data. Future studies investigating the effects of ActivABLES, should be conducted with larger samples and should investigate both short-term and long-term effects of ActivABLES on functional outcomes, as well as cost-effectiveness.

Clinical implications

Stroke survivors need to engage in exercise and physical activity to maintain and improve their function and independence in activities of daily living. Despite the importance of exercise and physical activity for stroke survivors, physical inactivity and sedentary behaviour is a major issue affecting community-dwelling stroke survivors. There is an urgent need to find ways to motivate stroke survivors to engage in exercise and physical activity on a daily basis with support from their caregivers and under the supervision of a physical therapist or nurses. Daily access to a physical therapist and other healthcare professionals is not possible and should not be necessary if the stroke survivors have other types of resources to promote own health in their homes. Use of ActivABLES in the home was found to be feasible by community-dwelling stroke survivors and their caregivers. In the future, ActivABLES may also be used in a broader context such as with stroke survivors residing in nursing homes, other patients and the elderly. We foresee ActivABLES as a low-cost technical solution which requires only a small space. The tools are not complicated to use and should not be expensive to produce.

Technical applications, like ActivABLES, have the potential to improve function in stroke survivors who reside in their homes since they encourage physical activity and self-initiated activities. Technical applications can offer games and feedback that motivate stroke survivors, helping them to engage in healthy behaviour. Stroke survivors can use technical applications for home-based exercise and physical activity, and they can be a resource to meet demand for follow-up service. Stroke survivors with slight to moderate impairments could possibly be self-reliant with technical applications that are simple and easy to use, provided that they are free of technical problems.

Technical solutions will be an increasing part of rehabilitation in the future but research has shown lack of confidence and competence of healthcare professionals in using those solutions [94]. Therefore, it is important to integrate use of technical resources into healthcare professionals' education as well as the support given by healthcare organisations. Stroke survivors with slight or moderate handicap and their caregivers need appropriate resources to be more active in healthy behaviour in the community. In this way, stroke survivors can be empowered and take more initiative in their exercise and physical activities.

Conclusion

There are many possibilities to encourage and help stroke survivors to be more physically active. ActivABLES is an intervention aiming to motivate and promote home-based exercise and physical activity of community-dwelling stroke survivors with support from their caregivers. The results from this feasibility study indicate that an interactive technical solution like ActivABLES is feasible to use and can be a good asset for stroke survivors with slight or moderate handicap to use in their homes. These results are encouraging for the researchers to further develop the prototypes of ActivABLES.

Abbreviations

5xSST: Five Times Sit to Stand Test; ABC: Activities-Specific Balance Confidence Scale; BBS: Berg Balance Scale; BBT: Box and Block Test; BREQ-2: Behaviour Regulation Exercise Questionnaire 2; MRC: Medical Research Council; PT: Physical therapist; RN: Registered nurse; SDT: Self-determined theory; TUG: Timed-Up-and-Go

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Authors' contributions
SAO, THB and HJ designed and coordinated the study and wrote the protocol. SAO and IB conducted the testing and SAA contributed to the data collection. CM, HC, DM, MK and LM developed the prototypes and HC and LM introduced the prototypes to the stroke survivors and the caregivers. CM is the grant holder for the programme that supported this work. SAO and TBH wrote the first draft of the manuscript, which was critically revised for important intellectual content by all authors. All authors have approved the final version of this manuscript prior to submission. TBH and SAO are the guarantors of the manuscript, and affirm that the manuscript is an honest, accurate, and transparent account of the research being reported, and that no important aspects of the study have been omitted.

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Availability of data and materials
Further information on the datasets is available from the corresponding author on reasonable request.

Ethics approval and consent to participate
The study was conducted according to the principles of the Declaration of Helsinki (World Medical Association, 2016). All the stroke survivors and caregivers received verbal and written information and signed an informed consent prior to participating in the study. Participation was voluntary, anonymous and confidential. Ethical approval for the study was granted by the National Ethics Committee of Iceland (Ref. VSNb2015110001/03.01).

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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References
1. Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990–2010: findings from the global burden of disease study 2010. Lancet. 2014;383:245–55.
2. Teasell R, Fernandez M, McIntyre A, et al. Rethinking the continuum of stroke rehabilitation. Arch Phys Med Rehabil. 2014;95(4):595–6.
3. English C, van de Port I, Lynch E. Group circuit class therapy for stroke survivors – a review of the evidence and clinical implications. In: Bettany-Saltikov J, Paz-Lourido B, editors. Physical therapy perspectives in the 21st century - challenges and possibilities. Croatia: IntechOpen; 2012. p. 337–68.
4. Biswas A, Oh PI, Faulkner GE, et al. Sedentary time and its association with risk for disease incidence, mortality, and hospitalization in adults: a systematic review and meta-analysis. Ann Intern Med. 2015;162(2):123–32.
5. English C, Manns PJ, Tucak C, et al. Physical activity and sedentary behaviors in people with stroke living in the community: a systematic review. Phys Ther. 2014;94(2):185–96.
6. English C, Healy GN, Coates A, et al. Sitting time and physical activity after stroke: physical ability is only part of the story. Top Stroke Rehabil. 2016;23(1):36–42.
7. Miller KK, Porter RE, DeBaun-Sprague E, et al. Exercise after stroke: patient adherence and beliefs after discharge from rehabilitation. Top Stroke Rehabil. 2017;24(2):142–8.
8. Nicholson S, Sniehotta FF, Wijck F, et al. A systematic review of perceived barriers and motivators to physical activity after stroke. Int J Stroke. 2012;8(5):357–64.
9. Mansfield A, Knorr S, Poon V, et al. Promoting optimal physical exercise for life: An exercise and self-management program to encourage participation in physical activity after discharge from stroke rehabilitation - A feasibility study. Stroke Res Treat. 2016. https://doi.org/10.1155/2016/9476541.
10. Lou S, Carstensen K, Jørgensen CR, et al. Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. Disabil Rehabil. 2017;39(3):301–13.
11. Pang MY. A caregiver-mediated home-based intervention improves physical functioning and social participation in people with chronic stroke. J Physiother. 2014;60(4):235.
12. Vloothuis J, Mulder M, Nijland RH, et al. Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): Study protocol for a randomized controlled trial. BMC Neurol. 2015;15:193.
13. Reunanen MA, Järvikoski A, Talvitie U, et al. Individualised home-based rehabilitation after stroke in eastern Finland - the client's perspective. Health Soc Care Community. 2016;24(1):77–85.
14. Galvin R, Cusack T, O'Grady E, et al. Family-mediated exercise intervention (FAME) - evaluation of a novel form of exercise delivery after stroke. Stroke. 2011;42(3):681–6.
15. Simpson LA, Eng JJ, Chan MJD. H-GRASP: the feasibility of an upper limb home exercise program monitored by phone for individuals post stroke. Disabil Rehabil. 2017;39(9):874–82.
16. Teasell R, Cotoi A, Chow J, et al. The stroke rehabilitation evidence-based review: (18th edition). In: Canadian stroke network: In; 2018. http://www.ebrsr.com/sites/default/files/documents/v18-SREBR-ExecutiveSummary-2.pdf.
17. Vloothuis JD, Mulder M, Veerbeek JM, et al. Caregiver-mediated exercises for improving outcomes after stroke. Cochrane Database Syst Rev. 2016;12:CD011058.
18. Galvin R, Cusack T, Stokes E. To what extent are family members and friends involved in physiotherapy and the delivery of exercises to people with stroke? Disabil Rehabil. 2009;31(11):898–905.
19. Lee MJ, Yoon S, Kang JJ, et al. Efficacy and safety of caregiver-mediated exercise in post-stroke rehabilitation. Ann Rehabil Med. 2018;42(3):406–15.
20. Galvin R, Stokes E, Cusack T. Family-mediated exercises (FAME): an exploration of participant's involvement in a novel form of exercise delivery after stroke. Top Stroke Rehabil. 2014;21(1):63–74.
21. Cameron JI, Stewart DE, Streiner DL, et al. What makes family caregivers happy during the first 2 years post stroke? Stroke. 2014;45:1084–9.
22. Lutz BJ, Camicia M. Supporting the needs of stroke caregivers across the care continuum. J Clin Outcomes Manag. 2016;23:557–66.
23. Hafsteinsdottir TB, Vergunst M, Lindeman E, et al. Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. Patient Educ Couns. 2011;85:14–25.
24. Vloothuis J, de Bruin J, Mulder M, et al. Description of the CARE4STROKE programme: A caregiver-mediated exercises intervention with e-health support for STROKE patients. Physiother Res Int. 2018;23(3):e1719.
25. Mawson S, Nasr N, Parker J, et al. A personalized self-management rehabilitation system with an intelligent shoe for stroke survivors: a realist evaluation. JMIR Rehabil Assist Technol. 2016;3(1):e1.
26. Adie K, Schofield C, Berrow M, et al. Does the use of Nintendo Wii sports™ improve arm function? Trial of Wii™ in stroke: a randomized controlled trial and economics analysis. Clin Rehabil. 2017;31(2):173–85.

