

# The use of eHealth in rehabilitation after stroke Wentink, M.M.

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## The use of eHealth in rehabilitation after stroke

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## The use of eHealth in rehabilitation after stroke

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## General introduction



## **Definition and epidemiology**

Stroke, or a cerebrovascular accident (CVA), occurs when a clot in the blood vessel blocks the blood flow to the brain cells (ischemic stroke) or when a blood vessel in the brain breaks or ruptures (hemorrhagic stroke). Subsequently, brain cells are deprived of oxygen and glucose, causing damage to the brain tissues [1]. Abilities controlled by these brain tissues, such as memory and/or speech control, can be lost. As a consequence, persons who survive a stroke can face long-term disability with a considerable impact on their lives and those of their relatives [2].





After ischemic heart disease, stroke is the second leading cause of death in the world [3]. According to the World Stroke Organization (WSO), 1 in 6 people worldwide will have a stroke in their lifetime, 15 million people worldwide suffer a stroke each year and 5.8 million people die from it [4]. In the Netherlands, the incidence of stroke was estimated to be 42.300 in 2016 and the prevalence in that year was estimated to be 320.000 in the community based population [5].

Overall, stroke incidence has mainly shown either declining time trends or stable rates in high income countries [6]. On the other hand, the absolute number of stroke is expected to increase because of the ageing population and declining mortality rates, largely as a result of better control of high blood pressure and faster and better treatment (e.g. intravenous thrombolytic therapy and stroke services) [7;8]. Consequently, the overall stroke burden across the globe, in terms of the number of people affected by or who remain disabled from stroke, has increased [9]. Estimates from the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD 2010) ranked stroke as the disease with the third-highest burden in disability, expressed in disability-adjusted life-years (DALY's), and the burden is projected to further rise from around 38 million DALYs globally in 1990 to 61 million DALYs in 2020 [10].

#### Consequences of stroke regarding functioning, disability and health

Stroke can have a broad and significant impact on a persons' physical, cognitive and social functioning. Especially cognitive impairment is common after stroke. A cohort study among 395 patients in the Netherlands showed that more than half of the stroke patients (66 percent) suffer from cognitive impairment two months post-stroke [12]. Although improvement is seen at six months post-stroke (prevalence of 50 percent), cognitive impairment still remains highly prevalent up to 6 months after stroke [12]. This often causes lifelong problems in activities of daily life and participation in society [11].

The International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO) is a helpful framework to classify a person's functioning and disability and plan delivery of care (Figure 1) [13]. The ICF is based on the biopsychosocial model and provides a coherent view of different perspectives of health: biological, individual and social. As the diagram indicates, in the ICF disability and functioning are viewed as outcomes of interactions between *health conditions* (diseases, disorders and injuries) *personal* [14;15] and *contextual factors* [13]. Because the ICF is very extensive, disease specific core sets (ICF Core Sets) have been developed for a number of chronic health conditions, including stroke, in order to provide an overview of categories of post-stroke disability [16]. The Brief ICF Core Set represents a selection of ICF domains or categories which can serve as a minimal standard for reporting of functioning and health in clinical studies and clinical encounters (Table 1-3) [17].



**Figure 2.** The model of the International Classification of Functioning, Disability and Health (ICF) shows the relationship between the different ICF components [18].

**Table 1.** International Classification of Functioning, Disability and Health (ICF) – categories of the components included in the Brief ICF Core Set for Stroke.

Body functions		
b110 Consciousness functions b114 Orientation functions b140 Attention functions b144 Memory functions b167 Mental functions of language b730 Muscle power functions		
Body structures		
s110 Structure of brain s730 Structure of upper extremity		
Activities and participation		
d310 Communicating with – receiving – spoken messages d330 Speaking d450 Walking d510 Washing oneself d530 Toileting d540 Dressing d550 Eating		
Environmental factors		
e310 Immediate family e355 Health professionals e880 Health services systems and policies		

#### Medical management after stroke

Each year approximately 9.600 people in the Netherlands die because of stroke [19]. Those who survive a stroke are treated with acute care in a hospital (intensive care, medium care, stroke unit and/or neurology ward). The stay in the hospital is generally short and ends when the patient is medically stable [20]. Afterwards, about 60-65% is discharged to their homes. If needed, treatment can be provided by health professionals close to home (primary care) or in a rehabilitation center (outpatient care) [21]. For 25-30% of the patients, mostly older patients with multiple impairments, a nursing home for specialized geriatric rehabilitation or long stay is required. Ten percent, often young patients with potential for recovery and higher participation goals, are eligible for rehabilitation in a specialized rehabilitation center [22]. A flow of the patient journey after stroke is presented in Figure 3.



**Figure 3.** Patient journey after stroke describing the possible pathways of a stroke patient through the healthcare system in the Netherlands.

## Specialized medical rehabilitation after stroke

Approximately 3.200 patients in the Netherlands use specialized medical rehabilitation stroke care yearly [22]. Medical specialist stroke rehabilitation is a comprehensive, multidimensional process including interventions that aim to facilitate restitution or substitution of limitations in impairment, activity or participation caused by stroke [23]. Rehabilitation typically follows a process of assessment of needs, goal setting, therapy and reassessment [24]. This process involves the patient, informal caregivers and various health care providers (e.g. physicians, physical and occupational therapists, speech-language therapists, psychologists and social worker). For each patient, a tailored treatment plan is defined, dependent on the type and severity of the impairments and the patients' goals. The length of these clinical pathways differs from 3 till 26 weeks [20]. After the rehabilitation period, about 90% of the patients are able to live independently [21]. The costs related to medical specialized rehabilitation were estimated at €147 million in 2015 [25]. The general health care costs for stroke were estimated at nearly €2.3 billion euros in 2011, 2.5% of the total healthcare costs [26]. As a result, stroke is one of ten most expensive diseases in the Netherlands.

#### eHealth in rehabilitation care (eRehabilitation)

Information and Communication Technology (ICT) is increasingly used in health care in general (eHealth) and in rehabilitation (eRehabilitation). eRehabilitation is applied for a number of (potential) purposes: 1) support of self-management and self-ownership [27], 2) improving access for (stroke) patients to health care services as well as bridging between services [28;29;30], 3) increasing the doses of treatment and more effective distribution

in time [27], 4) monitoring compliance and progress [27], 5) structuring treatment and collecting treatment related data, 6) offering opportunities for more cost-effective interventions in the future and coping with ageing society [31;32] and 7) fulfilling a need in the digitizing society, patients and health care. With the different goals for eHealth, the nature of the technology employed in health care may vary largely, and there is a demand for their classification. An example of such a classification is published in the 'Co-creation eHealthbook' (Table 2) [33].

**Table 2.** Classification of eHealth applications for each technology [Wentzel, 2014; translated from Dutch].

Technology	Explanation
Web applications and portals	Applications that are offered to users via a web browser such as patient portals or educational portals for health professionals.
Mobile applications	Applications that are offered via a mobile device such as a smartphone or tablet.
Electronic patient records	Systems of a mostly medical-administrative nature in which healthcare providers register medical patient data within their own care organization.
Health-sensors and wearable devices	A category of devices that are often used in the home situation of patients to measure (vital body) functions, collect the results and possibly pass them on to a health professional.
Video communication (telecommunication)	Applications in which a visual dimension is added to the usual forms of telecommunication with the aim to strengthen contact between the care recipient and the care provider and to increase the communication possibilities.
Domotics	A general term for the application of electronics for home automation. It is often a combination of environment-aware sensors and actuators (devices that can influence the environment) with which the living environment in a home can be regulated or things in the home can be automatically operated.
Robotics	Machines that can perform and take over certain tasks such as offering structure in the day.
Medical integration networks	Electronic networks on which medical information is exchanged, such as medication data and prescriptions or radiological images.
General integration networks	Electronic networks of a more general nature for the exchange of data between cooperating (business) partners, for example about orders.
Business intelligence and big data	Business intelligence systems are focused on analyzing structured and unstructured data to provide information that can be used for decision support. If this is done within the field of care, this is called 'medical intelligence'. An analysis of very large amounts of data from different sources is called 'big data'.
Serious gaming	Use of game technology by applying a game element to 'serious matters', such as exercises in the context of psychological or physical treatment.

In addition, Krijgsman et al. 2012 describes three dimension to structure eHealth initiatives: 1) *the setting of the care process in which the eHealth application is used* (e.g. in the public health domain, as part of a care process, or in the support of a care process); 2) *the persons who use the eHealth application* (e.g. for health care professionals, for communication between patient and health care professional or patients between themselves; 3) *the technological basis of the eHealth application* (e.g. which platform or application type) [34].

### Application of eRehabilitation after stroke

An established application of eHealth in stroke care management is *video communication*. Video patient-practitioner conferences are recommended in guidelines for acute stroke management in order to enroll a greater number of patients in therapies (e.g. correct diagnosis, promptly decide thrombolytic therapy and guide transfers to appropriate centers) [28;35]. More recently, video communication is applied for continuity of care [28]. Interactive patient-practitioner video consultations, as well as web portals, are used for both medical and educational services and stroke secondary prevention and monitoring [28].

In addition, 'off the shelve' *mobile and web applications* (e.g. exercises to train cognitive, speech and/or physical functioning) [36;37], *video games* (e.g. Nintendo Wii and Balance Board, Microsoft Kinect, etc.) [38] and *health sensors* (e.g. Fit-Bit, smartwatch, etc.) [39], developed for commercial purposes, are applied for stroke rehabilitation. Several applications have been developed for therapy purposes in general (e.g. Physitrack, Minddistrict, etc.) or for stroke specific (i.e. Care4Stroke, etc.). These technologies, mostly used on the initiative of patients and practitioners as a supplement to traditional care [28], are being applied in order to increase doses of treatment, monitor compliance and/or improve rehabilitation outcomes. *Robotics*, like exoskeleton types, also deliver high-intensity training for stimulation of motor disorders caused by stroke [40].

Furthermore, *electronic patient records* and *general/medical integration networks* have facilitated data-collection and data-analysis of aspects of stroke care in past years (e.g. team response time and time to other specific aspects of the care protocol, treatment outcomes, etc.). Registering accurate data and continue comparing data with other medical centers will further improve quality of stroke care and assist to identify patients who are eligible for clinical trials in the stroke population in the future [28].

#### Evidence for effectiveness of stroke eRehabilitation

This thesis concerns research on cognitive and comprehensive eRehabilitation interventions in patients with stroke. In general, in medical specialist rehabilitation, comprehensive multidisciplinary eRehabilitation that covers multiple aspects of stroke management (e.g. physical and cognitive functioning) is highly recommended and might become available in the future [28], but is not yet studied in clinical trials.

The effects of cognitive eHealth interventions on cognitive functioning in stroke patients are summarized in one meta-analyses of Laver et al. (2017) [41]. The aim of this meta-analyses was to determine the efficacy of virtual reality compared with an alternative intervention or no intervention on multiple outcome measures (i.e. upper limb function and activity, gait and balance, global motor function, activity limitation, participation restriction, quality of life and adverse events), including cognitive functioning. They searched different databases (e.g. Cochrane Stroke Group Trials Register (April 2017), CENTRAL, MEDLINE, Embase), trials registries and reference lists. A total of 72 studies (n=2470) were included, from which only three studies evaluated the effect of virtual reality interventions on cognition. These three trials [42;43;44] did not allow analysis, so that there are no results available on the effect of virtual reality on cognitive functioning. Other meta-analysis or systematic reviews of eHealth interventions on cognitive functioning in stroke patients are absent.