27. Rooij I, van de Port I, Meijer J. Feasibility and effectiveness of virtual reality training on balance and gait recovery early after stroke: A pilot study. Int J Phys Med Rehabil. 2017;5(417):2.
28. Mirza-Babaei P, Kamkarhaghighi M, Gerling K. Opportunities in game-based stroke rehabilitation. In: Proceedings of the 2014 IEEE games media entertainment: GEM; 2014 Oct 22. Toronto: IEEE Xplore; 2015. Available from: https://ieeexplore.ieee.org/document/7118436.
29. Saywell N, Taylor N, Rodgers E, et al. Play-based interventions improve physical function for people with adult-acquired brain injury: a systematic review and meta-analysis of randomised controlled trials. Clin Rehabil. 2017; 31(2):145–57.
30. Ezeugwu VE, Manns PJ. The feasibility and longitudinal effects of a home-based sedentary behavior change intervention after stroke. Arch Phys Med Rehabil. 2018;99(12):2540–7.
31. Lohse KR, Hilderman CG, Cheung KL, et al. Virtual reality therapy for adults post-stroke: a systematic review and meta-analysis exploring virtual environments and commercial games in therapy. PLoS One. 2014;9(3): e93318.
32. Edgar MC, Monsees S, Rhebergen J, et al. Telerehabilitation in stroke recovery: a survey on access and willingness to use low-cost consumer technologies. Telemed E-Health. 2017;23(5):421–9.
33. Wingham J, Adie K, Turner D, et al. Participant and caregiver experience of the Nintendo Wii sports™ after stroke: qualitative study of the trial of Wii™ in stroke (TWIST). Clin Rehabil. 2015;29(3):295–305.
34. Hung Y-X, Huang P-C, Chen K-T, et al. What do stroke patients look for in game-based rehabilitation: a survey study. Medicine. 2016;95(11):e3032.
35. Ferreira V, Carvas N Jr, Artilheiro MC, et al. Interactive video gaming improves functional balance in poststroke individuals: meta-analysis of randomized controlled trials. Eval Health Prof. 2020;43(1):23–32.
36. Veerbeek JM, Langbroek-Amersfoort AC, Van Wegen EE, et al. Effects of robot-assisted therapy for the upper limb after stroke: a systematic review and meta-analysis. Neurorehabil Neural Repair. 2017;31(2):107–21.
37. Laver KE, George S, Thomas S, et al. Virtual reality for stroke rehabilitation. Cochrane Database of Syst Rev. 2017;11:CD008349.
38. Creswell JW, Planco CVL. Designing and conducting mixed methods research. California: SAGE Publications; 2018.
39. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new medical research council guidance. BMJ. 2008;337: 979–83.
40. Bleijenberg N, de Man-van Ginkel JM, Trappenburg JCA, et al. Increasing value and reducing waste by optimizing the development of complex interventions: enriching the development phase of the Medical Research Council (MRC) framework. Int J Nurs Stud. 2018;79:86–93.
41. Bowen DJ, Kreuter M, Spring B, et al. How we design feasibility studies. Am J Prev Med. 2009;36(5):452–7.
42. Bonita R, Beaglehole R. Recovery of motor function after stroke. Stroke. 1988;19(12):1497–500.
43. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975;12(3):189–98.
44. Winograd TE. Bringing design to software. New York: ACM Press; 1996.
45. Olafsdottir SA, Jonsdottir H, Magnusson C, et al. Developing ActivABLES for community-dwelling stroke survivors using the Medical Research Council framework for complex interventions. BMC Health Serv Res. 2020;20(1):463.
46. Magnusson C, Caltenco H, Rassmus-Gröhn K, et al. Universal balance? Stud Health Technol Inform. 2018;256:847–53.
47. Magnusson C, Rassmus-Gröhn K, Rydeman B, et al. Walk after stroke: initial development of a step counting game for stroke survivors. In: Proceedings of the 20th international conference on human-computer interaction with mobile devices and services adjunct: MobileHCI 18; 2018 Sep 3; Barcelona, Spain. New York: Association for Computing Machinery; 2018. p. 237–44.
48. Kytö M, McGookin D, Bock W, et al. Designing bimanual tangible interaction for stroke survivors. In: Proceedings of the twelfth international conference on tangible, embedded, and embodied interaction: 2018 Mar 18. Stockholm; 2018. p. 245–52. https://doi.org/10.1145/3173225.3173269.
49. Berg KO, Wood-Dauphinee SL, Williams JI, et al. Measuring balance in the elderly: validation of an instrument. Can J Public Health. 1992;83(2):S7–11.
50. Berg K, Wood-Dauphinee S, Williams J. The balance scale: reliability assessment with elderly residents and patients with an acute stroke. Scan J Rehabil Med. 1995;27(1):27–36.
51. Stevenson TJ. Detecting change in patients with stroke using the Berg balance scale. Aust J Physiother. 2001;47(1):29–38.
52. Flansbjer U-B, Blom J, Brogårdh C. The reproducibility of Berg balance scale and the single-leg stance in chronic stroke and the relationship between the two tests. Phys Med Rehabil. 2012;4(3):165–70.
53. Blum L, Korner-Bitensky N. Usefulness of the Berg balance scale in stroke rehabilitation: a systematic review. Phys Ther. 2008;88(5):559–66.
54. Arnadottir SA, Lundin-Olsson L, Gunnarsdottir ED, et al. Application of Rasch analysis to examine psychometric aspects of the activities-specific balance confidence scale when used in a new cultural context. Arch Phys Med Rehabil. 2010;91(1):156–63.
55. Salbach NM, Mayo NE, Hanley JA, et al. Psychometric evaluation of the original and Canadian French version of the activities-specific balance confidence scale among people with stroke. Arch Phys Med Rehabil. 2006; 87(12):1597–604.
56. Botner EM, Miller WC, Eng JJ. Measurement properties of the activities-specific balance confidence scale among individuals with stroke. Disabil Rehabil. 2005;27(4):156–63.
57. Mathias S, Nayak US, Isaacs B. Balance in elderly patients: the "get-up and go" test. Arch Phys Med Rehab. 1986;67(6):387–9.
58. Flansbjer U-B, Holmbäck AM, Downham D, et al. Reliability of gait performance tests in men and women with hemiparesis after stroke. J Rehabil Med. 2005;37(2):75–82.
59. Hafsteinsdottir TB, Rensink M, Schuurmans M. Clinimetric properties of the timed up and go test for patients with stroke: a systematic review. Top Stroke Rehab. 2014;21(3):197–210.
60. Csuka M, McCarty DJ. Simple method for measurement of lower extremity muscle strength. Am J Med. 1985;78(1):77–81.
61. Silva PFS, Quintino LF, Franco J, et al. Measurement properties and feasibility of clinical tests to assess sit-to-stand/stand-to-sit tasks in subjects with neurological disease: a systematic review. Braz J Phys Ther. 2014;18(2): 99–110.
62. Mathiowetz V, Volland G, Kashman N, et al. Adult norms for the box and block test of manual dexterity. Am J Occup Ther. 1985;39(6):386–91.
63. Platz T, Pinkowski C, van Wijck F, et al. Reliability and validity of arm function assessment with standardized guidelines for the Fugl-Meyer test, action research arm test and box and block test: a multicentre study. Clin Rehabil. 2005;19(4):404–11.
64. Lin K, Chuang LL, Wu CY, et al. Responsiveness and validity of three dexterous function measures in stroke rehabilitation. J Rehabil Res Dev. 2010;47(6):563–72.
65. Markland D. Exercise motivation measurement: The Behavioural Regulation in Exercise Questionnaire. 2009. Archived at: http://pages.bangor.ac.uk/~pes004/exercise_motivation/scales.htm.
66. Markland D, Tobin V. A modification to the behavioural regulation in exercise questionnaire to include an assessment of amotivation. J Sport Exerc Psychol. 2004;26(2):191–6.
67. Sweet SN, Fortier MS, Strachan SM, et al. Testing a longitudinal integrated self-efficacy and self-determination theory model for physical activity post-cardiac rehabilitation. Health Psychol Res. 2014;2(1):30–7.
68. Wilson PM, Sabiston CM, Mack DE, et al. On the nature and function of scoring protocols used in exercise motivation research: an empirical study of the behavioral regulation in exercise questionnaire. Psychol Sport Exerc. 2012;13(5):614–22.
69. Mohr DC, Cuijpers P, Lehman K. Supportive accountability: a model for providing human support to enhance adherence to eHealth interventions. J Med Internet Res. 2011;13(1):e30.
70. Ingledew DK, Markland D. The role of motives in exercise participation. Psychol Health. 2008;23(7):807–28.
71. Wilson PM, Rodgers WM. The relationship between perceived autonomy support, exercise regulations and behavioral intentions in women. Psychol Sport Exerc. 2004;5(3):229–42.
72. Milne HM, Wallman KE, Gordon S, et al. Impact of a combined resistance and aerobic exercise program on motivational variables in breast cancer survivors: a randomized controlled trial. Ann Behav Med. 2008;2(36):158–66.
73. Vancampfort D, De Hert M, Vansteenkiste M, et al. The importance of self-determined motivation towards physical activity in patients with schizophrenia. Psychiatry Res. 2013;210(3):812–8.
74. Edwardson CL, Winkler EA, Bodicoat DH, et al. Considerations when using the activPAL monitor in field-based research with adult populations. J Sport Health Sci. 2017;6(2):162–78.

75. Yang CC, Hsu YL. A review of accelerometry-based wearable motion detectors for physical activity monitoring. Sensors. 2010;10(8):7772–88.
76. Field MJ, Gebruers N, Shanmuga Sundaram T, et al. Physical activity after stroke: A systematic review and meta-analysis. ISRN Stroke. 2013. https://doi.org/10.1155/2013/464176.
77. Borg G. Borg's perceived exertion and pain scales. Human Kinetics: Champaign; 1998. ISBN: 0-88011-623-4.
78. Holloway I, Galvin K. Qualitative research in nursing and healthcare. 4th ed. Wiley: Chichester; 2016.
79. Landerman LR, Land KC, Pieper CF. An empirical evaluation of the predictive mean matching method for imputing missing values. Sociol Methods Res. 1997;26(1):3–33.
80. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277–88.
81. Grimby G, Willén C, Engardt M, et al. Stroke. In: Sundberg CJ, editor. Physical activity in the prevention and treatment of disease. Östersund: Swedish National Institute of Public Health; 2010. p. 611–21.
82. Liepert J, Bauder H, Miltner WH, et al. Treatment-induced cortical reorganization after stroke in humans. Stroke. 2000;31(6):1210–6.
83. Langhorne P, Coupar F, Pollock A. Motor recovery after stroke: a systematic review. Lancet Neurol. 2009;8(8):741–54.
84. Galvin R, Murphy B, Cusack T, et al. The impact of increased duration of exercise therapy on functional recovery following stroke—what is the evidence? Top Stroke Rehabil. 2008;15(4):365–77.
85. Lohse KR, Lang CE, Boyd LA. Is more better? Using metadata to explore dose–response relationships in stroke rehabilitation. Stroke. 2014;45(7):2053–8.
86. Fini NA, Holland AE, Keating J, et al. How physically active are people following stroke? Systematic review and quantitative synthesis. Phys Ther. 2017;97(7):707–17.
87. Held JP, Ferrer B, Mainetti R, et al. Autonomous rehabilitation at stroke patients home for balance and gait: safety, usability and compliance of a virtual reality system. Eur J Phys Rehabil Med. 2018;54:545–53.
88. Putrino D, Zanders H, Hamilton T, et al. Patient engagement is related to impairment reduction during digital game-based therapy in stroke. Games Health J. 2017;6:295–302.
89. Dyrstad SM, Hansen BH, Holme IM, et al. Comparison of self-reported versus accelerometer-measured physical activity. Med Sci Sports Exerc. 2014;46(1):99–106.
90. Kunkel D, Fitton C, Burnett M, et al. Physical inactivity post-stroke: a 3-year longitudinal study. Disabil Rehabil. 2015;37(4):304–10.
91. Teixeira PJ, Carraça EV, Markland D, et al. Exercise, physical activity, and self-determination theory: a systematic review. Int J Behav Nutr Phy. 2012;9(1):78.
92. Parker J, Mawson S, Mountain G, et al. The provision of feedback through computer-based technology to promote self-managed post-stroke rehabilitation in the home. Disabil Rehabil Assist Technol. 2014;9(6):529–38.
93. Tamayo-Serrano P, Garbaya S, Blazevic P. Gamified In-Home Rehabilitation for Stroke Survivors: Analytical Review. Int J Serious Games. 2018;5(1):2384–8766.
94. Konttila J, Siira H, Kyngäs H, et al. Healthcare professionals' competence in digitalisation: a systematic review. J Clin Nurs. 2019;28(5–6):745–61.

Publisher's Note

Appendices

The following is some material relevant to the research on community-dwelling stroke survivors which was described in this thesis. All this material is in Icelandic.

Appendix I includes the Icelandic survey questionnaire that was mailed to the community-dwelling stroke survivors, along with an information letter.

Appendix II includes material related to the process of developing ActivABLES.

- the interview guide for the semi-structured interviews with the stroke survivors participating in the preliminary testing in the development phase.
- the interview guide for the semi-structured interviews with the caregivers participating in the preliminary testing in the development phase.
- the information letter and an informed consent.
- the form of the adherence diary.
- the interview guide for the semi-structured interviews with the stroke survivors participating in the feasibility study.
- the interview guide for the semi-structured interviews with the caregivers participating in the feasibility study.

LANDSPÍTALI HÁSKÓLI ÍSLANDS SAk SJÚKRAHÚSIÐ Á AKUREYRI AKUREYRI HOSPITAL

apríl 2018

<u>**Upplýsingabréf**</u>

Heilsa, færni og aðstæður
Einstaklingar í heimahúsum eftir eitt heilaslag

Ágæti viðtakandi

Tilgangur þessa bréfs er að bjóða þér að taka þátt í könnun á högum einstaklinga sem hafa fengið heilaslag (einnig kallað heilablóðfall). Undirrituð, Steinunn A. Ólafsdóttir, er sjúkraþjálfari í doktorsnámi og er þessi könnun hluti af doktorsverkefni sem unnið er á heilbrigðisvísindasviði Háskóla Íslands og er samstarfsverkefni námsbrautar í sjúkraþjálfun í Læknadeild og Hjúkrunarfræðideildar. Ábyrgðarmaður rannsóknarinnar er Ingibjörg Hjaltadóttir dósent við Háskóla Íslands. Aðrir rannsakendur eru Sólveig Ása Árnadóttir dósent, Helga Jónsdóttir prófessor og Þóra Berglind Hafsteinsdóttir prófessor. Þessi könnun er unnin í samstarfi við Landspítala og Sjúkrahúsið á Akureyri.

Tilgangur og markmið
Markmið könnunarinnar er að fá upplýsingar um heilsu, færni og aðstæður þeirra sem hafa fengið heilaslag og búa í heimahúsum. Spurt er um hvaða áhrif heilaslag hefur haft á einstaklinginn út frá ýmsum sjónarhornum og heilbrigðisþjónustu í kjölfar heilaslagsins. Tilgangurinn er að varpa ljósi á aðstæður og þörf fyrir markvissa þjálfun og þjónustu til lengri tíma.

Þátttakendur
Þú færð þessa könnun senda vegna þess að þú ert að minnsta kosti 18 ára og samkvæmt sjúkraskrá Landspítala eða Sjúkrahússins á Akureyri fékkst þú heilaslag á tímabilinu 1.apríl 2016 - 31.mars 2017.

Fyrirkomulag
Þátttaka þín felst í að svara meðfylgjandi könnun sem samanstendur af spurningum um þætti sem snerta heilsufar, færni, líðan, þjónustu, þjálfun og lífshætti. Í lok könnunarinnar er staðlaður spurningalisti sem þýddur hefur verið eftir erlendri fyrirmynd, *Mælistika á áhrif heilaslags (e. Stroke Impact Scale)* en þessi listi hefur mikið verið notaður til að rannsaka einstaklinga sem hafa fengið heilaslag.

Við viljum biðja þig um að lesa ítarlega leiðbeiningar fyrir hverja spurningu því svarmöguleikar eru mismunandi, og svara síðan spurningunum eftir bestu getu. Það getur tekið 30-60 mínútur að svara þeim öllum. Ef þú vilt sleppa því að svara einstökum spurningum er þér frjálst að gera það. Rétt er þó að benda á að vegna úrvinnslu gagna og áreiðanleika niðurstaðna, er æskilegt að sem flestum spurningum sé svarað. Þú mátt að sjálfsögðu fá aðstoð frá aðstandanda eða vini við að svara spurningunum. Fáir þú slíka aðstoð, biðjum við þig um að merkja í viðeigandi reit á fyrstu blaðsíðunni.

Rannsóknarmiðstöð Háskólans á Akureyri (RHA) mun sjá um að safna saman svörum og afhenda okkur. Þegar þú hefur lokið við að svara könnuninni skaltu setja hana í meðfylgjandi svarumslag og loka því. Við viljum síðan biðja þig um að setja það í næsta póstkassa. Þú þarft ekki að greiða sendingarkostnað heldur má umslagið fara ófrímerkt í póst. Ef við höfum ekki fengið svör frá þér innan þriggja vikna frá útsendingu, hringjum við í þig til að að bjóða fram aðstoð. Könnunin er send út í apríl 2018 og gert er ráð fyrir rannsóknarlokum þar sem allar niðurstöður muni liggja fyrir í janúar 2023. Fyrstu niðurstöður munu þó birtast fyrr.

Trúnaður og persónuvernd

Öll svör sem þátttakendur veita verða meðhöndluð samkvæmt ströngustu reglum um trúnað og nafnleynd og farið verður að lögum um persónuvernd, vinnslu og eyðingu gagna. Spurningalistarnir eru merktir með rannsóknarnúmeri og verða varðveittir í læstri hirslu með aðgangsstýringu hjá ábyrgðarmanni. Listi sem tengir rannsóknarnúmer við þátttakendur verður varðveittur á sama hátt, meðan á rannsókn stendur, og honum eytt að rannsókn lokinni. Unnið verður úr spurningalistanum í sérstökum tölfræðiforritum þar sem allar upplýsingar verða ópersónugreinanlegar. Ekki verður hægt að rekja svör til einstakra þátttakenda þegar niðurstöður verða birtar. Öllum rannsóknargögnum verður eytt eigi síðar en tveimur árum eftir rannsóknarlok eða í janúar 2025. Niðurstöðurnar verða kynntar á erlendum og innlendum vísindaráðstefnum og skrifaðar verðar vísindagreinar í innlend og erlend vísindatímarit. Vísindasiðanefnd Íslands hefur gefið leyfi fyrir þessari rannsókn (nr. VSNb2017110024/03.01), þar með talið að leita í sjúkraskrám að einstaklingum sem fengu heilaslag á áðurnefndu tímabili. Persónuvernd hefur einnig verið tilkynnt um könnunina.

Ávinningur og áhætta

Það felst enginn beinn ávinningur fyrir þig í þátttöku í þessari könnun en segja má að óbeinn ávinningur sé að fá tækifæri til að leggja lóð á vogarskálarnar til að bæta þekkingu á högum einstaklinga sem hafa fengið heilaslag og búa í heimahúsum. Slík þekking gefur meðal annars möguleika á að bæta og þróa þjónustu þannig að hún mæti betur þörfum þessa hóps. Ekki felst nein bein áhætta í að svara þessari könnun.

Lokaorð

Meðfylgjandi eru spurningarnar sem við biðjum þig um að svara. Eins og áður hefur komið fram, þá er þér í sjálfsvald sett hvort þú svarir þessum spurningum. Ef þú kýst að svara ekki mun það ekki hafa neina eftirmála. Eftirstöðvar heilaslags eru mjög mismunandi og hafa sumir mikil einkenni og búa við fötlun á meðan aðrir hafa mjög lítil einkenni. Við óskum eftir því að þú svarir þessari könnun <u>hvort sem þú ert með lítil eða mikil einkenni</u> eftir heilaslag. Hvert svar skiptir máli.

Hafir þú spurningar eða viljir koma á framfæri athugasemdum eða kvörtunum í tengslum við könnunina, er þér velkomið að hafa samband við undirritaða.