However, recently two RCTs addressing this question were performed [45;46]. Faria et al. (2016) studied the potential benefits of virtual reality based cognitive rehabilitation after stroke through simulated activities of daily living as compared to conventional therapy only [45]. The intervention involved a virtual simulation of a city where memory, attention, visuo-spatial abilities and executive functions tasks are integrated in the performance of several daily routines. A between groups analysis showed significantly greater improvements in global cognitive functioning, attention and executive functions in patients with stroke when comparing virtual reality to conventional therapy.

Van de Ven et al. (2017) investigated whether computer-based cognitive flexibility training improved subjective cognitive functioning and quality of life after stroke [46]. In the trial, adults ( $30\pm80$  years old) who had suffered a stroke within the last 5 years were assigned to either an intervention group (n = 38), active control group (i.e., mock training; n=35), or waiting list control group (n=24). It was found both training groups improved on training tasks and all groups improved on executive functioning tasks, attention, reasoning, and psychomotor speed. However, the amount of improvement in executive and general cognitive functioning in the intervention group was similar to that of both control groups (active control and waiting list). Therefore, this improvement was likely due to training-unspecific effects. Overall, there is a lack of studies assessing the effect of eHealth intervention for cognitive functioning and quality of life after stroke.

## Uptake of stroke eRehabilitation

Uptake of eRehabilitation can be described as a planned process and systematic introduction of eRehabilitation with the aim that it is given a structural place in rehabilitation care [47]. According to the theory of Grol and Wensing (2004), implementation can be influenced by several barriers and facilitators at different levels: Innovation, Individual health care professional, Individual Patient, Social context, Organizational context and Political and economic context [48]. For instance, for eRehabilitation a potential barrier at the level of the Innovation might be the variability in resources between different virtual rehabilitation networks [28]. Moreover, eHealth interventions often do not match with the requirements of intended users (e.g. patients and health care professionals), impairing the adoption of eHealth interventions [49;50]. At the level of the Individual health care professional, there are barriers to technology adoption related to the absence of a composite set of knowledge and skills among health care professionals regarding the use of eHealth [51]. Subsequently, there is a demand for new knowledge, skills and attributes among (future) health care professionals and new initiatives in education of health professions [52].

## **Outline of this thesis**

Given the lack of knowledge the aims of this thesis are to:

- I. Evaluate the outcome and process of an eHealth intervention for cognitive stroke rehabilitation.
- II. Explore the (readiness for) use of eHealth among patients in rehabilitation.
- III. Investigate the requirements of patients, informal caregivers, health professionals, teachers and students regarding the use of eHealth interventions in stroke rehabilitation.

*Chapter 2* presents a randomized controlled trial (RCT) to determine the effect of an online serious brain training programme on multiple aspects of cognitive functioning in comparison to a control intervention in patients with self-perceived cognitive impairments 12–36 months after stroke (aim I).

*Chapter 3* describes the adherence of patients with the online brain training programme by comparing two types of health professionals' supervision (aim I).

In *Chapter 4* the perspective of patients on use of eHealth in rehabilitation care is described by exploring their usage of common devices and investigating their preferences regarding usage of these devices in rehabilitation care (aim II).

*Chapter 5* describes the results of a qualitative study, in which the requirements of patients with stroke, their informal caregivers and health professionals for the accessibility, usability

and content of comprehensive eRehabilitation after stroke were identified (aim III). The identified requirements were prioritized in *Chapter 6* by using a quantitative study design in order to assess which requirements found in the qualitative research are most important (aim III).

*Chapter 7* provides an overview of the requirements (barriers and facilitators) according to students and teachers for the uptake of eHealth in curricula of two allied health professions, based on qualitative focus groups (aim III).

In *Chapter 8* a discussion is conducted on/elaborates the overall findings and recommendations are provided.

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The effects of an 8-week computerbased brain training programme on cognitive functioning, QoL and self-efficacy after stroke

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## Abstract

Cognitive impairment after stroke has a direct impact on daily functioning and guality of life (OoL) of patients and is associated with higher mortality and healthcare costs. The aim of this study was to determine the effect of a computer-based brain training programme on cognitive functioning. OoL and self-efficacy compared to a control condition in stroke patients. Stroke patients with self-perceived cognitive impairment were randomly allocated to the intervention or control group. The intervention consisted of an 8-week brain training programme (Lumosity Inc.®). The control group received general information about the brain weekly. Assessments consisted of a set of neuropsychological tests and guestionnaires. In addition, adherence with trained computer tasks was recorded. No effect of the training was found on cognitive functioning. Ool, or self-efficacy when compared to the control condition, except for very limited effects on working memory and speed. This study found very limited effects on neuropsychological tests that were closely related to trained computer tasks, but no transfers to other tests or self-perceived cognitive failures, OoL or self-efficacy. These findings warrant the need for further research into the value of computer-based brain training to improve cognitive functioning in the chronic phase after stroke

#### Introduction

The crude incidence of stroke in Western countries in the past decades is estimated to be 1.14 cases per 1000 persons per year for first ever strokes and 3.5 cases per 1000 persons per year for all strokes (Zhang et al., 2012). About 20–50% of the patients die within the first month (Truelsen et al., 2006). For the patients who survive, the disease impact is considerable, with the estimated proportions of patients with cognitive impairments being 50% directly after stroke (Douiri, Rudd, & Wolfe, 2013) and about 30% three years after a first stroke (Patel, Coshall, Rudd, & Wolfe, 2003). Cognitive impairment has a direct impact on daily functioning and quality of life (QoL) of patients and their relatives (Paker, Buğdaycı, Tekdöş, Kaya, & Dere, 2010). It is also associated with greater rates of institutionalisation (Pasquini, Leys, Rousseaux, Pasquier, & Henon, 2007), higher mortality (Tatemichi et al., 1994) and higher healthcare costs (Claesson, Lindén, Skoog, & Blomstrand, 2005).

Cognitive rehabilitation after stroke is usually based on specific learning strategies with differences between compensatory approaches: (1) focused on learning strategies to improve performance on cognitive tasks and restitution-based approaches, or (2) focused on training and stimulation of impaired cognitive functions for recovery. Among this last approach, computer-based cognitive rehabilitation (CBCR) has been shown to significantly improve performance on cognitive tasks assessing the specific domains trained within CBCR programmes (Lynch, 2002; Owen et al., 2010; Smith et al., 2009). CBCR interventions are based on principles that the impaired system(s) can be restored or at least improved by structured drills and practice using tasks that contain similar elements to the target skill (e.g., attention span, reaction time) (Lynch, 2002). A widely used CBCR intervention in stroke patients is CogMed®, a training targeting the cognitive domain of working memory (WM) by games aimed at remembering multiple stimuli at the same time, during short delays and in a unique order. Other examples of CBCR interventions are BrainGymmer® and Lumosity®, both designed to improve people's general cognitive performance with various games and mental exercises in multiple cognitive domains.

Regarding the effectiveness of CBCR interventions after stroke, several randomised controlled trials (RCTs) have been published in the last decade. Three RCTs specifically examined the effect of a computer-based attention (Barker-Collo et al., 2009) or WM training (Cogmed) (Åkerlund, Esbjörnsson, Sunnerhagen, & Björkdahl, 2013; Westerberg et al., 2007) as compared to standard care and no intervention. In Barker-Collo et al. (2009), 78 stroke patients received 30 hours of computerised attention training (intervention group) or standard care alone (control group) 6 months after stroke. Statistically significant effects were seen regarding a test combining visual and auditory attention scores, either separately or combined, but this was not reflected in statistically significant improvement on other attention measures, such as the Trail Making Task A and B, or in wider outcomes.

Westerberg et al. (2007) concluded that the treatment group improved significantly more than the passive control group on tests that measured WM and subjective cognitive failures. Effect sizes between groups were respectively 0.83 on the Span Board (p = .05), 1.58 on the Digit Span (p < .01), and 0.80 on the Cognitive Failures Questionnaire (CFQ) (p < .01). Åkerlund et al. (2013) also showed that results on the Digit span after WM training differed significantly compared to the results of usual rehabilitation at the same time, with greater improvement in the training group (Digit Span forward p = .04, Digit Span backward p < .01).

A review by Laver, George, Thomas, Deutsch, and Crotty (2015) pointed out that it is still unclear how effective virtual reality may be for cognitive rehabilitation after stroke. Akinwuntan et al. (2005) studied the effect on fitness to drive of a 5-week 15-hour simulator-based training (experimental group) compared to a driving-related cognitive tasks (control group) among 83 stroke patients. At 6–9 months post-stroke, significant differences between both groups were found in "road sign recognition" and "fitness to drive" in favour of the experimental subjects.

Overall the interpretation of the results of RCTs is hampered by relatively small sample sizes with 18, 47, and 78 participants in total (Åkerlund et al., 2013; BarkerCollo et al., 2009; Westerberg et al., 2007). Moreover, none of these trials included a training focused on multiple cognitive domains, although the literature suggests that targeting a variety of cognitive functions is needed to promote generalisation of abilities beyond the trained task and to achieve an outcome that also impacts on daily life (Buitenweg, Murre, & Ridderinkhof, 2012; Green & Bavelier, 2008; Sohlberg & Mateer, 2001). In addition, the effects on QoL have not been studied (Barker-Collo et al., 2009). Thus, there is a need for large studies focusing not only on WM and attention, but also on other cognitive domains and on QoL.

The aim of this study was to determine the effect of a CBCR intervention on multiple aspects of cognitive functioning, QoL, and self-efficacy, and compare it to a control intervention in patients with self-perceived cognitive impairments 12–36 months after stroke. Additionally, within the intervention group the aim was to study adherence with the intervention. The hypothesis of the study was that a CBCR training targeting multiple cognitive domains leads to greater improvements on processing speed, flexibility and fluid intelligence in stroke patients than the provision of information through the internet (Rebok et al., 2014; Van der Oord, Ponsioen, Geurts, Ten Brink, & Prins, 2012).

#### Materials, methods and patient characteristics

#### Design

This study had a randomised, controlled design and tookplace in The Netherlands between January 2013 and September 2013 at the Rijnlands Rehabilitation Centre in Leiden and Sophia Rehabilitation in The Hague. The study was approved by the Medical Ethical Review Board of the Leiden University Medical Centre (P 12.190). All participants gave written informed consent prior to participation and were rewarded with a gift card of 50 euros for participating in the trial, with no difference between those who completed the games and those who did not. The CONSORT (Consolidated Standards of Reporting Trials) guidelines were used for adequate reporting of the study (Moher et al., 2010).

#### **Recruitment and inclusion**

Inclusion criteria for participation in the study were: age between 45 and 75 years, diagnosed with stroke 12–36 months ago, having self-perceived cognitive impairments (extracted from the checklist accompanying the recruitment letter), having access to the internet, being able to visit the rehabilitation centre, and having time to participate. Exclusion criteria were: antidepressant use, receiving actual treatment for cognitive impairments, severe aphasia, lack of computer skills, and not being proficient in Dutch. In addition, participants with psychological disorders in need of treatment, for example depression, and patients with physical disorders known to impact cognition were excluded.

Potentially eligible patients were identified by first searching the electronic patient registers of the rehabilitation centres for patients who were aged between 45 and 75 years and who had had a stroke 12–36 months ago. The chosen age range constitutes the largest proportion of patients admitted to rehabilitation and to prevent age-specific bias (e.g., stroke patient 18 years old versus 75 years old). Onset of stroke was "not more recently than 12 months" to minimise the influence of natural recovery and "not longer ago than 36 months" to prevent the risk of impaired learning due to age group specific comorbidities (e.g., Alzheimer's). Potential participants received a letter with information about the study, a checklist concerning the other four inclusion criteria (having self-perceived cognitive impairments, having access to internet, being able to visit the rehabilitation centre and having time to participate) and a form to indicate their willingness to participate in the study. All responding patients received a telephone call from one of the researchers (MW, IV, AK) to make sure they met the inclusion criteria and did not meet the exclusion criteria. Also they were asked to state their age (years), sex and educational level (categorised as low: lower technical and vocational training; medium: secondary technical and vocational training; and high: higher technical and vocational training and university) (Centraal Bureau voor de Statistiek [CBS], 2006).

#### Randomisation

Included patients were subsequently randomised by an administrative assistant who was not involved in the study. A blocked randomisation scheme (blocks of six), with stratification for age and education level (extracted from the recruitment form and checked by examining the electronic patient registers), made up by a random digit generator (Microsoft Excel 2010), was used to allocate the patients either to the intervention group or control group. Stratification for age and education level was based on findings in a study of Patel et al. (2003) who studied the relationship between different variables and cognitive functioning among 645 stroke patients. As the majority of patients was of the same ethnic origin, stratification for that variable was not performed. The variable "age" was divided into two categories ( $\leq$  58 and > 58), since the median age was 58 years. The variable "education level" was divided into the categories "low", "moderate" and "high", by using a standardised classification system (CBS, 2006).

#### Blinding

The randomisation sequence was concealed (blinded) from research personnel, so that assessors were not aware of whether a subject was randomised to the intervention or control group.

## Intervention and control conditions

The conditions compared in the study consisted of a CBCR training (intervention) versus weekly information about the brain (control). All participants received a user identification and password to log on to a website specifically designed for this study (www. spelenderwijsbeter.nl). After log-on, the website provided either access to the training or the information. All participants were given the contact details of a research assistant, whom they could contact by telephone in case of difficulties using the website or, in case of participants in the intervention group, with the training software.

#### Intervention

The training consisted of gaming at home during a period of 8 weeks, at least 5 days per week, approximately 15–20 minutes per day, resulting in a requested play time of 600 minutes. The training software was supplied by Lumosity Inc.<sup>®</sup>. This software was chosen because it targets more cognitive domains than other CBCR interventions (e.g., Cogmed), since effective training should include games in several cognitive areas, including flexibility (Buitenweg et al., 2012). Moreover, frequent switches prevent boredom and thereby therapy compliance is stimulated. The recently developed training software of BrainGymmer<sup>®</sup> was

not available when this study took place.

Sixteen games were used and five cognitive domains were targeted: attention, speed, memory, flexibility and problem solving. Three games were randomly assigned to the participant per session. The duration of each game was approximately five minutes. After finishing all sessions of a single game, a new game started after pressing the "next" button. When all three games were completed, participants received feedback that the session for that day was finished. Participants were able to play longer by selecting games from the menu themselves after finishing the training session.

With each game, all participants began at the same level of difficulty. The difficulty level was then raised or lowered depending on the performance in the previous round of the respective game. The software provided feedback about game scores. Furthermore, participants were instructed to complete an extra game session when they missed a session and/or were not able to play five days a week. After eight weeks, participants still had access to the games, but were instructed to temporarily quit playing.

#### Control

The participants in the control group received weekly information about stroke after logon at the website of the study. The information provision was not interactive, it provided unidirectional explanations about brain differences between men and woman, the influence of stress on brain function and possible difficulties with living with a damaged brain. Each week, during a period of 8 weeks, new information (text or a video clip) was added to the website. The information was accessible for the participants during the period of 8 weeks. The total duration of the control intervention was on average 70 minutes per person.

#### Assessments

All assessments were done before the intervention (t0), and 8 and 16 weeks thereafter (t1 and t2). At all time points, the assessments consisted of a set of electronic questionnaires and computer-based performance tests. With respect to the questionnaires, participants received an e-mail with a digital link to the questionnaires one week before each planned assessment, with the request to complete it at home. All computerised performance tests, which took approximately one hour to complete, were conducted in the rehabilitation centre. Tests were administered in a fixed order and every patient received the same instructions. Assistance during testing was provided by the principal investigator (MB) and two students and consisted of logging the participant on to the computer, setting up the tests, providing support in case of technical problems, explaining the test procedure if necessary and saving test results.

#### Sociodemographic and disease characteristics

Characteristics recorded at baseline by means of a questionnaire were: living situation (alone/ together), daily functioning (dependent/independent), and participation in paid work (yes/no). In addition, the affected hemisphere (left/right/other), type of stroke (infarction/ haemorrhage), time between stroke and enrolment, and time spent in rehabilitation centre (in months) were recorded from the medical records. The group of responders was compared to the group of non-responders regarding their age and gender using the Mann Whitney U test, the Chi-square test.

#### Adherence

Data about participants' total play time (in days and minutes) were provided by the software of the training programme.

#### **Primary outcome measures**

The primary outcome measures included five neuropsychological tests and the Cognitive Failures Questionnaire (CFQ). Secondary outcomes included a measure of QoL and of self-efficacy. As patients in the intervention group were discouraged from playing the games after 8 weeks, and under the assumption that a present effect would diminish afterwards, time point 1 was chosen as the primary endpoint for both primary and secondary outcome measures.

#### Attention and flexibility

The Trail Making Test (TMT; Reitan & Wolfson, 1985) was used to assess attention and flexibility. It consists of two parts (TMT-A and TMT-B): In TMT-A the participants were asked to draw lines sequentially connecting 25 encircled numbers distributed on the screen. In TMT-B task requirements were similar, however the participants must alternate between numbers and letters (e.g., 1, A, 2, B, 3, C, etc.). The scores represent the amount of time required to complete task A and B (attention) and the mean difference between time A and B (flexibility) (Strauss, Sherman, & Spreen, 2006). Lower scores for attention and higher scores for flexibility indicate better functioning. In addition, the number of correct connections made by the patients was scored. Both tests were proven to be valid indicators of organic brain damage (Lezak, Howieson, & Loring, 2004).

#### Working memory

The Block Span Task (Corsi, 1972) and Digit Span Task (Wechsler, 1945) were used to assess working memory with two subtests: blocks/digits forward (sequential order) and blocks/

digits backward (reversed order). The scores consist of the highest number of blocks/digits a participant can correctly reproduce, so that higher scores indicate better functioning. A number of studies have published data on the Block Span Task in stroke patients and concluded that it can be used effectively to assess visuospatial short-term memory in patients with brain damage (Chechlacz, Rotshtein, & Humphreys, 2014; De Renzi, Faglioni, & Previdi, 1977; Kessels, Van Zandvoort, Postma, Kappelle, & De Haan, 2000).

#### Speed and flexibility

With the Eriksen Flanker Task (Eriksen & Schultz, 1979) participants are instructed to respond as quickly as possible to a central target stimulus, which was flanked by either four congruent (e.g.,  $\leftarrow \leftarrow \leftarrow \leftarrow \leftarrow \leftarrow$ ) or four incongruent (e.g.,  $\leftarrow \leftarrow \leftarrow \leftarrow \leftarrow \leftarrow \leftarrow$ ) stimuli (Eriksen, 1995). The score of the test is the reaction time in milliseconds (speed) and the mean difference between reaction time incongruent and congruent (resistance to interference, flexibility) (Levin & Cross, 2004). Better functioning is indicated by lower scores for speed and higher scores for flexibility.

#### Fluid intelligence

The Raven Standard Progressive Matrices (SPM; Raven, 1958) is a multiple-choice test consisting of incomplete figures, in which participants are asked to choose the correct missing part depicted in one of the six alternatives. Three versions of equal difficulty with 20 items each were derived from the original 60-item version to assess fluid intelligence at the three time points in a counterbalanced order. The score of the test is the number of correct items translated in IQ scores. Higher scores indicate better functioning. Internal consistency coefficients tend to cluster around .90 for adults (Llabre, 1984) and retest reliability correlations are in the range of .70 and .90 (Llabre, 1984).

#### **Cognitive Failures Questionnaire (CFQ)**

The CFQ (Broadbent, Cooper, FitzGerald, & Parkes, 1982) in a Dutch version (Merckelbach, Muris, Nijman, & de Jong, 1995) was used to measure self-perceived cognitive failure. The CFQ includes 25 questions, for example: "Do you fail to notice signposts on the road?". The 5-point scale ranges from 0 (never) to 4 (very often). The total score ranges from 0 to 100, with higher scores indicating less cognitive failure. Broadbent et al. (1982) reported that the questionnaire has high test-retest correlation and high internal consistency. This was confirmed in a Dutch study by Merckelbach et al. (1995), in which the test-retest reliability (.83) and internal validity (Cronbach's  $\alpha = .81$ ) were high. The questionnaire was also completed by the spouse or a person related to the participant.

#### Secondary outcome measures

#### Stroke Specific Quality of Life Scale (SS-QoL-12)

A Dutch and short version of the SS-QoL was used to measure health-related QoL (HRQoL) (Post et al., 2011). The self-rating 5-point scale consisted of 12 items. The total score ranges from 12 to 60, with higher scores indicating better function (Williams, Weinberger, Harris, Clark, & Biller, 1999). The questionnaire has been validated in patients with haemorrhage and ischaemic stroke (Post et al., 2011).

#### General Self-Efficacy Scale (GSES)

A Dutch version of the GSES, a 10-item self-rating scale (Schwarzer & Jerusalem, 1995), was used to assess participants' belief in the ability to respond to and cope with novel or difficult situations and unexpected setbacks or obstacles. The scale ranged from 1 (not at all true) to 4 (exactly true), resulting in a sum score ranging from 10 to 40, with higher scores indicating greater self-efficacy.

#### **Data analysis**

The target sample size was based on the ability to detect a difference of 25% in the proportion of patients (35% in the intervention group and 10% in the control group) showing a 25% improvement of the Raven SPM. Although larger than the effects seen in previous similar studies (Jaeggi, Buschkuehl, Jonides, & Perrig, 2008; Karbach & Kray, 2009; Klingberg et al., 2005; Klingberg, Forssberg, & Westerberg, 2002; Schmiedek, Lövdén, & Lindenberger, 2010; Shipstead, Redick, & Engle, 2012; Van Muijden, Band, & Hommel, 2012), this difference was considered to be clinically relevant. Based on a power of .80 to detect a significant difference (2-sided p = .05), 43 patients would be required for each study group. To compensate for an expected dropout rate of 15%, we planned to enrol at least 50 patients in each study group.

Adherence of participants in the intervention group was analysed using descriptive statistics and presented as the mean with the range or numbers and percentages. Change scores of endpoint measures over time between t0 and t1 and t1 and t2 in both the intervention and control groups were computed with the 95% confidence interval and analysed by means of paired t-tests or Wilcoxon Signed Rank test, where appropriate. Differences in the change scores between the groups were analysed by independent t-tests or Mann-Whitney U tests, where appropriate.

In addition, a linear mixed model with patient number as a random factor and group and measurement moments interaction as fixed factors were used to determine effects over the total period (t0-t1-t2). Corrections were made for differences in type of stroke between the intervention and control group. Moreover, Spearman correlation coefficients were calculated to determine correlations between subjective cognitive impairment (CFQ) at baseline and change scores on neuropsychological tests between t0 and t1 and between play time on WM games and change scores on neuropsychological tests between t0 and t1.