Með fyrirfram þökkum,

____

Fyrir hönd rannsóknarhópsins
Steinunn A. Ólafsdóttir sjúkraþjálfari og doktorsnemi
sími 849 4733, netfang sao9@hi.is

Ef þú hefur spurningar varðandi rétt þinn sem þátttakandi í könnuninni, getur þú snúið þér til Vísindasiðanefndar, Borgartúni 21, 105 Reykjavík. Sími 551 7100, tölvupóstur visindasidanefnd@vsn.stjr.is

HÁSKÓLI ÍSLANDS

LANDSPÍTALI HÁSKÓLASJÚKRAHÚS

SAk SJÚKRAHÚSIÐ Á AKUREYRI AKUREYRI HOSPITAL

Heilsa, færni og aðstæður

Einstaklingar í heimahúsum eftir eitt heilaslag

Háskóla Íslands, apríl 2018

Kæri þátttakandi

Takk fyrir að gefa þér tíma til að svara þessari könnun. Við viljum minna þig á að lesa ítarlega leiðbeiningar fyrir hverja spurningu, því svarmöguleikar eru mismunandi, og svara síðan spurningunum eftir bestu getu. Mundu að ekkert svar er réttara en annað. Við viljum fyrst og fremst fá að vita hvaða svar þér finnst lýsa best þér og þinni reynslu.

Við viljum jafnframt nefna aftur að algjör nafnleynd verður viðhöfð. Nafn þitt eða aðrar upplýsingar sem benda til þess hver þú ert, munu hvergi koma fram þegar niðurstöður þessarar rannsóknir verða birtar.

Við viljum biðja þig um að merkja við hér ef þú hefur fengið aðstoð við að svara spurningunum.

☐ Já, ég fékk aðstoð við að svara spurningunum.

Eitthvað sem þú vilt taka fram:

____

____

____

Bestu þakkir fyrir þátttökuna

Steinunn A. Ólafsdóttir sjúkraþjálfari í doktorsnámi við Háskóla Íslands (HÍ)
Ingibjörg Hjaltadóttir dósent við hjúkrunarfræðideild HÍ, ábyrgðarmaður rannsóknarinnar
Sólveig Ása Árnadóttir dósent við námsbraut í sjúkraþjálfun HÍ
Helga Jónsdóttir prófessor við hjúkrunarfræðideild HÍ
Þóra Berglind Hafsteinsdóttir prófessor við hjúkrunarfræðideildi HÍ

A. Lýðfræði- og félagslegar upplýsingar

A1. **Hvað ert þú gamall/gömul?** ⎵⎵ **ára**

A2. **Kyn** ☐ Karl ☐ Kona

A3. **Í hvaða póstnúmeri býrð þú?** ⎵⎵⎵

A4. **Hversu margir búa á heimili þínu að þér meðtöldum/meðtalinni?**

- ☐ ég bý ein/einn
- ☐ tveir
- ☐ þrír eða fleiri

A5. **Hvert er hæsta stig menntunar sem þú hefur lokið?**

- ☐ skyldunám (t.d. barnaskólapróf, grunnskólapróf, gagnfræðapróf, landspróf)
- ☐ stúdentspróf eða annað próf á framhaldsskólastigi
- ☐ iðnnám eða tækniskólapróf
- ☐ háskólapróf (BS/BA, MS/MA, PhD)
- ☐ önnur menntun, hver? ________________________________

B. Heilsufar, færni og líðan

B1. **Hvenær fékkst þú heilaslag?** *Ritaðu mánuðinn og árið.* ________________________

B2. **Hver var orsök heilaslagsins?**

- ☐ blóðtappi í heila
- ☐ blæðing í heila
- ☐ veit það ekki

B3. **Hver voru helstu einkennin eftir heilaslagið?** *Merktu við allt sem við á.*

- ☐ máttminnkun/lömun í hægri handlegg
- ☐ máttminnkun/lömun í hægri hendi
- ☐ máttminnkun/lömun í hægri fótlegg
- ☐ máttminnkun/lömun í hægri fæti
- ☐ máttminnkun/lömun í vinstri handlegg
- ☐ máttminnkun/lömun í vinstri hendi
- ☐ máttminnkun/lömun í vinstri fótlegg
- ☐ máttminnkun/lömun í vinstri fæti
- ☐ jafnvægisskerðing
- ☐ verkstol
- ☐ gaumstol
- ☐ málstol
- ☐ kyngingarörðugleikar
- ☐ minnisleysi
- ☐ önnur einkenni, hver? ________________________

B4. **Hefur þú greinst með aðra sjúkdóma eða kvilla?** *Merktu við allt sem við á.*

- ☐ hjarta- og æðasjúkdóma
- ☐ sykursýki
- ☐ kvíða eða þunglyndi
- ☐ langvinna lungnateppu
- ☐ slitgigt eða liðagigt
- ☐ beinþynningu
- ☐ krabbamein
- ☐ þvagleka
- ☐ annað, hvað ______________________________

B5. **Eftirfarandi staðhæfingar eru um þreytu og orku**. *Merktu við það sem þér finnst eiga best við þig við hverja staðhæfingu.*

	Aldrei	**Einstöku sinnum**	**Stundum**	**Oftast**	**Alltaf**
Ég þreytist mjög fljótt	☐	☐	☐	☐	☐
Ég hef næga orku til að komast í gegnum daginn	☐	☐	☐	☐	☐
Þreyta er mín mesta fötlun	☐	☐	☐	☐	☐

B6. **Eftirfarandi staðhæfingar eru um verk**i. *Merktu við það sem þér finnst eiga best við þig í dag.*

- ☐ Ég finn hvorki fyrir verkjum né óþægindum
- ☐ Ég finn fyrir vægum verkjum eða óþægindum
- ☐ Ég finn fyrir miðlungs miklum verkjum eða óþægindum
- ☐ Ég finn fyrir miklum verkjum eða óþægindum
- ☐ Ég finn fyrir óbærilegum verkjum eða óþægindum

B7. **Á síðustu 12 mánuðum, hefur þú dottið þannig að þú hafir lent á jörðinni eða gólfinu ?**

- ☐ nei
- ☐ já Hversu oft hefur þú dottið á síðustu 12 mánuðum? ________

Beinbrotnaðir þú eða hlaust alvarlegar tognanir við byltu sem hafði áhrif á daglega færni þína?

- ☐ nei
- ☐ já

C. Umhverfi og aðstæður

C1. **Hvernig var störfum þínum háttað áður en þú fékkst heilaslag**? *Merktu við allt sem við á.*

- ☐ Ég var í fullu starfi
- ☐ Ég var í hlutastarfi
- ☐ Ég var í námi
- ☐ Ég var ekki í vinnu sökum aldurs
- ☐ Ég var atvinnulaus
- ☐ Ég sinnti sjálfboðaliðastarfi
- ☐ Annað, hvað ______________________________

C2. **Hvernig er störfum þínum háttað í dag**? *Merktu við allt sem við á.*

- ☐ Ég er í fullu starfi
- ☐ Ég er í hlutastarfi
- ☐ Ég er í námi
- ☐ Ég er ekki í vinnu vegna aldurs
- ☐ Ég er ekki í vinnu því ég er ekki fær um það
- ☐ Ég er ekki í vinnu því ég fæ ekki vinnu við hæfi
- ☐ Annað, hvað ______________________________

C3. **Þurftir þú að skipta um húsnæði eftir heilaslagið vegna aðgengis** ?

- ☐ nei
- ☐ já

C4. **Hvernig er aðgengi fyrir þig að heimili þínu í dag**? *Merktu við það sem lýsir best aðstæðum á heimili þínu.*

- ☐ Gott, þarf ekki að fara stiga
- ☐ Gott, þarf að fara stiga og kemst auðveldlega milli hæða
- ☐ Ekki gott, þarf að fara stiga og á erfitt með að fara á milli hæða

C5. **Hvernig var ferðamáti þinn áður en þú fékkst heilaslag**? *Merktu við allt sem við á.*

- ☐ Ég ók bíl
- ☐ Ég notaði strætó/almenningssamgöngur/leigubíl
- ☐ Ég notaði Ferðaþjónustu fatlaðra
- ☐ Ég var háður öðrum en Ferðaþjónustu fatlaðra með ferðir

C6. **Hvernig er ferðamáti þinn í dag** ? *Merktu við allt sem við á.*

- ☐ Ég ek bíl
- ☐ Ég nota strætó/almenningssamgöngur/leigubíl
- ☐ Ég nota Ferðaþjónustu fatlaðra
- ☐ Ég er háður öðrum en Ferðaþjónustu fatlaðra með ferðir

C7. **Notar þú hjálpartæki?** *Merktu við allt sem við á.*

☐ nei, ég nota engin hjálpartæki
☐ já

	Innanhúss	Utanhúss
Staf eða hækjur	☐	☐
Göngugrind	☐	☐
Handknúinn hjólastól	☐	☐
Rafmagnshjólastól	☐	☐
Rafskutlu	☐	☐
Önnur hjálpartæki við athafnir daglegs lífs (t.d. sokkaífæru, griptöng eða salernisupphækkun)	☐	☐

C8. **Ertu með öryggishnapp t.d. frá Securitas eða Öryggismiðstöðinni?**

☐ nei
☐ já

C9. **Hér er spurt um aðgengi þitt og notkun á snjalltækjum.** *Merktu við allt sem við á.*

	snjallsíma	spjaldtölvu	borðtölvu/ fartölvu
Ég á eða hef aðgengi að ...	☐	☐	☐
Ég nota reglulega ...	☐	☐	☐

Hvernig / til hvers notar þú þessi snjalltæki? ______________________

____

____

	snjallsíma	spjaldtölvu	borðtölvu/ fartölvu
Ég tel að að þessi tæki geti nýst mér til þjálfunar heimavið.	☐	☐	☐

Hvernig telur þú að þessi snjalltæki gætu nýst þér til þjálfunar? ______________________

____

____

D. Þjónusta og hreyfing

D1. **Fórstu á stofnun til endurhæfingar eftir heilaslagið (t.d. Grensás, Landakot, Reykjalund eða Kristnes) ?**

- ☐ nei
- ☐ já, strax eftir sjúkrahúsdvöl
- ☐ já, en fór heim í millitíðinni

Hvað leið langur tími þar til þú fórst í endurhæfingu (í dögum, vikum eða mánuðum)? ____________

Hvert fórstu í endurhæfingu? ____________

Hvað dvaldir þú lengi þar (í vikum eða mánuðum)? ____________

D2. **Hvaða þjónustu fékkstu strax eftir útskrift af sjúkrahúsi eða endurhæfingarstofnun?**
Merktu við allt sem við á.