All effectiveness analyses were based on intention to treat, meaning all available data were used. Per protocol analysis was performed, including the participants from the intervention group who played at least 600 minutes. For all analyses, the level of statistical significance was set at .05. All analyses were done with the software SPSS version 21.

#### Results

According to the registers, 889 patients who were aged between 45 and 75 years and had had a stroke between 12–36 months ago, were identified and invited to participate (Figure 1). Of these, 146 patients (64 in Leiden, 82 in The Hague) indicated they fulfilled the inclusion criteria and were interested in the study, of whom 142 were screened for eligibility (4 could not be reached). From these 142 patients, 27 were excluded because they either did not fulfil one or more inclusion criteria or met one or more of the exclusion criteria, so that 115 patients were included and randomised. Directly after randomisation, five patients refused further participation. Eventually, 110 patients were present at the first assessment day and included in the analysis (53 intervention and 57 control). Of these, 107 participants (97%) completed the study, 50/53 (94%) in the treatment group and 57/57 (100%) in the control group.

#### **Demographic characteristics**

The demographic and clinical characteristics of the 110 study participants are shown in Table 1. Participants' characteristics were similar in the intervention and control groups at baseline. However, in the intervention group significantly more patients had had a haemorrhage (21/53; 40%) compared to the control group (13/57; 23%) (p = .02).

No significant differences were found between age and gender for the group of 146 responders (median age 59, range 46–74; male n = 69, 63%) compared to the group of 743 non-responders (median age 61, range 45–75; male n = 459, 59%), p = .62 for age and p = .66 for gender, respectively.



Figure 1. Trial profile.

#### Adherence to the intervention

Seven out of 53 patients in the intervention group failed to play games due to technical problems with their computer (n = 3), lack of motivation (n = 2) or not feeling well (n = 2). The number of days and total play time of the remaining 46 patients who actually played are shown in Table 2. The median number of days these patients played was 45 (range = 4-63) and the median total time played in minutes was 562 (range = 63-1264).

Two patients logged on only once and three patients between three and five times, so their play time was very limited. Reasons for not playing, according to the participants' personal coaches were: having difficulties playing the games due to health status, not sufficiently motivated, or technical problems with the computer. A group of seven patients played more than the 600 minutes requested. Two patients (4%) in the intervention group completed 2–3 training sessions during the follow-up period (8–16 weeks) despite explicit discouragement to do so.
	Intervention group (n = 53)	Control group (n = 57)
Age in years; median (range)	59 (46–74)	59 (46–73)
Sex, male n (%)	34 (64)	35 (61)
Type of stroke Infarction n (%)	29 (55)	44 (77)
Haemorrhage n (%)	21 (40)	13 (23)
Unknown <sup>a</sup> n (%)	3 (5)	0 (0)
Location of stroke		
Hemisphere left n (%)	23 (43)	28 (49)
Hemisphere right n (%)	26 (49)	26 (47)
Basal ganglia n (%)	3 (6)	0 (0)
Unknown <sup>a</sup> n (%)	1 (2)	2 (4)
Time from stroke onset to randomisation in months; mean $\pm$ SD	26 ± 9.1	25 ± 7.4
Time spent in rehabilitation centre in months; mean $\pm$ SD	6 ± 3.6	5 ± 3.4
Educational status <sup>b</sup>		
Low n (%)	17 (32)	20 (35)
Intermediate n (%)	18 (34)	18 (32)
High n (%)	18 (34)	19 (33)
Living alone n (%)	13 (25)	15 (25)
Independent in daily functioning n (%)	52 (98)	54 (95)
Participation in paid work n (%)	14 (26)	20 (32)
Subjective cognitive failure (CFQ); median (IQR)	63 (19)	64 (21)

 Table 1. Baseline demographic and clinical characteristics of the 110 stroke patients.

<sup>a</sup> No data were available for medical status.

<sup>b</sup> Low: lower technical and vocational training; medium: secondary technical and vocational training; and high: higher technical and vocational training and university.

### **Primary outcome measures**

### Intention-to-treat analysis

Baseline and follow-up scores of primary outcomes are shown in Table 3(a). At baseline, no significant differences were found between the groups. A significant difference between the groups of changes between t0 and t1 was found regarding the number of correct items in favour of the intervention group on the Block Span Forward Test (p = .02) and the reaction time incongruent on the Eriksen Flanker Test (p < .01). No differences in improvement were seen between the two groups on other outcome measures.

Within both groups significant improvements were found between t0 and t1 regarding the cognitive domain attention for the parameters Time B and Items Correct B, but not for

Time A and Items Correct A. Moreover, participants in the intervention group improved between t0 and t1 within the cognitive domain flexibility (TMT-A/TMT-B), reaction time congruent (Eriksen Flanker Task) and fluid intelligence (Raven SPM, Peck score), whereas no significant changes were seen within the control group. In addition, there were no statistically significant differences between the groups taking into account all time points (T0-T1-T2) (mixed model analysis of variance).

The following correlations were found between baseline scores of subjective cognitive impairment (CFQ) and mean differences between t0 and t1 on the neuropsychological tests: TMT A Spearman, r = .180 (p = .07), and TMT B, r = .308 (p < .01), Block Span forward, r = -.181 (p = .06), and backward, r = -.079 (p = .42), Digit Span forward, r = -.184 (p = .06), and backward, r = -.295 (p < .01), Flanker incongruent, r = .168 (p = .09), and congruent, r = .158 (p = .11), and the Raven SPM, r = -.158 (p = .15). No significant correlations were found between play time on WM games and change scores on neuropsychological tests between t0 and t1.

Characteristics	Med	lian (IQR) ª
Participants who played	46	
Total time played (days)	45	(4–63)
Total time played (minutes)	528	(63–1264)
Total time played per cognitive domain (minutes):		
Attention	60	(3–408)
Speed	53	(3–139)
Memory	232	(26–646)
Flexibility	111	(6–349)
Problem solving	81	(1–265)

**Table 2.** Total days and minutes played during the 8-week training period in the intervention group (46 out of 53 patients).

<sup>a</sup> IQR's are expressed as the net result of 75th percentile minus 25th percentile.

		٦	го	T0-T1			T1-T2		
					Within	Between		Within	Between
					group	groups		group	groups
		Me	dian	Mea	n difference		Mea	n difference	
		(IC	QR)ª	(	(95% CI) <sup>ь</sup>	<i>p</i> -value <sup>c</sup>	(9	95% CI)⁵	<i>p</i> -value <sup>c</sup>
Working memory									
Items forward (Block Span Task)	1:	3	(2)	0.7	(0.3,1.1)	0.02	-0.1	(-0.4,0.3)	0.59
(0-9 items)	C:	4	(2)	-0.1	(-0.6,0.4)		0.2	(-0.2,0.6)	
Items backward (Block Span Task)	1:	3	(2)	0.3	(-0.2,0.8)	0.45	-0.2	(-0.7,0.2)	0.56
(0-8 items)	C:	3	(4)	0.1	(-0.3,0.6)		-0.1	(-0.6,0.4)	
Items forward (Digit Span Task)	1:	5	(2)	0.1	(-0.6,0.5)	0.23	0.4	(-0.1,0.8)	0.43
(0-9 items)	C:	5	(3)	0.5	(-0.0,0.1)		0.0	(-0.3,0.3)	
Items backward (Digit Span Task)	1:	4	(2)	0.1	(-0.5,0.8)	0.28	0.1	(-0.5,0.7)	0.25
(0-8 items)	C:	3	(3)	0.6	(0.1,1.1)		-0.2	(-0.7,0.2)	
Attention									
Time A (TMT-A)	1:	78	(49)	-7	(-21.6,7.8)	0.54	-5	(-17.2,8.1)	0.87
(0-2880s)	C:	74	(42)	-19	(-39.8,1.9)		8	(-12.3,27.7)	
Time B (TMT-B)	1:	169	(142)	-73	(-134.1,-11.5)	0.10	-11	(-27.5,4.9)	0.40
(0-2880s)	C:	144	(202)	-58	(-102.3,-12.8)		25	(-18.6,68.0)	
Items correct A (TMT-A)	1:	24	(0)	0.6	(-0.3,1.5)	0.85	0.1	(-0.7,0.9)	0.11
(0-24)	C:	24	(0)	0.7	(-0.4,1.8)		-0.3	(-0.7,0.1)	
Items correct B (TMT-B)	1:	17	(13)	2.5	(0.7,4.2)	0.38	1.1	(-0.3,2.6)	0.30
(0-24)	C:	20	(15)	1.6	(0.2,2.9)		-0.2	(-1.4,1.1)	
Speed (Flanker Task)									
Reaction time congruent	1:	770	(258)	-51	(-97.1,-5.4)	0.08	-16	(-38.8,6.6)	0.48
(0-2000 milliseconds)	C:	816	(285)	-4	(-57.9,50.7)		-42	(-86.0,2.5)	
Reaction time incongruent	1:	797	(268)	-63	(-118.9,-7.4)	0.00	-14	(-38.2,9.3)	0.08
(0-2000 milliseconds)	C:	833	(342)	9	(-49.5,67.1)		-46	(-91.1,-0.9)	
Flexibility									
Difference time A/time B	1:	-80	(125)	66	(6.5,124.7)	0.18	7	(-13.0,26.9)	0.56
(TMT-A/TMT-B)	C:	-61	(145)	34	(-15.7,84.5)		-17	(-65.9,31.8)	
Difference reaction time congruent/	1:	-31	(39)	10	(-9.4,29.0)	0.62	1	(-9.0,11.5)	0.56
incongruent (Flanker Task)	C:	-33	(62)	-12	(-39.8,15.0)		4	(-11.9,20.5)	
Fluid intelligence (Raven SPM)									
Peck-score	1:	110	(19)	6	(1.3,9.8)	0.47	-3	(-7.4:1.0)	0.34
(0-150)	C:	111	(17)	3	(-1.4,7.3)		-1	(-5.7:3.1)	
Cognitive failure (CFQ)									
Total score (participant)	1:	63	(19)	-0.5	(-3.9,2.9)	0.14	-0.9	(-5.5,3.8)	0.87
(0-100)	C:	64	(21)	1.4	(-1.0,3.6)		-1.6	(-4.9,1.7)	
Total score (relatives)	1:	63	(35)	-0.2	(-4.4,3.9)	0.75	1.5	(-2.8,5.8)	0.81
(0-100)	C:	59	(19)	3.2	(-2.0,8.5)		-0.05	(-5.6,5.5)	

**Table 3a.** Baseline, follow-up and change scores for attention, flexibility, memory, speed, fluid intelligence and cognitive failure in the intervention versus the control group.

<sup>a</sup> IQRs are expressed as the net result of 75th percentile minus 25th percentile. All analyses were done with adjustment for significant differences in baseline characteristics between patients.

<sup>b</sup>Values are the difference in mean change values between groups (treatment effect with 95% confidence interval). <sup>c</sup> *p*-values were analysed using Mann-Whitney U test or mixed model analyses where appropriate. **Table 3b.** Baseline and follow-up scores of variables attention, flexibility, working memory, and speed with significance between groups per protocol (n = 19).