- ☐ sjúkraþjálfun
- ☐ iðjuþjálfun
- ☐ talþjálfun
- ☐ göngudeildarþjónustu hjúkrunarfræðinga
- ☐ heimahjúkrun (t.d. aðstoð við lyf, aðstoð við klæðnað eða böðun)
- ☐ heimaþjónustu sveitarfélags (t.d. þrif eða heimsendan mat)
- ☐ dagþjónustu (t.d. hjá Sjálfsbjörg eða á öldrunarheimilum)
- ☐ annað, hvað? ____________

D3. **Hvaða þjónustu hefur þú fengið <u>síðastliðinn mánuð</u> og í hverju hefur hún falist?** *Merktu við allt sem við á og svaraðu viðeigandi spurningum.*

☐ **sjúkraþjálfun** hversu oft í viku? ___________

í hverju felst þjálfunin? ___________

☐ **iðjuþjálfun** hversu oft í viku? ___________

í hverju felst þjálfunin? ___________

☐ **talþjálfun** hversu oft í viku? ___________

í hverju felst þjálfunin? ___________

☐ **göngudeildarþjónusta hjúkrunarfræðinga** hversu oft í viku? ___________

í hverju felst þjónustan? ___________

☐ **heimahjúkrun** hversu oft í viku? ___________

í hverju felst þjónustan? ___________

☐ **heimaþjónusta sveitarfélags** hversu oft í viku? ___________

í hverju felst þjónustan? ___________

☐ **dagþjónustu** hversu oft í viku? ___________
(*t.d hjá Sjálfsbjörgu eða á öldrunarstofnunum*)

í hverju felst þjónustan? ___________

D4. **Uppfyllir sú þjónusta sem þú hefur fengið síðastliðinn mánuð þarfir þínar?**

- ☐ já
- ☐ nei

Hvernig myndir þú vilja bæta/breyta þjónustunni? ______________________

____

____

Annað sem þú vilt taka fram um þjónustu: ______________________

____

____

D5. **Hefur þú gengið í að minnsta kosti 10 mínútur samfellt einhvern daginn á síðustu sjö dögum?**

- ☐ nei
- ☐ já
  - Hversu marga daga af síðustu sjö dögum varstu á göngu í að minnsta kosti 10 mínútur samfellt? ______________
  - Hvað gekkstu lengi í hvert sinn að jafnaði ? ______________

D6. **Hvað situr þú lengi á hverjum degi að jafnaði?** *Miðaðu við síðustu sjö daga.*

____

D7. **Stundar þú reglulega líkamsrækt eða æfingar?** *Merktu við allt sem við á.*

		Hversu oft í viku?
☐	nei	
☐	já, á líkamsræktarstöð	______
☐	já, í skipulagðri hópþjálfun t.d. á sjúkraþjálfunarstöð, HL-stöð eða félagsmiðstöð	______
☐	já, ég fer í sundleikfimi og/eða syndi	______
☐	já, ég geri æfingar heima	______
☐	já, annað, hvað?	______

D8. **Hvers vegna gerir þú æfingar eða ekki?** Okkur leikur hugur á að vita hvað liggur að baki ákvörðun einstaklinga um að gera æfingar eða ekki. Merktu við tölustaf (0-4) sem lýsir best hvernig eftirfarandi staðhæfingar eiga við þig

	Á ekki við mig		**Á stundum við mig**		**Á mjög vel við mig**
Ég geri æfingar af því að aðrir segja að ég eigi að gera þær	0	1	2	3	4
Ég fæ samviskubit þegar ég geri ekki æfingar	0	1	2	3	4
Ég met gagnsemi eða ávinning æfinga	0	1	2	3	4
Ég geri æfingar af því að það er gaman	0	1	2	3	4
Ég sé ekki ástæðu til að gera æfingar	0	1	2	3	4
Ég geri æfingar af því að vinir/fjölskylda segja að ég eigi að gera þær	0	1	2	3	4
Ég skammast mín þegar ég geri ekki æfingar	0	1	2	3	4
Það er mikilvægt fyrir mig að gera æfingar reglulega	0	1	2	3	4
Ég skil ekki af hverju ég ætti að gera æfingar	0	1	2	3	4
Ég nýt þess að gera æfingar	0	1	2	3	4
Ég geri æfingar af því að aðrir verða óánægðir með mig ef ég geri þær ekki	0	1	2	3	4
Ég sé ekki tilgang með æfingum	0	1	2	3	4
Mér finnst ég hafa brugðist ef ég geri ekki æfingar í nokkurn tíma	0	1	2	3	4
Ég tel mikilvægt að leggja mig fram við að gera æfingar reglulega	0	1	2	3	4
Mér finnst skemmtilegt að gera æfingar	0	1	2	3	4
Ég finn fyrir þrýstingi frá vinum/fjölskyldu að gera æfingar	0	1	2	3	4
Ég verð eirðarlaus ef ég geri ekki æfingar reglulega	0	1	2	3	4
Ég finn fyrir gleði og ánægju við að gera æfingar	0	1	2	3	4
Mér finnst það tímaeyðsla að gera æfingar	0	1	2	3	4

Mælistika á áhrif heilaslags

Tilgangur spurningalistans er að meta hvernig heilaslagið hefur haft áhrif á heilsu þína og líf. Okkur langar að fá að vita hvernig heilaslagið hefur haft áhrif á þig, út frá ÞÍNU SJÓNARHORNI. Eftirfarandi spurningar eru um skerðingu og fötlun sem heilaslagið hefur mögulega valdið, og einnig um hvernig heilaslagið hefur haft áhrif á lífsgæði þín. Að lokum, viljum við biðja þig að meta hversu mikinn bata þér finnst þú hafa fengið eftir heilaslagið.

Spurningar 1-8 fela í sér nokkra liði hver, þar sem boðið er upp á fimm svarmöguleika. Merktu við tölustaf (1-5) til að svara. Í spurningu 9 er kvarðinn 0-100 og þar merkir þú á kvarðann svar þitt.

1. **Eftirfarandi spurningar eru um líkamleg vandamál sem hafa mögulega komið upp vegna heilaslagsins.** ***Spurningarnar eiga við <u>síðastliðna viku.</u>***

Hvernig myndir þú meta kraft þinn í ...	**Mikill kraftur**	**Fremur mikill kraftur**	**Miðlungs kraftur**	**Lítill kraftur**	**Enginn kraftur**
a. handleggnum sem varð fyrir *meiri áhrifum* heilaslagsins?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
b. gripi þeirrar handar sem varð fyrir *meiri áhrifum* heilaslagsins?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
c. fótleggnum sem varð fyrir *meiri áhrifum* heilaslagsins?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
d. fætinum/ökklanum sem varð fyrir *meiri áhrifum* heilaslagsins?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐

2. **Eftirfarandi spurningar eru um minni og hugsun.** ***Spurningarnar eiga við <u>síðastliðna viku.</u>***

Hversu erfitt fannst þér að ...	**Ekki erfitt**	**Svolítið erfitt**	**Miðlungs erfitt**	**Fremur erfitt**	**Afar erfitt**
a. muna það sem fólk var nýbúið að segja þér?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
b. muna það sem gerðist daginn áður?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
c. muna að leysa fyrirhuguð verkefni (t.d. að mæta á réttum tíma eða að taka lyfin)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
d. muna hvaða dagur vikunnar er?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
e. einbeita þér?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
f. hugsa hratt?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
g. leysa dagleg vandamál?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐

3. **Eftirfarandi spurningar eru um líðan þína, breytingar á skapi þínu og getu þína til að stjórna tilfinningum þínum eftir heilaslagið.** ***Spurningarnar eiga við <u>síðastliðna viku.</u>***

Hversu oft ...	**Aldrei**	**Einstökum sinnum**	**Stundum**	**Oft**	**Alltaf**
a. fannst þér þú vera döpur/dapur?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
b. fannst þér eins og enginn stæði þér nærri?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
c. fannst þér þú vera byrði á öðrum?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
d. fannst þér þú ekki hafa neitt til að hlakka til?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
e. álasaðir þér þig fyrir mistök sem þú gerðir?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
f. naustu lífsins eins og áður?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
g. fannstu fyrir taugaspennu?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
h. fannst þér lífið hafa tilgang?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
i. brostir þú og hlóst a.m.k. einu sinni á dag?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐

4. **Eftirfarandi þættir eru um getu þína til að hafa samskipti við fólk og getu þína til að skilja það sem þú lest og heyrir í samtali.** ***Spurningarnar eiga við <u>síðastliðna viku.</u>***

Hversu erfitt fannst þér að ...	**Ekki erfitt**	**Svolítið erfitt**	**Miðlungs erfitt**	**Fremur erfitt**	**Afar erfitt**
a. segja nafn þess sem var auglitis til auglitis við þig?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
b. skilja það sem sagt var við þig?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
c. svara spurningum?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
d. nefna hluti réttu nafni?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
e. taka þátt í samræðum í hópi fólks?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
f. eiga samtal í síma?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
g. hringja í annan einstakling (þar með talið að finna rétt símanúmer og velja númerið)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐

5. **Eftirfarandi spurningar varða athafnir sem þú framkvæmir mögulega á hverjum degi.** ***Spurningarnar eiga við <u>síðastliðnar tvær vikur.</u>***

Hversu erfitt fannst þér að ...	**Ekki erfitt**	**Svolítið erfitt**	**Miðlungs erfitt**	**Fremur erfitt**	**Gat alls ekki gert**
a. matast með hníf og gaffli (m.a. að skera matinn)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
b. klæða þig að ofan (frá mitti og upp úr)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
c. baða þig?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
d. klippa táneglurnar?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
e. komast tímanlega á klósett?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
f. stjórna þvaglátum (slysalaust)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
g. stjórna hægðum (slysalaust)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
h. sinna léttum heimilisstörfum (t.d. þurrka af, búa um rúmið, fara út með ruslið eða vaska upp)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
i. fara í búðir?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
j. sinna erfiðum heimilisstörfum (t.d. ryksuga, þvo þvott eða vinna í garðinum)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐

6. **Eftirfarandi spurningar varða getu þína í að komast um heima hjá þér og úti í samfélaginu.** ***Spurningarnar eiga við <u>síðastliðnar tvær vikur.</u>***

Hversu erfitt fannst þér að ...	**Ekki erfitt**	**Svolítið erfitt**	**Miðlungs erfitt**	**Fremur erfitt**	**Gat alls ekki gert**
a. sitja án þess að missa jafnvægið?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
b. standa án þess að missa jafnvægið?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
c. ganga án þess að missa jafnvægið?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
d. flytja þig úr rúmi yfir í stól?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
e. ganga um í hverfinu (u.þ.b. 200 metra)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
f. ganga hratt?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
g. ganga milli hæða upp einn stiga?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
h. ganga upp nokkrar hæðir í stiga?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
i. fara inn í og út úr bíl?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐

7. **Eftirfarandi spurningar eru um getu þína til að nota hendina sem hefur orðið meira fyrir áhrifum heilaslagsins.** ***Spurningarnar eiga við <u>síðastliðnar tvær vikur.</u>***

Hversu erfitt fannst þér að nota hendina, sem varð fyrir meiri áhrifum heilaslagsins, þegar þú ...	**Ekki erfitt**	**Svolítið erfitt**	**Miðlungs erfitt**	**Fremur erfitt**	**Gat alls ekki gert**
a. barst þunga hluti (t.d. fullan innkaupapoka með mat)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
b. snérir hurðarhúni?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
c. opnaðir niðursuðudós eða krukku?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
d. reimaðir skó?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
e. tókst lítinn hlut upp af gólfinu (t.d. smámynt)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐

8. **Eftirfarandi spurningar eru um hvernig heilaslagið hefur mögulega haft áhrif á getu þína til þátttöku í venjubundnum athöfnum, verkum sem eru þýðingarmikil fyrir þig og hjálpa þér í að finna tilgang með lífinu.** ***Spurningarnar eiga við <u>síðastliðnar fjórar vikur.</u>***

Hversu oft hefur geta þín takmarkað þátttöku þína ...	**Aldrei**	**Einstökum sinnum**	**Stundum**	**Oftast**	**Alltaf**
a. í vinnu þinni (launaðri vinnu, sjálfboðavinnu eða annarri vinnu)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
b. í félagslegri virkni?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
c. í þögulli afþreyingu (t.d. handavinnu eða lestri)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
d. í virkri/líkamlegri afþreyingu (t.d. íþróttum, útivist eða ferðalögum)?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
e. í hlutverki þínu sem fjölskyldumeðlimur eða vinur?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
f. í menningarviðburðum (t.d. að fara í leikhús eða á söfn) ?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
g. við að stjórna lífi þínu eins og þú vilt?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐
h. við að hjálpa öðrum?	5 ☐	4 ☐	3 ☐	2 ☐	1 ☐

9. **Bati eftir heilaslag.**

Á kvarðanum 0 til 100, þar sem 100 stendur fyrir fullan bata og 0 stendur fyrir engan bata, hversu mikinn bata hefur þú fengið eftir heilaslagið?*Merktu svar þitt á kvarðann.*

_______ 100 Fullur bati

—

_______ 90

—

_______ 80

—

_______ 70

—

_______ 60

—

_______ 50

—

_______ 40

—

_______ 30

—

_______ 20

—

_______ 10

—

_______ 0 Enginn bati

Forprófun – febrúar 2107

ActivABLES fyrir einstaklinga eftir heilaslag og nánustu aðstandendur þeirra - rannsókn á þróun og mati á notkunargildi

Viðtalsrammi
aðstandendur einstaklings með heilablóðfall

Spurningar:

1. *Gerir maki/einstaklingur æfingar heima ?*
2. *Gerir maki/einstaklingur með heilablóðfall æfingar sjálfur (án þess að hann sé hvattur til þess)?*
3. *Hveturðu maka/einstakling með heilablóðfall til að gera æfingar?*
4. *Hjálparðu maka/einstakling með heilablóðfall til að gera æfingar?*
    a. *Ef þú gerir það – hvernig? Geturðu lýst því nánar?*
    b. *Ef þú gerir það ekki – hvers vegna? Geturðu lýst því nánar?*
5. *Hvaða æfingar finnst honum/henni (maka/einstakling með heilablóðfall) gaman að gera?*
6. *Hvaða æfingar finnst honum/henni erfitt að gera eða gerir hann/hún ekki?*
    a. *Veistu hvers vegna hann/hún gerir ekki æfingar?*
    b. *Hvað myndi hjálpa þér?*
7. *Sérðu fyrir þér að þessi tæki gætu nýst honum/henni til æfingar heima við?*
    a. *Af hverju?*
    b. *Af hverju ekki?*
8. *Áttaðir þú þig á því hvað hann/hún átti að gera með tækjunum?*
9. *Heldur þú að honum/henni hafi þótt þetta skemmtilegt/leiðinleg?*
10. *Heldur þú að honum/henni hafi þótt þetta of erfitt/of auðvelt?*
11. *Heldur þú að þessi tæki séu hvetjandi eða letjandi til að gera æfingar?*
    a. *Af hverju / Hvernig þá?*
12. *Hvernig væri hægt að bæta þessi tæki?- Sérðu eitthvað sem mætti fara betur eða vera öðruvísi?*

Questions:

1. *Does your spouse/relative exercise at home*
2. *Does your spouse/relative exercise by him/herself (without encouragement?)*
3. *Do you encourage your spouse/relative to exercise?*
4. *Do you help your spouse/relative to exercise?*
    a. *If you do, how? Can you describe?*
    b. *If you don´t, why not? – Can you describe?*
5. *What kind of exercises does your spouse/relative like to do?*
6. *What kind of exercises does he/she feel like are difficult to do or doesn´t do at all?*
    a. *Do you know why he/she doesn´t do the exercises?*
    b. *What would help you?*
7. *Do you think these tools could benefit for you spouse/relative to do exercises?*
    a. *Why?*
    b. *Why not?*
8. *Did you realize what your spouse/relative was supposed to do while using the tools?*
9. *Do you think your spouse/relative liked to these exercises ?*
10. *Do you think it was too easy/too difficult for your spouse/relative?*
11. *Do you think these tools could motivate (or not) your spouse/relative to do exercises?*
    a. *Why and how?*
12. *How can we improve these tools? Do you see something we should do differently?*

<u>Forprófun – febrúar 2107</u>

ActivABLES fyrir einstaklinga eftir heilaslag og nánustu aðstandendur þeirra - rannsókn á þróun og mati á notkunargildi

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aðstandendur einstaklings með heilablóðfall

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    a. *Ef þú gerir það – hvernig? Geturðu lýst því nánar?*
    b. *Ef þú gerir það ekki – hvers vegna? Geturðu lýst því nánar?*
5. *Hvaða æfingar finnst honum/henni (maka/einstakling með heilablóðfall) gaman að gera?*
6. *Hvaða æfingar finnst honum/henni erfitt að gera eða gerir hann/hún ekki?*
    a. *Veistu hvers vegna hann/hún gerir ekki æfingar?*
    b. *Hvað myndi hjálpa þér?*
7. *Sérðu fyrir þér að þessi tæki gætu nýst honum/henni til æfingar heima við?*
    a. *Af hverju?*
    b. *Af hverju ekki?*
8. *Áttaðir þú þig á því hvað hann/hún átti að gera með tækjunum?*
9. *Heldur þú að honum/henni hafi þótt þetta skemmtilegt/leiðinleg?*
10. *Heldur þú að honum/henni hafi þótt þetta of erfitt/of auðvelt?*
11. *Heldur þú að þessi tæki séu hvetjandi eða letjandi til að gera æfingar?*
    a. *Af hverju / Hvernig þá?*
12. *Hvernig væri hægt að bæta þessi tæki?- Sérðu eitthvað sem mætti fara betur eða vera öðruvísi?*

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    a. *If you do, how? Can you describe?*
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mars 2018

Kynning á rannsókninni

„ActivABLES fyrir einstaklinga eftir heilaslag og nánustu aðstandendur þeirra.

Rannsókn á notkunargildi og möguleikum í þjálfun í heimahúsum."

Kæri viðtakandi

Undanfarin tvö ár hefur farið fram þróun á ActivABLES-endurhæfingartækjum fyrir einstaklinga með afleiðingar heilaslags. Um er að ræða samnorrænt verkefni, sem einstaklingar með afleiðingar heilaslags, aðstandendur og fagfólk á Íslandi, í Svíþjóð og Finnlandi hafa unnið að. Nú er þróun á lokastigi og tímabært að gera rannsókn á því hvernig endurhæfingartækin nýtast einstaklingum eftir heilaslag sem búa í heimahúsum. Áður hefur farið fram stutt forprófun á endurhæfingartækjunum meðan á þróunarferlinu stóð.