		Ī	0		<u>T0-T1</u>		<u>T1-T2</u>		
			Within group		Between	Wit	hin group	Between	
						groups			groups
		Me	dian	Mea	an difference		Mear	difference	
	_	(IC	2R)ª		(95% CI) <sup>8</sup>	<i>p</i> -value <sup>c</sup>	(9	5% CI) <sup>8</sup>	<i>p</i> -value <sup>c</sup>
Working memory									
Items forward (Block Span Task)	I:	4	(3)	0.9	(0.4,1.8)	.09	-0.3	(-0.4,0.3)	.66
(0-9 items)	C:	4	(2)	-0.1	(-0.6,0.4)		0.2	(-0.2,0.6)	
Items backward (Block Span Task)	I:	3	(2)	0.4	(-0.2,0.7)	.42	-0.2	(-0.8,0.2)	.35
(0-8 items)	C:	3	(4)	0.1	(-0.3,0.6)		-0.1	(-0.6,0.4)	
Items forward (Digit Span Task)	I:	5	(2)	0.1	(-0.8,0.5)	.50	0.4	(-0.1,0.7)	.21
(0-9 items)	C:	5	(3)	0.5	(-0.0,0.1)		0.0	(-0.3,0.3)	
Items backward (Digit Span Task)	I:	4	(3)	0.1	(-0.5,0.7)	.40	0.2	(-0.6,0.7)	.88
(0-8 items)	C:	3	(3)	0.6	(0.1,1.1)		-0.2	(-0.7,0.2)	
Attention									
Time A (TMT-A)	I:	76	(45)	-27	(-45,2,-3.8)	.69	-9	(-14.1,10.1)	.93
(0-2880s)	C:	74	(42)	-19	(-39.8,1.9)		8	(-11.5,34.7)	
Time B (TMT-B)	I:	169	(143)	-81	(-160.0,-3.0)	.04	-12	(-14.9,3.7)	.30
(0-2880s)	C:	144	(202)	-58	(-102.3,-12.8)		25	(-18.6,68.0)	
Items correct A (TMT-A)	I:	24	(0)	0.6	(-0.3,1.5)	.35	0.1	(-0.9,1.1)	.20
(0-24)	C:	24	(0)	0.7	(-0.4,1.8)		-0.3	(-0.7,0.1)	
Items correct B (TMT-B)	I:	17	(15)	2.5	(0.7,4.2)	.45	1.4	(-0.3,2.6)	.12
(0-24)	C:	20	(15)	1.6	(0.2,2.9)		-0.2	(-1.4,1.1)	
Speed (Flanker Task)									
Reaction time congruent	1:	696	(244)	-59	(-110.1,-13.2)	.09	-22	(-40.2,7.8)	.48
(0-2000 milliseconds)	C:	816	(285)	-4	(-57.9,50.7)		-42	(-86.0,2.5)	
Reaction time incongruent	1:	719	(266)	-71	(-125.0,-5.4)	.07	-19	(-36.6,12.3)	.08
(0-2000 milliseconds)	C:	833	(342)	9	(-49.5,67.1)		-46	(-91.1,-0.9)	
Flexibility									
Difference time A/time B	I:	-91	(119)	71	(12.2,136.9)	.00	-14	(-3.6,32,8)	.56
(TMT-A/TMT-B)	C:	-61	(145)	34	(-15.7,84.5)		-17	(-65.9,31.8)	
Difference reaction time congruent	I:	-26	(32)	15	(-5.4,32.2)	.62	4	(-11.5,9.9)	.56
/incongruent (Flanker Task)	C:	-33	(62)	-12	(-39.8,15.0)		4	(-11.9,20.5)	
Fluid intelligence (Raven SPM)									
Peck-score	1:	107	(21)	7	(1.0,9.3)	.47	-3	(-7.4:1.0)	.34
(0-150)	C:	111	(17)	3	(-1.4,7.3)		-1	(-5.7:3.1)	
Cognitive failure (CFQ)									
Total score (participant)	l:	63	(19)	-0.4	(-4.0,3.19)	.14	-0.5	(-3.6,2.3)	.87
(0-100)	C:	64	(21)	1.4	(-1.2,3.4)		-1.6	(-4.9,1.7)	
Total score (relatives)	l:	63	(35)	-0.2	(-4.2,3.2)	.75	0.5	(-2.8,3.6)	.81
(0-100)	C:	59	(19)	3.2	(-2.0,8.5)		-0.05	(-5.6,5.5)	

<sup>a</sup> IQRs are expressed as the net result of 75th percentile minus 25th percentile. All analyses were done with adjustment for significant differences in baseline characteristics between patients.

<sup>b</sup> Values are the difference in mean change values between groups (treatment effect with 95% confidence interval).

<sup>c</sup> *p*-values were analysed using Mann-Whitney U test or mixed model analyses where appropriate.

### Per protocol analysis

Comparisons of change scores between the intervention and control group (n = 57), while including only the 19 patients who played at least 600 minutes in the intervention group are shown at Table 3(b). A significant difference between groups was found at 8 weeks regarding attention (TMT-B, Time B, p = .04) and flexibility (TMT-A/TMT-B, Difference time A and time B, p < .01), both in favour of the intervention group. In the intention-to-treat (ITT) analysis no significant differences were found between groups regarding the TMT. However, effects found in the ITT analysis between groups did not remain significant in the per protocol analysis when compared to the control group regarding Block Span items correct forward (p = .07) and reaction time incongruent on the Flanker Task (p = .09).

When compared to ITT analysis, the magnitude of improvements in the per-protocol analysis increased within the intervention group between t0 and t1 regarding speed (Eriksen Flanker Task, reaction time congruent; reaction time incongruent), working memory (Block Span backward), flexibility (difference time A/time B; difference reaction time congruent/ incongruent), fluid intelligence (Raven SPM) and subjective cognitive failure (CFQ).

### Secondary outcome measures

Baseline and follow-up scores of secondary outcomes are shown in Table 4. At baseline, no significant differences were found between both groups and no differences were seen in change scores between the two groups. In addition, there were no statistically significant difference between the groups taking into account all time points (T0-T1-T2) (mixed model analysis of variance).

		Т0	T0-T1		T1-T2	
		Median	Mean difference		Mean difference	
		(IQR)ª	(95% CI) <sup>b</sup>	<i>p</i> -value <sup>c</sup>	(95% CI) <sup>b</sup>	<i>p</i> -value <sup>c</sup>
QoL <sup>d</sup>	l:	3.9 (1.5)	0.0 (-0.2,0.2)	.76	0.1 (-0.1,0.3)	.45
Total score (0–5)	C:	3.8 (1.3)	0.0 (-0.1,0.2)		0.0 (-0.1,0.1)	
Self-efficacy <sup>e</sup>	l:	31 (10)	1.0 (0.3,2.2)	.15	0.52 (-0.6,1.6)	.86
Total score (0–40)	C:	30 (8)	-0.6 (-1.8,0.6)		0.29 (-1.1,1.7)	

**Table 4.** Baseline and follow-up scores of QoL and self-efficacy with significance in the intervention versus the control group.

<sup>a</sup> IQR's are expressed as the net result of 75th percentile minus 25th percentile. All analyses were done with adjustment for significant differences in baseline characteristics between patients.

<sup>b</sup>Values are the difference in mean change values between groups (treatment effect with 95% confidence interval).

<sup>c</sup> p-values were analysed using Mann-Whitney U test or mixed model analyses where appropriate.

<sup>d</sup>Measured with the Stroke Specific Quality of Life Questionnaire (SSQoL).

<sup>e</sup>Measured with the General Self-efficacy Scale (GSES).

# Discussion

In this randomised study an 8-week computer-based brain training programme was compared with providing information to patients with cognitive complaints after stroke. In general only performances on cognitive function tests that were similar to the games included in the intervention improved in the CBCR training group compared to the control group. However, no near transfer effect was found to tasks such as the Digit Span Task or Trail Making Task.

The effects found in our study on the WM tests; effect size 0.23 regarding the Span board and 0.11 regarding the Digit Span between groups, were smaller than other studies using CBCR training primarily focused on one cognitive function among stroke patients. Westerberg et al. (2007), who compared a computerised 5-week WM training (Cogmed) on various WM tasks with a passive control group, reported significant improvements in favour of the intervention group on the WM tests; effect size Span Board 0.83 and effect size Digit Span 1.58. Åkerlund et al. (2013) also found a significant difference on the Digit Span Task in favour of the group who received WM training in the sub-acute phase compared to usual rehabilitation. Smith et al. (2009) evaluated the effect of a 40-hour CBCR training targeting speed and information processing among healthy adults and found an effect size of 0.26 between groups on the Digit Span Backward in favour of the intervention group. Based on these results it can be concluded that the effects of the CBCR training were limited in this group of patients.

Moreover, other CBCR studies found improvements of daily functioning after training. Westerberg et al. (2007) reported a significant change on the CFQ (p < .01) and Åkerlund et al. (2013) found less depressive symptoms after WM training between groups (p = .03), in both studies in favour of the intervention group. In the current study, no far transfer effects were shown, i.e., no significant difference was found on cognitive functioning by means of the CFQ, QoL scale or self-efficacy scale. Although results of the studies cannot be easily compared to the current study, since the total training period was lower in our study, they indicate that interventions primarily focused on one cognitive function instead of multiple cognitive domains might be more effective for stroke patients. However, in line with the results in our study, Barker-Collo et al. (2009) found very limited effects on tests that were related to the trained tasks and no result in a near or far transfer.

There are a number of potential explanations for the observed lack of effect. Apart from the intervention not being effective, it remains unclear to what extent responsiveness of the outcome measures also played a role, although the neuropsychological tests have proven ability to measure changes over time in studies among stroke patients (Åkerlund et al., 2013; Barker-Collo et al., 2009; Broadway & Engle, 2010; Chechlacz et al., 2014; Kessels et al., 2000; Nys et al., 2006; Sanchez-Cubillo et al., 2009; Spikman, 2001; Westerberg et al., 2007).

Second, it is questionable whether the dose of the training was enough to achieve responses (dose-response relation). Seven out of the 53 people in the intervention group did not follow the training and only 19 out of the 53 patients, who actually played, completed the training (playing > 600 minutes). This was why a per protocol analysis was done. Indeed, within the intervention group the magnitude of change was larger in the per protocol analysis than with the ITT analysis. However, the difference with the control condition did not reach statistical significance, most likely due to a lack of power because of the limited sample size.

Of note was the finding that some significant improvements were also seen in the control group (time B and items correct B). This might be explained by a learning effect on the neuropsychological tests, since patients became more familiar with using the computer while testing more frequently. For instance, the TMT requires skills moving the mouse on the screen to connect items. By using strategies, for example, using the non-affected hand, scores can increase. Although the primary focus of our study was to investigate an intervention based on restitution approaches, it cannot be ruled out that patients developed strategies that had positive effects on the outcomes. Unfortunately, the average time spent on the control intervention was not available at the level of the individual patient.

Overall, significant differences between both groups were found on 2 out of the 17 outcome measures used in the study. Since multiple outcomes are used, appearances of significant differences can occur from chance alone. However, no corrections for multiple testing were performed for the reason that as the number of tests increases, the p-value that has to be exceeded to achieve statistical significance decreases markedly, lowering the statistical power (Armstrong, 2014; Nakagawa, 2004).

The observation that only 19/53 completed the intervention as it was intended indicates that the feasibility of a programme in the present form is limited. Non-users were also found in other CBCR studies among stroke patients (Connor & Standen, 2012; Cruz et al., 2013), where it was suggested that CBCR training is not well used by all patients, probably due to high demands of training and the motivation needed to complete the training. On the other hand, the fact that 46 out of 53 patients (partly) followed the training (93%), indicates that there is a need among some stroke patients for online training in the chronic phase after stroke. More research is needed to determine patient characteristics that can impair or improve compliance and which stroke patients can benefit the most from CBCR or cognitive rehabilitation in general.

A limitation of the study is that participants were selected on the basis of subjective cognitive impairment and that scores on the CFQ showed that the level of impairment varied widely among patients. Selection bias could have occurred when included patients had lower ability to improve because they were objectively not impaired. Moreover, patients with aphasia or patients unable to use a computer were excluded. This implies that the

patients who were selected were in better health.

A second limitation is that all patients (age: 45–75 years, CVA: 12–36 months ago) were invited by letter to participate in the trial by their treating physician, but were only asked to return the letter if they were willing to participate. Therefore, it is not clear why non-responders did not wish to participate.

In addition, the sample size was based on the assumption that the intervention would lead to a relatively large difference in neuropsychological function as compared to the control group. This assumption was probably too optimistic, leading us to the conclusion that in future research even larger studies are needed to detect changes over time and/ or differences between groups. With more knowledge about the clinical relevance of improvements becoming available in stroke research, future sample size calculations will be better underpinned, using empirical data.

A strength of the study is that it was one of the first to examine the effect of CBCR on multiple cognitive functions and also to assess the transferability to QoL and self-efficacy after stroke. Additionally, it is one of the few RCT CBCR studies with a large sample and follow-up that has investigated long-term effects. Furthermore, only three participants did not complete the follow-up assessments, so the drop-out rate was relatively low.

Overall, the results of this study and similar research imply that CBCR interventions targeting one cognitive domain are more effective for stroke patients in terms of near and far transfer effects compared to those targeting multiple cognitive domains. In order to improve daily activities of stroke patients, computer tasks need to be closely related to the impaired task itself. Thus, CBCR training needs to be tailored and adapted to each patient's individual profile. It would appear important to support stroke patients with CBCR training, since training is not well used by all patients. It is possible patients benefit more when they learn how to use strategies in their training and when motivated by clinicians (Lynch, 2002). Further research is needed to determine if CBCR training can improve cognitive functioning in chronic stroke patients. Brain mapping techniques, such as functional magnetic resonance imaging, might be helpful in identifying effects on brain plasticity (Carter et al., 2010).

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Adherence of stroke patients with an online brain training program: the role of health professionals' support

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# Abstract

**Background:** Computer-based cognitive rehabilitation is used to improve cognitive functioning after stroke. However, knowledge on adherence rates of stroke patients is limited.

**Objective:** To describe stroke patients' adherence with a brain training program using two frequencies of health professionals' supervision.

**Methods:** This study is part of a randomized controlled trial comparing the effect of the brain training program (600 min playtime with weekly supervision) with a passive intervention in patients with selfperceived cognitive impairments after stroke. Patients randomized to the control condition were offered the brain training after the trial and received supervision twice (vs weekly in intervention group). Adherence was determined using data from the study website. Logistic regression analyses were used to examine the impact of supervision on adherence.

**Results:** 53 patients allocated to the intervention group (group S8; 64% male, mean age 59) and 52 patients who were offered the intervention after the trial (group S2; 59% male, mean age 59) started the brain training. The median playtime was 562 min (range 63– 1264) in group S8 vs. 193 min (range 27–2162) in group S2 (p < 0.001, Mann Whitney U).

**Conclusions:** The overall adherence of stroke patients with a brain training was low and there are some implications that systematic, regular interaction with a supervisor can increase training adherence of stroke patients with a restitution-focused intervention performed at home.

# Introduction

Although stroke mortality rates in the past two decades have decreased, according to the World Health Federation stroke is still the second leading cause of death in the world. In 2010, the absolute number of people with first stroke was 16.9 million and the number of stroke survivors was 33 million.<sup>1</sup>

Among the survivors of stroke, 22–50%<sup>2,3</sup> experience cognitive impairment, such as aphasia, neglect, reduced processing speed and impaired attention,<sup>4</sup> with direct consequences for dependency in activities of daily living and functional outcomes.<sup>5</sup>

Neurorehabilitation after stroke is focused on compensational strategy training and restitution-focused training.<sup>6</sup> Compensational training aims to compensate for the lost function using remaining intact functions. Restitution-focused treatments consist of frequent repetition or stimulation of the affected function by high-intensity training.<sup>7,8</sup> Therefore, therapists often prescribe intensive exercise regimes for patients.<sup>9</sup> However, a study found that only 31% of patients actually performed exercises as recommended.<sup>10</sup>

Recently, computer-based cognitive rehabilitation (CBCR) programs, especially serious brain games, have emerged as a tool for restitution-focused treatment in stroke patients. It is expected that serious brain training helps patients in recovering from a stroke by making training more fun, as monotony of repeated motions is decreased and direct feedback about performance is provided.<sup>9,11,12</sup> However, results about the effect of restitution-focused computer training are still conflicting.<sup>13–15</sup> Studies are often hampered by low adherence rates,<sup>16–19</sup> although this is one of the main requirements for success of an intervention as well as improved patient outcomes.<sup>20</sup> Laver et al. concluded in their review that studies should provide more detail in their reporting of adherence of stroke patients with CBCR interventions.<sup>15</sup> Moreover, the impact of the extent of supervision on stroke patients' adherence with restitution-focused interventions is unknown. It was found in a review of Kelders et al. that frequency of interaction with a counselor was a significant predictor for adherence with web-based health interventions in different patient groups (p < 0.001).<sup>21</sup>

The goal of this study was to contribute to a better understanding of the impact of supervision on stroke patients' training adherence with restitution-focused interventions, as a potential factor to increase adherence, ultimately leading to better treatment outcomes for those recovering from stroke. The aim of the study was to describe stroke patients' adherence with a home-based 8-week brain training program (Lumosity Inc.®) by comparing two frequencies of health professional's supervision. The hypothesis of the study was that a CBCR training with more supervision would lead to higher training adherence in stroke patients.<sup>21</sup>

# **Materials & methods**

### Study design

The present study on adherence was part of a randomized controlled trial (RCT) evaluating the effectiveness of an 8-week CBCR program on cognitive functioning, quality of life (QoL) and self-efficacy as compared to a passive intervention.<sup>22</sup> In this study no effect of the CBCR program were found on cognitive functioning, quality of life or self-efficacy when compared to the control group, except for very limiting effects on working memory and speed. A profile of the study is shown in Figure 1.

The current study compares patients in the original intervention group who received supervision eight times during the CBCR intervention period (S8) vs. the original control group who underwent the CBCR intervention after the original RCT and received supervision twice during the intervention period (S2). For the present analysis the data from all patients who agreed to take part in the program were used.

Patients in the S2 group received weekly information about stroke during the period that the S8 group received their intervention. The information provision was not interactive, it provided unidirectional information about brain differences between men and woman, the influence of stress on brain function and possible difficulties with living with a damaged brain. No new information was provided in these brain facts that were not already extensively addressed during previous rehabilitation treatment. Each week, during a period of 8 weeks, new information (text or a video clip) was added to the website. The study was approved by the Medical Ethical Review Board of The Leiden Medical Center (P 12.190). The CONSORT (Consolidated Standards of Reporting Trials) guidelines were used for adequate reporting of the study.<sup>22</sup>



\*Weekly contacts with a supervisor during the 8-week training period (S8) ^Contacts with a supervisor twice (S2)

Figure 1. Study profile.

### **Recruitment and inclusion**

Inclusion criteria for participation in the study were: age between 45 and 75 years, diagnosed with stroke 12–36 months ago, having self-perceived cognitive impairments (extracted from a checklist accompanying the recruitment letter), having access to the Internet, being able to visit the rehabilitation center and having time to participate. Exclusion criteria were: antidepressant use; receiving actual treatment for cognitive impairments; severe aphasia; lack of computer skills; not being proficient in Dutch; participants with psychological disorders in need of treatment; patients with physical disorders known to impact cognition. Patients were recruited from the participating rehabilitation centers.

The recruitment procedure is described in more detail in a previous report.<sup>23</sup> In total, 142 patients meeting the inclusion criteria were screened for eligibility, of whom 53 were eventually randomised to the S8 group and 57 patients to the S2 group. 50 patients (94%) in the treatment group and 57 patients (100%) in the control group completed the study. Of the S2 group, 52 accepted the offer to participate in the program after the trial was completed. A flow chart of the inclusion is shown in Figure 2.

### Intervention

The CBCR intervention was a home-based brain training program with duration of 8 weeks. The duration of 8 weeks for both the intervention and the follow-up were based on clinical expertise by the research team and the health professionals involved in the project team. All participants received a user identification and password to log on to a website providing access to the brain training (www.spelenderwijsbeter.nl). The training software was supplied by Lumosity Inc.<sup>®</sup>. This program was selected because it targets multiple cognitive domains and adapts the level of difficulty of games to patients' own abilities. In total, 16 games were used targeting five cognitive domains: attention, speed, memory, flexibility, and problem solving.

The minimum requested total playtime was 600 min. Patients were encouraged to complete at least one session a day (approximately 15–20 min) on at least 5 days per week. Each session, random selections of three games were assigned to the participant, each game lasting about five minutes. Patients were able to play longer after finishing the training session. Furthermore, participants were instructed to complete an extra game session when they missed one game session and/or were not able to play 5 days a week. With each game, all patients started at the same level of difficulty. The difficulty level was then raised or lowered depending on the performance in the previous round of the respective game. The software provided feedback about game scores and how much games were completed. Patients could receive reminders for training by email or a text message for mobile phone.



Figure 2. Flow of inclusion.

#### **Supervision**

During the training period, patients from the S8 group received digital support by a supervisor. Supervisors were three health care providers (a psychologist, physical therapist, and occupational therapist) from the two rehabilitation centers that participated in the study. The supervision consisted of a short meeting with their own supervisor at the first assessment day in the rehabilitation center. Moreover, digital support was provided to patients weekly during the 8-week training period by their supervisor by telephone if training adherence was lower than five times a week.

A structured plan with instructions and a timeline was provided to the supervisors. Moreover, during a meeting at the start of the intervention and evaluations during the intervention these instructions were discussed with the supervisors. Supervisors were instructed that contact was aimed at: (1) providing assistance needed to solve problems impairing a patient to play (e.g. help with software problems, explaining game instructions, install a reminder for training appointments, etc.), (2) providing strategies to achieve or improve adherence by using the PlanDo-Check-Act method and (3) encourage patients to increase training frequency using motivational interviewing. Moreover, patients were able to contact their supervisor themselves by email or telephone anytime they needed assistance, for instance, in case of problems with training software or questions about a certain game.

Patients from the S2 group received supervision twice during the training period: a short meeting with their supervisor at the start of the brain training and contact by telephone once, after 4 weeks of training. They were encouraged to contact the supervisor by email or telephone in case they experienced difficulties using the training.

#### Assessments

The main outcome of interest in the current study was training adherence during the intervention period. Moreover, patient characteristics were used to determine which variables predict adherence. These data were retrieved from medical records and online questionnaires.

#### Adherence

Training adherence was measured by registering the patients' frequency of logging on to the website of the study during the total training period of 8 weeks and for each week. This was done in order to determine whether patients played 40 times in total (five times a week during 8 weeks) as was required. Data were automatically recorded by the software of the website and therefore gathered independently of the provider of the software. In addition, the patients' playtime, expressed as the minutes played during the 8-week training period for all cognitive domains together and for each cognitive domain (attention, memory, speed, flexibility, problem solving) were registered. These data were provided by Lumosity Inc.<sup>®</sup>. Logging into the brain training and not playing any game was not registered as playtime.