Einstaklingar með afleiðingar heilaslags geta glímt við margs konar vandamál sem m.a. felast í minni hreyfifærni og sjálfsbjargargetu. Endurhæfing, sem felur í sér sértækar æfingar og líkamsþjálfun, eykur getu einstaklingsins og almenn lífsgæði og talið er að endurhæfing eftir heilaslag sé oft á tíðum ævilangt ferli. Eftir útskrift af endurhæfingarstofnun eiga einstaklingar sem hafa fengið heilaslag gjarnan erfitt með að halda áfram að gera æfingar og viðhalda líkamlegri virkni og áhuga á þjálfun. Maki eða annar aðstandandi hafa oft miklu hlutverki að gegna við að hvetja viðkomandi til að ná góðum árangri við æfingar sem skilar sér í aukinni hreyfifærni og sjálfsbjargargetu.

Þessi hluti rannsóknar okkar beinist að notkun ActivABLES-endurhæfingartækjanna og verður **einstaklingum með afleiðingar heilaslags og búa í heimahúsum boðin þátttaka ásamt einum aðstandanda**. Skilyrði fyrir þátttöku einstaklings með afleiðingar heilaslags er að hann hafi minnkaða hreyfigetu og geti tjáð sig. Skilyrði fyrir þátttöku maka/aðstandanda er að hann hafi ekki skerta hreyfifærni.

Ef þú hefur áhuga á þátttöku, færðu þetta upplýsingabréf um hvað þátttaka felur í sér.

Markmið rannsóknarinnar er að kanna notkunargildi og möguleika endurhæfingartækjanna til þjálfunar í heimahúsum (með stuðningi aðstandenda) með það að markmiði að auka líkamlega virkni, hreyfifærni og sjálfsbjargargetu einstaklinga með afleiðingar heilablóðfalls. Ændurhæfingartækin miða að þjálfun á jafnvægi og hreyfifærni í efri útlimum en einnig er þeim ætlað er að vera hvetjandi til meiri líkamlegrar virkni. Þátttaka felur í sér að einstaklingar með afleiðingar heilaslags taka þátt í **fjögurra vikna þjálfun** með endurhæfingartækjunum með aðstoð aðstandanda. Þegar þjálfunartímabilinu eru lokið verða tekin einstaklingsviðtöl um gildi ActivABLES-tækjanna og möguleika þeirra til frekari þróunar. Þekking og reynsla þátttakenda mun hjálpa okkur við áframhaldandi þróun tækjanna sem síðan vonandi leiðir til bættrar endurhæfingar einstaklinga eftir heilaslag.

Ef þú ert einstaklingur með afleiðingar eftir heilaslag, felst þátttaka þín í því að þú samþykkir:

a) að þátt í prófum á hreyfifærni og svara spurningalistum um heilsufarslegt ástand þitt og áhugahvöt til hreyfingar,
b) að nota ActivABLES-tækin í fjórar vikur, a.m.k. 30 mín daglega fimm sinnum í viku,
c) að ganga með hreyfimæli sem mælir hreyfingu þína þrisvar sinnum, í eina viku í senn (viku áður en þjálfunin hefst, í viku á meðan á þjálfuninni stendur og í viku að lokinni þjálfun),
d) að taka þátt í einstaklingsviðtali að loknu þjálfunartímabili.

Ef þú ert aðstandandi, felst þátttaka þín í því að þú samþykkir:

a) að aðstoða við notkun ActivABLES-tækjanna í fjórar vikur,
b) að skrá niður notkun á endurhæfingartækjunum og upplifun ykkar af notkun á þeirra á sérsniðin dagbókarform,
c) að taka þátt í einstaklingsviðtali að loknu þjálfunartímabili.

Nánari lýsing á þátttöku

Undirritaðar, Steinunn A. Ólafsdóttir sjúkraþjálfari og Ingibjörg Bjartmarz hjúkrunarfræðingur, munu hafa samband við þig símleiðis og veita þér frekari upplýsingar um verkefnið. Ef þú hefur áhuga á þátttöku verður ákveðinn tími fyrir fyrstu heimsókn. **Allir þættir rannsóknarinnar fara fram á heimili þínu og má gera ráð fyrir að rannsóknin taki um sex vikur með mælingunum sem framkvæmdar verða fyrir og eftir þjálfunartímabilið.**

1. Í fyrstu heimsókn koma Ingibjörg og Steinunn og fara yfir formsatriði og segja frá ActivABLES-tækjunum. Steinunn mun framkvæma mælingar á jafnvægi, göngugetu og færni í efri útlimum en auk þess færð þú afhenta þrjá spurningalista um áhrif heilaslagsins á líf þitt, öryggi í tengslum við jafnvægi og áhrifahvöt til æfinga. Þú færð einnig hreyfimæli sem festur er á læri þitt sem þú ert beðinn um að hafa í eina viku. Áætlaður tími fyrir þessa heimsókn er um **60-90 mínútur.**

2. Um það bil viku síðar koma Ingibjörg og Steinunn á nýjan leik og þá með tvo erlenda rannsakendur (frá Svíþjóð og Finnlandi) sem hafa verið að vinna að þróun endurhæfingartækjanna. Farið verður ítarlega yfir þau endurhæfingartæki sem þú munt nota til þjálfunar næstu fjórar vikurnar og útskýrt til hvers er ætlað af þér og aðstandanda þínum á meðan þjálfunartímabilið stendur yfir. Áætlaður tími heimsóknarinnar er um **90 mínútur**.

3. Um miðbik þjálfunartímabilsins mun rannsakandi hafa samband við þig og koma með hreyfimæli sem þú þarft að hafa á öðru lærinu í eina viku. Hreyfimælirinn verður sóttur að viku liðinni. Áætlaður tími fyrir ásetningu mælisins er um **15 mínútur**.

4. Þegar notkun á endurhæfingartækjunum hefur staðið yfir í fjórar vikur, koma Steinunn og Ingibjörg til að sækja endurhæfingartækin og framkvæma sömu færnimælingar og í fyrstu heimsókn. Einnig verða afhentir sömu spuringalistar og hreyfimælir til að hafa á læri í eina viku. Áætlaður tími fyrir þessar heimsókn er um **60-90 mínútur.**

5. Eftir þjálfunartímabilið munu rannsakendur taka viðtöl við þig og aðstandanda þinn í sitt hvoru lagi. Viðtölin munu beinast að upplifun ykkar á notkun endurhæfingartækjanna og verður lögð áhersla hvernig ykkur fannst ganga, hvaða þættir virka hvetjandi fyrir hreyfingu og hvað mætti bæta eða vera öðruvísi. Við viljum biðja ykkur um að vera ófeimin við að segja hvað ykkur finnst og hvað mætti betur fara. Viðtölin verða hljóðrituð og er áætlaður tími fyrir viðtölin um **45-60 mínútur.**

6. Að viku lokinni, mun rannsakandi koma og sækja hreyfimælinn og spurningalistana.

Hvenær sem er á rannsóknartímabilinum verður hægt að hafa samband við rannsakendur í síma og/eða tölvupósti. Rannsakendur munu einnig hringja í þig á tímabilinu til að kanna hvort einhver vandamál hafi komið upp. Tækjabúnaðurinn er frekar hrár þar sem tækin eru á frumstigi og því er mikilvægt að meðhöndla þau samkvæmt leiðbeiningum.

Við framkvæmd þessarar rannsóknar verður að gæta þess að fylgja fyrirmælum og taka tillit til heilsu þinnar t.d. ef þú er slappur/slöpp eða veikist á tímabilinu. Ef þú þreytist er sjálfsagt að gera hlé og halda áfram þegar þú treystir þér til en mikilvægt er að skrá það í dagbókina.

Þagnarskylda

Nafnleynd er heitið og trúnaðar verður gætt þannig að hvorki nafn þitt eða aðstandanda, né önnur persónuauðkenni munu koma fram í niðurstöðum eða umfjöllun um þær, þar með talið erindum og tímaritsgreinum. Allar persónurekjanlegar upplýsingar verða dulkóðaðar og greiningarlykilinn geymdur á öruggum stað. Einungis rannsakendur hafa aðgang að þeim upplýsingum sem skráðar verða og þeim er óheimilt að nota upplýsingarnar til annars en tilgangur rannsóknarinnar segir til um. Öllum rannsóknargögnum verður eytt að lokinni úrvinnslu, þar með talið upptökum úr viðtölunum. Því verður ekki hægt að rekja niðurstöður til ákveðinna einstaklinga.

Þátttaka í rannsókninni hefur hverfandi áhættu í för með sér. Þér ber engin skylda til að taka þátt í þessari rannsókn. Þú getur hætt þátttöku hvenær sem er án eftirmála og án áhrifa á þá heilbrigðisþjónustu sem þú færð. Persónulegur ávinningur getur hlotist af betri líkamlegri líðan, mögulega færni, en þjálfunartímabilið er einungis fjórar vikur þannig að það er ólíklegt að meiriháttar framfarir verði í færni og hreyfigetu. Hins vegar eru líkur á því að aukin þekking fáist um gildi endurhæfingartækjanna til notkunar í heimahúsum hjá einstaklingum eftir heilaslag.

Rannsóknin hefur hlotið samþykki Vísindasiðanefndar og verið tilkynnt til Persónuverndar. Ekki verður greitt fyrir þátttöku í rannsókninni.

Með fyrirfram þakklæti.

Fyrir hönd rannsóknarhópsins

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Ef þú hefur spurningar um rétt þinn sem þátttakandi í þessari vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til rannsakenda eða Vísindasiðanefndar, Borgartúni 21- 4. hæð, 105 Reykjavík; Sími: +354 5517100, tölvupóstur: vsn@vsn.is.