### **Patient characteristics**

Demographic characteristics included gender, age (years) and level of education (low: primary and lower vocational education; middle: secondary and middle vocational education; high: higher vocational and university education).<sup>24</sup> In addition, living situation (alone/together with spouse or other(s)), daily functioning (dependent/independent) and participation in paid work (yes/no) were recorded. Stroke characteristics included the affected hemisphere (left/right/other), type of stroke (infarction/hemorrhage), time between stroke and enrollment and length of stay in the rehabilitation center (in months).

Physical and psychological characteristics included Health related quality of life (HRQoL), measured with a Dutch version of the short Stroke Specific Quality of Life Questionnaire (SSQoL) with higher scores indicating better quality of life (range 12–60),<sup>25</sup> self-perceived cognitive failures, measured with a Dutch version of the 25-item Cognitive Failures Questionnaire (CFQ) with higher scores indicating less cognitive failure (range 0–100)<sup>26</sup> and self-efficacy, measured with a Dutch version of the general self-efficacy scale (SES) with higher scores indicating greater self-efficacy (range 10–40).<sup>27,28</sup>

#### Analysis

Patients' baseline characteristics and adherence with the CBCR program were analysed using descriptive analyses. Data were presented as the number with percentage, median with the range or mean with SD. It was tested if variables were normally distributed by means of the Kolmogorov-Smirnov normality-test. Differences between the S8 group and S2 group were analysed with independent t-tests, Mann-Whitney U tests or Chi-square test, where appropriate.

Logistic regression analyses were used to examine the impact of the extent of supervision on training adherence. Adherence (high and moderate versus low) was dichomotized to be used as dependent variable. Moderate/high adherence was defined as  $\geq$  300 min, as this was half of the required amount of total playtime (600 min). Low adherence was defined as <300 min of total playtime. All cognitive domains were included. The impact of supervision (group S8/ group S2) was included as independent variable, while adjusting for the following potential confounders: age, sex, educational level, type of stroke, affected hemisphere, cognitive failure (CFQ), quality of life (QoL), and self-efficacy (SES). Moreover, multiple logistic regression analyses with a stepwise backward selection procedure were executed in order to determine which variables predict adherence. Variables with the highest *P* value were removed one by one from the prediction model, until all remaining variables were *p* < 0.05. All analyses were performed with the SPSS statistical software package (version 21).

# Results

#### Patient characteristics

The analysis on adherence concerned 53 patients who were allocated to group S8 and 52 patients in group S2, who agreed to participate in the CBCR program after the trial ended (Figure 2). Characteristics of the 105 patients included in the study are presented in Table 1. The mean age of all patients was 59 (range 46–74) and 66 (63%) of the patients were male. Patient characteristics were similar for group S8 (baseline) and group S2 (t = 16 weeks), except for more patients who had a hemorrhage in group S8 (21/53; 40%) compared to group S2 (11/52; 21%) (p = 0.04).

### Adherence

A number of 21 out of the 105 (20%) included patients failed to complete any game. Reasons for not playing at all, as recorded by the supervisor, were: technical problems with the computer (n = 6), lack of motivation (n = 6), health problems (n = 4), vacation (n = 3), hospital stay (n = 1), finding training too difficult (n = 1). From the remaining 84 patients who completed at least one training session, 46 patients (87%) were in the S8 group and 38 (73%) in the S2 group (p < 0.01, Chi-Square). Data about adherence for both groups are presented in Table 2.

The median total play time was 424 min (range 27–216; 71%) in the total population. The median playtime in group S8 was 528 min (range 63–1264; 88%) vs. 193 min (range 27–2162; 32%) in group S2 (p < 0.001 Mann Whitney U). In the total group, 24 out of 84 patients (29%) played ≥600 min. In groups S8 and S2, 19/53 (36%) and 5/52 (10%), of the patients played ≥600 min (p < 0.001, Chi-Square). The median frequency of logging into the website during the training period was 66 (1–164) in group S8 and 47 (1–318) in group S2 (p < 0.001 Mann Whitney U). A number of seven patients from group S2 did not receive interaction with their supervisor after 4 weeks of brain training, since they did not respond to any of the calls.

The Odds Ratio of being in the moderate and high adherence group was 3.4 [95% Cl 1.98–5.96] (p = 0.00) for patients who received weekly supervision (group S8), -0.9 [95% Cl 0.86 -1.02] (p = 0.06) for older age (each year of life), 1.65 [95% Cl 0.78–3.46] (p = 0.19) for higher self-perceived quality of life (SSQoL), 1.0 [95% Cl 0.99–1.05] (p = 0.26) for higher subjective cognitive failure (CFQ), 1.1 [95% Cl 0.92–1.08] (p = 0.50) for higher self-efficacy (SES) and 1.8 [0.67–4.60] (p = 0.25) for patients with a high educational level.

	All patients	Group 1	Group 2	Between groups
	( <i>n</i> =105)	( <i>n</i> =53)	( <i>n</i> =52)	(p-value)ª
Age in years; median (range)	59 (46-74)	59 (46-74)	59 (46-73)	0.85
Sex, male;	66 (63)	34 (64)	32 (62)	
Type of stroke:				
Infarction, n (%)	68 (67)	29 (55)	41 (79)	
Haemorrhage, n (%)	34 (32)	21 (40)	11 (21)	0.04
Unknown ‡, n (%)	3 (6)	3 (5)	0 (0)	
Location of stroke:				
Hemisphere left, n (%)	50 (48)	23 (43)	27 (52)	
Hemisphere right, n (%)	50 (48)	26 (49)	24 (46)	0.21
Basal ganglia, n (%)	3 (3)	3 (6)	0 (0)	
Unknown <sup>ь</sup> , n (%)	2 (2)	1 (2)	1 (2)	
Time from stroke onset to randomization in	25 (8.2)	26 (9.1)	25 (7.5)	0.32
months; mean (SD)				
Time spent in rehabilitation centre in	5.8 (3.6)	6 (3.6)	5 (3.4)	0.23
months; mean (SD)				
Educational status:				
Low, n (%)	36 (34)	17 (32)	19 (36)	
Intermediate, n (%)	33 (32)	18 (34)	15 (29)	0.94
High, n (%)	36 (34)	18 (34)	18 (35)	
Living alone, n (%)	26 (25)	13 (25)	13 (25)	0.84
Independent in daily functioning, n (%)	101 (96)	52 (98)	54 (95)	0.35
Participation in paid work, n (%)	32 (31)	14 (26)	18 (35)	0.33
Subjective cognitive failure <sup>d</sup> ; median (IQR)	63 (20)	63 (19)	63 (20)	0.62
Quality of life <sup>e</sup> median (IQR)	3.7 (2.5)	3.7 (2.4)	3.8 (2.4)	0.57
Self-efficacy <sup>f</sup> ; median (IQR)	30 (15)	28 (14)	30 (15)	0.83

**Table 1.** Baseline characteristics of patients with stroke who participated in an 8-week cbcr program, presented for all patients and per group.

<sup>a</sup> Differences between the groups were analysed with independent t-tests, Mann-Whitney U tests or Chi-square test, where appropriate.

<sup>b</sup> No data were available for medical status.

<sup>c</sup> Low: lower technical and vocational training; median: secondary technical and vocational training; and high: higher technical and vocational training and university.

<sup>d</sup> Measured with the Cognitive Failures Questionnaire (CFQ): range 0-100; higher scores indicating less cognitive failure.

<sup>e</sup> Measured with the Stroke Specific Quality of Life Questionnaire (SSQoL): range 12-60; higher scores indicating better quality of life.

<sup>f</sup> Measured with the General Self Efficacy Scale (GSES): range 10-40; higher scores indicating greater self-efficacy.

	All patients	Group 1	Group 2	Between groups
	( <i>n</i> = 84)	( <i>n</i> = 46)	( <i>n</i> = 38)	(P-value) <sup>b</sup>
Total time played (minutes):	424	528	193	
	(27–2162)	(63–1264)	(27–2162)	< 0.001
Total time played per cognitive domain (minutes), %:				
Attention	58 (2–466)	60 (3–408)	37 (2–466)	0.002
	(14)	(11)	(19)	
Speed	49 (1–139)	53 (3–139)	6 (1–48)	
	(12)	(10)	(3)	< 0.001
Memory	168 (4–646)	232 (26–646)	95 (4–645)	
	(40)	(44)	(49)	< 0.001
Flexibility	87 (4–1009)	109 (6–349)	50 (4–1009)	
	(21)	(20)	(26)	0.001
Problem solving	53 (1–265)	81 (1–265)	7 (2–168)	
-	(13)	(15)	(3)	< 0.001
Frequency of logging on to the website (number):	50 (1–318)	66 (1–164)	47 (1–318)	<0.001

**Table 2.** Training adherence with an 8-week cbcr program, presented for all stroke patients and per group<sup>a</sup>.

<sup>a</sup> Presented as the median total play time (in minutes) with the range and percentage of the total play time, unless indicated otherwise.

<sup>b</sup> Differences between the groups were analysed with independent t-tests, Mann–Whitney U tests or Chi-square test, where appropriate.

# Discussion

The aim of this study was to compare two different types of support on training adherence in chronic stroke patients. This study found that only 24 out of 105 patients (23%) were able to complete the required amount of playtime (600 min) of brain training. Training adherence was significantly higher for the patients in group S8 (median 528 min, range 63–1264) compared to patients in group S2 (median 193 min, range 27–2162). A small proportion of patients (5/52, 10%), who had interaction with a supervisor twice (group S2), were able to complete the training. Therefore, there are some implications that systematic, regular interaction with a supervisor can increase stroke patients' training adherence with a restitution-focused intervention performed at home.

The observation of non-adherence to a CBCR training program in patients with stroke is in line with findings of other studies.<sup>16-19</sup> The adherence rate for all patients found in the current study was 29% (36% in group S8 vs. 10% in group S2), but cannot be compared to those studies because of lack of adequate reporting of training adherence.<sup>15</sup> Compared to an average adherence rate of 50% found in a review of 101 publications about Webbased interventions in different areas (chronic conditions, lifestyle, and mental health) adherence was low,<sup>21</sup> which confirms non-adherence with CBCR programs is a problem

among patients with stroke.

Although a number of patient characteristics were examined with respect to their association with training adherence, apart from the extent of supervision, no other predictors were found in the current study. Therefore, it remains unclear for which patients with stroke a CBCR program in its current form is most suitable. The intensity of training (600 min within 8 weeks) might be too demanding for stroke patients. It should be further investigated if lower intensity of training can improve adherence among patients with stroke.

The current study has a number of limitations. First, patients in the S8 group were allocated to the intervention group during the RCT and probably received in general more attention (outside the weekly contact) compared to patients from group S2. Second, interactions between the supervisors and patients were not logged (e.g. topics of conversation and duration of contacts) and could therefore not be verified. It cannot be truly concluded that patients who received more support from supervisors showed greater levels of adherence than those who received very little support.

Third, there should be the same time difference between being informed about the study and the start of the intervention in both groups. Patients in the S8 group started the training straight away when it was still exciting and novel, while patients in the S2 group had to wait 16 weeks when excitement could have waned. On the other hand, those patients were probably still motivated to participate in the brain training, given the option to start the training themselves (self-selection). Moreover, the control group has been given some information about stroke at the time when the intervention group was underwent the brain training procedure. This passive intervention could have had limited impacts on the patients. But the information was very general and previously received by patients during their rehabilitation process.