Upplýst samþykki fyrir þátttöku í rannsókninni

*„ActivABLES fyrir einstaklinga með afleiðingar heilaslags
og nánustu aðstandendur þeirra.
Rannsókn á notkunargildi og möguleikum í þjálfun í heimahúsum.“*

Kynningarbréf og upplýst samþykki fyrir þessari rannsókn, er beinist *að þróun ActivABLES-endurhæfingartækjanna*, eru í tvíriti og þátttakandi mun halda eftir eintaki af hvoru tveggja. Kynningarbréf er jafnframt hluti upplýsts samþykkis.

Mér hefur verið kynntur tilgangur þessarar vísindarannsóknar og í hverju þátttaka mín er fólgin. Ég staðfesti hér með undirskrift minni að ég hef lesið upplýsingarnar um rannsóknina sem mér voru afhentar. Ég hef fengið tækifæri til að spyrja spurninga um rannsóknina og fengið fullnægjandi svör og útskýringar á atriðum sem mér voru óljós. Ég hef af fúsum og frjálsum vilja ákveðið að taka þátt í rannsókninni. Mér er ljóst, að þó ég hafi skrifað undir þessa samstarfsyfirlýsingu, get ég stöðvað þátttöku mína hvenær sem er án útskýringa og án áhrifa á þá heilbrigðisþjónustu sem ég á rétt á í framtíðinni.

Mér er ljóst að rannsóknargögnum verður eytt að rannsókn lokinni og eigi síðar en fimm árum eftir úrvinnslu rannsóknargagna.

Ég samþykki þátttöku.

Dagsetning: ___________________________

____

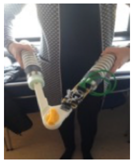
Þátttakandi (nafn og kennitala)

____

Rannsakandi

Ef þú hefur spurningar um rétt þinn sem þátttakandi í þessari vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til rannsakenda eða Vísindasiðanefndar, Borgartúni 21- 4. hæð, 105 Reykjavík; Sími: +354 5517100, tölvupóstur: vsn@vsn.is.

ActivABLES

5.apríl 2018	Hvaða æfingar gerði aðstandandi þinn í dag ?	Hversu lengi stóðu æfingar (ca í mín.) og hversu oft yfir daginn?	Hvernig gekk að gera æfingarnar (0-10)?	Hvað gekk vel? Hvað gekk illa?	Þurftir þú að aðstoða við æfingarnar? Ef já, við hvað?	Þurftir þú að hvetja aðstandanda þinn til að gera æfingar?	Til slagbola: Hversu léttar / erfiðar fannst þér æfingarnar vera (0-10)?
 jafnvægisplata							
 prik							

Hvernig líkaði þér við tónlistina ?

Merktu við á línuna (0 merkir mjög illa og 10 merkir mjög vel) 0 ------- 1 ------- 2 ------- 3 ------- 4 ------- 5 ------- 6 ------- 7 ------- 8 ------- 9 ------- 10

Hvernig fannst þér tónlistin virka? Var hún við hæfi?

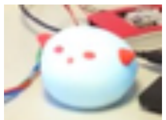
Hvernig líkaði þér við leikina ?

Merktu við á línuna þar sem 0 merkir mjög illa og 10 merkir mjög vel 0 ------- 1 ------- 2 ------- 3 ------- 4 ------- 5 ------- 6 ------- 7 ------- 8 ------- 9 ------- 10

Hvernig fannst þér leikirnir virka?

ActivABLES

	Hvernig gekk að fylgja eftir fyrirmælum / nota smáforritið	Þurftir þú að aðstoða við notkun á smáforritinu? Ef já, við hvað?	Annað sem þú vilt taka fram
 STARR hundur			

	Fylgdist aðstandandi þinn með framgangi þjálfunar með þessum úrræðum? Ef já, hvernig?	Fannst þér þessi úrræði virka hvetjandi / letjandi fyrir aðstandanda þinn?	Annað sem þú vilt taka fram
 Ljósatré			
 Ljósafés			

Eitthvað sem þú vilt taka fram eftir daginn?

ActivABLES

Blað í lokin með spurningum:

Hver er heildarupplifun þín af notkun maka þíns á hanskanum?

Telur þú að virknihanskinn hafi virkað hvetjandi fyrir maka þinn til að gera æfingar?

Telur þú að virknihanskinn gæti virkað til æfinga til lengri tíma? Ef ekki, hvernig þarf hann að vera öðruvísi til að hann virki?

Prófun á ActivABLES– vor 2108

Viðtalsrammi – Slagþoli

1. *Hvernig fannst þér að taka þátt í þessari rannsókn? Hvað varð til þess að þú ákvaðst að taka þátt í þessari rannsókn?*
2. *Gerðir þú æfingar áður?*
    a. *Af hverju? (aðrir segja að ég eigi að gera þær, gaman, ávinningur, samviskubit?)*
    b. *Af hverju ekki? (sé ekki ástæðu/tilgang, tímaeyðsla)*
3. *Hvernig finnst þér hafa gengið að gera æfingar síðustu fjórar vikurnar (nota dagbókina)?*
4. *Hefur þú náð að fylgja eftir æfingaprógrammi fram á síðasta dag? Minnkaði áhuginn þegar leið á þjálfunartímann eða var alltaf jafn spennandi að gera æfingarnar?*
5. *Fannst þér tækin/æfingarnar vera hvetjandi fyrir þig til að halda áfram? Fannst þér tækin/æfingarnar ná að auka áhuga þinn til að gera æfingar?*
6. *Hvaða æfingar/tæki kveiktu mestan áhuga hjá þér?*
    a. *Hvað var það við æfinguna/tæki sem kveikti áhugann?*
    b. *Hefði þetta höfðað til þín fyrir heilaslagið?*
7. *Hvaða æfingar/tæki fannst þér kveikja minnsta áhugann?*
    a. *Hvað var það við æfinguna/tæki sem þér þótti óspennandi?*
8. *Voru einhverjar æfingar/tæki sem þér fannst meira erfiðara/léttara að nota en önnur?*
    a. *Hvað var það við æfinguna/tækið sem þér þótti erfitt?*
9. *Hefur þú orðið var við að þú notir handlegginn öðruvísi en áður?*
10. *Hefur þú orðið var við breytingar á jafnvægi?*
11. *Hefur þú orðið var við breytingar á göngugetu/úthaldi/?*
12. *Finnst þér hreyfimynstur/athafnir þínar hafa breyst á þessum fjórum vikum? Gerir þú eitthvað dags daglega sem þú gerðir ekki mikið af áður en þú hófst að nota tækin?*
13. *Líður þér á einhvern hátt öðruvísi eftir að hafa tekið þátt í þessum æfingum? (verkir, vanlíðan)*

14. *Sérðu fyrir þér að þessi tæki gætu nýst þér til æfinga heima við til frambúðar?*
    a. *Af hverju?*
    b. *Af hverju ekki?*
15. *Sérðu fyrir þér að þessi tæki gætu nýst þér til æfinga heima við? / sérðu tilgang með notkun tækjanna í víðara samhengi þess á ná meiri heilsu/viðhalda heilsu ?*
    a. *Hvernig þá?*
    b. *Af hverju ekki?*
16. *Hvernig væri hægt að bæta þessi tæki?- Sérðu eitthvað sem mætti fara betur eða vera öðruvísi?*
17. *Hvernig væri hægt að bæta það hvernig við höfum lagt upp með notkun á tækjunum?*

Þakka fyrir þátttökuna

Er eitthvað sem þú vilt segja að lokum?

Prófun á ActivABLES– vor 2108

Viðtalsrammi

aðstandendur einstaklings sem hefur fengið heilaslag

1. *Hvernig hefur þér fundist aðstandanda þínum ganga að gera æfingar síðustu fjórar vikurnar (nota dagbókina)?- fara yfir öll tækin*
2. *Hefur aðstandandi þinn náð að fylgja eftir æfingaprógrammi fram á síðasta dag? Breyttist áhuginn þegar leið á þjálfunartímann? Hvernig?*
3. *Hvað getur þú sagt mér með áhuga aðstanda þíns á því að gera æfingar með þessum tækum? Þurftir þú að hvetja maka þinn til að gera æfingar með tækjunum? Alltaf jafn mikið? (nota dagbók)*
4. *Þurftir þú að hjálpa aðstandanda þínum til að gera æfingar/nota tækin?*
    a. *Ef þú gerir það – hvernig? Geturðu lýst því nánar?*
    b. *Ef þú gerir það ekki – hvers vegna? Geturðu lýst því nánar?*
    c. *Náði aðstandandi þinn tökum á æfingunum/tækjunum eða þurfti hann alltaf aðstoð?*
5. *Voru einhverjar æfingar/tæki sem kveiktu meiri áhuga hjá aðstandanda þínum á að nota en önnur?*
    a. *Hvað var það við æfinguna/tæki sem kveikti áhugann?*
6. *Voru einhverjar æfingar/tæki sem aðstandanda þínum fannst erfiðara/léttara að nota en önnur?*
    a. *Hvað var það við æfinguna/tækið sem honum þótti erfitt?*
7. *Finnst þér hreyfimynstur/athafnir aðstandanda þíns hafa breyst á undanförnum vikum? Gerir hann eitthvað dags daglega sem hann gerði ekki eða minna af áður?*
    a. *Notar hann handlegginn öðruvísi?*
    b. *Skynjar þú breytingu á jafnvægi?*
    c. *Gengur hann meira en áður? Fer út?*
8. *Sérðu fyrir þér að þessi tæki gætu nýst honum/henni til æfingar heima við til frambúðar?*
    a. *Af hverju?- Hvernig?*
    b. *Af hverju ekki?*

9. *Hver er heildarupplifun þín af notkun aðstandanda þíns á tækjunum?*
10. *Hvernig væri hægt að bæta þessi tæki?- Sérðu eitthvað sem mætti fara betur eða vera öðruvísi?*
11. *Hvernig væri hægt að bæta það hvernig við höfum lagt upp með notkun á tækjunum?*

Þakka fyrir þátttökuna

Er eitthvað sem þú vilt segja að lokum?