In conclusion, the overall adherence with an online brain training was low and it seems that serious brain training is not suitable for all initially motivated chronic stroke patients. Moreover, despite a number of methodological limitations in the study design, this study provides ground to further investigate the effect of the extent of supervision on training adherence of stroke patients with restitution-focused training. Although only little or no effects were found on cognitive functioning, self-efficacy and quality of life of the restitution-focused brain training in the overall study,<sup>23</sup> this seems important since low adherence rates undermine the effect of interventions. A future study is recommended comparing three groups operating simultaneously with one intervention group receiving weekly support, a second intervention group receiving only two episodes of support and a control group.

#### **Disclosure statement**

No potential conflict of interest was reported by the authors.

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The patient perspective on the use of information and communication technologies and e-health in rehabilitation

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# Abstract

**Introduction:** Success of e-health relies on the extent to which the related technology, such as the electronic device, is accepted by its users. However, there has been limited research on the patients' perspective on use of e-health-related technology in rehabilitation care.

**Objective:** To explore the usage of common electronic devices among rehabilitation patients with access to email and investigate their preferences regarding their usage in rehabilitation.

**Methods:** Adult patients who were admitted for inpatient and/or outpatient rehabilitation and were registered with an email address were invited to complete an electronic questionnaire regarding current and preferred use of information and communication technologies in rehabilitation care.

**Results:** 190 out of 714 invited patients completed the questionnaire, 94 (49%) female, mean age 49 years (SD 16). 149 patients (78%) used one or more devices every day, with the most frequently used devices were: PC/laptop (93%), smartphone (57%) and tablet (47%). Patients mostly preferred to use technology for contact with health professionals (mean 3.15, SD 0.79), followed by access to their personal record (mean 3.09, SD 0.78) and scheduling appointments with health professionals (mean 3.07, SD 0.85).

**Conclusion:** Most patients in rehabilitation used one or more devices almost every day and wish to use these devices in rehabilitation.

# Introduction

In The Netherlands, approximately 90,000 persons are admitted to specialized rehabilitation each year due to illness, an accident or a congenital disease [1]. Multidisciplinary inpatient and outpatient rehabilitation is one of the most expensive health care sectors in the Netherlands [2]. Rising healthcare costs and decreasing number of health professionals [3] as well as the increasing number of patients having access to and using the Internet warrant the need for innovative and efficient rehabilitation strategies.

E-health allows cost-effective disease management as well as patients' empowerment and health promotion [4]. The definition of e-health is "the use of new Information and communication technologies (ICT), mostly internet technology, to improve or support health and health care" [4]. Examples of e-Health in rehabilitation include virtual reality, computer games, assistive technology and online communication tools. Especially, longterm medical care needs could be addressed at significant lower expenditures [5], by means of improved accessibility to rehabilitation programs for clients with mobility impairments [6–8], expanded continuity of care and increased self-management by promoting personalized care, choice and personal autonomy [9]. Indeed, a number of studies showed that e-health is acceptable for subgroup of patients in rehabilitation care [9–11] and has the potential to support management of chronic conditions such as Alzheimer's/ dementia [12], diabetes [13,14] and COPD [15,16].

Despite the many advantages, limited uptake and non-use of ehealth interventions is still a common problem in health care [7,8]. The Normalization Process Theory explain problems with embedding an innovation in practice by the complex interplay between the new technology, individual actions and context [17]. In line with the Diffusion of Innovations theory of Rogers, the fit between the

needs of individuals and groups and the e-health services is of utmost importance [18]. Thus, identifying patients' preferences is required before development and implementation of e-health [18–20]. Indeed, in previous studies it was found that adoption of ehealth was associated with a persons' positive attitude toward technology, self-efficacy and perceived usefulness [19–21]. Moreover, Vankatesh's Unified Theory of Acceptance and Use of Technology (UTAUT) explains current performance and use behaviour explain a large proportion of the variance in the intention to use a new technology [22,23]. In addition, a few studies identified patients' preferences for e-health in rehabilitation by using a qualitative research design [7,24,25]. These studies found that patients with cancer and diabetes were willing to use ICT in (rehabilitation) care for self-monitoring of symptoms, web-based physical exercise programs [7], communication with peers [24,25] and access to their health record [7]. However, a lack of studies with a quantitative design impaired generalization of results and so far it is unclear what usage preferences are for other patient

groups in rehabilitation care.

In summary, for the rehabilitation setting specifically it is unclear which ICT devices are most commonly used by patients in rehabilitation and what their needs and preferences are regarding e-health services needs to be delivered.

This paper aims to contribute to future research and use of ICT tools in rehabilitation care. Therefore, we aim (1) to explore usage of ICT devices among rehabilitation patients and (2) to investigate patients' perspective to incorporate this technology in the rehabilitation process.

# Methods

### Study design

This cross-sectional study, involving a one-time online survey, was conducted between March 2014 and May 2014 among (former) patients who had been admitted to a Rehabilitation Centre in The Netherlands. The study protocol was presented to the Medical Ethical Committee of the Leiden University Medical Center. They judged the study as non-medical research according to the Medical Research Involving Human Subjects Act.

# Patients

Patients were invited to participate in the study if they met the following criteria: (1) 18 years and older, (2) admitted for inpatient and/or outpatient rehabilitation between 2008 and 2013 and (3) being registered with an email address to select patients with access to and using ICT. Potentially eligible patients were first identified by searching the electronic patient registers of the rehabilitation centre. All eligible patients received an email with information about the study and an invitation to fill in the survey by using the digital link.

# Survey

An online questionnaire was developed in collaboration with patient representatives in order to measure usage preferences of electronic devices in rehabilitation health care. The self-developed questionnaire comprised a maximum of 61 questions that aimed to identify current possession and use of ICT devices (maximum of 27 questions) and desired usage of ICT devices in the rehabilitation process in the future (maximum of 15 questions).

In addition, 19 questions were about following socio-demographics and disease characteristics: gender, age, living status (living alone or living with partner/family), educational level (low: up to and including lower technical and vocational training; medium: up to and including secondary technical and vocational training; and high: up to and including higher technical and vocational training and university) [26] and occupational

status (student, employed, unemployed and disabled of retired).

For 27 out of 61 questions, patients were able to select one or more answers from a given set of options questions (a minimal of two and a maximum of eight options), 14 questions required an open answer and 10 questions required the answer "Yes" or "No". Moreover, 10 questions that were used to examine user preferences were initially measured on a 4-point Likert scale (1 ¼ totally disagree, 2 ¼ disagree, 3 ¼ agree and 4 ¼ totally agree). These items were used to calculate the mean per item in order to make a ranking from highest till lowest preference.

The questionnaire was pilot tested among 59 patients from the rehabilitation centre for completeness, feasibility, readability and presentation (e.g., perceived question difficulties, response errors, screen layout, etc.). The pilot testing lead to minor changes in the wording and format of the final questionnaire.

A total of three reminders were sent for participation in the study. Patients received the first reminder 2 weeks after invitation. The second reminder was sent 1 week after the first reminder. All data from the online survey were collected anonymously.

#### **Statistical analysis**

Patient characteristics, possession and use of ICT devices and user preferences of ICT in rehabilitation were analyzed using descriptive statistics and presented as numbers with percentages, means with standard deviations (SD) or medians with ranges (Inter Quartile Range; IQR), i.e., 25th percentile–75th percentile) where appropriate. Results about possession and use of ICT devices were presented for the total group and for different age categories based on the 25% percentile distribution of age. Age was divided in four categories: (1) 18–36 years, (2) 37–51 years, (3) 52–61 years and (4) 62 > years. The group of eligible patients was compared to the group of responded patients regarding their age and gender using the independent ttests and the Mann Whitney U test, the Chi-square test. All statistical analyses were performed using Statistical Packages for the Social Sciences (IBM SPSS 22.0 for Windows).

# Results

According to the registers, 714 patients who were aged 18 years old, received outpatient or inpatient rehabilitation between 2008 and 2013 and were registered with an e-mail address, were identified and invited to participate in the study by email (Figure 1). A number of 233 patients filled in the questionnaire, from which 43 questionnaires were incomplete, resulting in a total of 190 completed questionnaires out of 714 invited patients (27%).



Figure 1. Flow of patients.

### **Patient characteristics**

Table 1 shows that the 190 patients who completed the questionnaire had a mean age of 49 years (SD=16), 94 (49%) were female and 52 (27%) were living alone. The majority of patients followed either a "higher education" (41%) or "middle education" (41%) and 19% received "lower education". Most patients were diagnosed with "acquired brain injury" (42%), followed by "neuromuscular disease" (13%) and "orthopaedics" (6%). The majority of the patients (73%) had outpatient rehabilitation treatment, 20 patients (10%) had inpatient rehabilitation, 26 patients (14%) had had both and two patients (1%) received a short rehabilitation program for heart rehabilitation.

The eligible patients had a mean age of 44 years (SD=19) and 341 (49%) were female. No significant differences were found for age and gender between the group of eligible patients and group of responded patients.

Characteristics	
Age in years (mean, SD)	49 (16)
Female gender (number, %)	94 (49)
Living status (number, %)	
Living alone	52 (27)
Living with partner/family	138 (73)
Educational level (number, %) <sup>a</sup>	
Lower	36 (19)
Middle	77 (40)
Higher	77 (40)
Type of rehabilitation (number, %)	
Inpatient	20 (10)
Outpatient	142 (73)
Both	26 (14)
None <sup>b</sup>	2 (1)
Diagnostic group (number, %)	
Acquired Brain Injury (stroke, tumour, trauma)	79 (42)
Cardiological	5 (3)
Chronic pain	9 (5)
Hand injury	4 (2)
Neuromuscular disease	24 (13)
Orthopaedics	13 (6)
Spinal cord injury	12 (6)
Trauma surgery (amputation)	4 (2)
Other	40 (21)

**Table 1.** Patient characteristics of 190 patients in rehabilitation care who participated in this cross-sectional study.

<sup>a</sup> Low: up to and including lower technical and vocational training; medium: up to and including secondary technical and vocational training; and high: up to and including higher technical and vocational training and university. <sup>b</sup> A short heart rehabilitation program.

### Possession and usage of ICT devices

Possession and use of ICT devices among the 190 patients who responded to the questionnaire are shown in Table 2 for the total group and four categories of age. The most frequently possessed ICT device was a computer/laptop (93%), followed by a smartphone (57%), tablet (47%), game console (16%), smart TV (15%) and e-reader (14%). Five patients (3%) possessed no ICT device at all. The mean number (SD) of possessed ICT devices per patient was 2.8 (SD ¼ 1.5).

In the first age category (1st quartile of patients between 18–37 years old), the mean number (SD) of possessed ICT devices was 3.1 (SD ¼ 1.6). The most possessed ICT devices

were the laptop (75%) and smartphone (75%). In the second age category (38–51 years old), the mean number of ICT devices was 2.9 (SD 1.5), with most possessed ICT devices being the smartphone (62%), the tablet (62%) and the pc (62%). In the third age category (52–61 years old), the mean number of ICT devices was 3.2 (SD 1.5). The two most possessed devices were the laptop (75%) and the pc (71%). In the fourth age category (62 > years old), the mean number of possessed ICT devices was 1.9 (SD 1.1). The two most possessed ICT devices where the pc (57%) and the laptop (47%).

A number of 149/190 (78%) responded to use their ICT devices all 7 days of the week, whereas two patients (1%) reported to use their devices less than once a week. From the patients who used their ICT device all 7 days a week, 36 patients (77%) were from the first age category (18–37 years old), 38 patients (91%) from the second age category, 37 (77%) from the third age category (52–61 years old) and 38 (75%) from the fourth age category (62 > years old).

The computer/laptop was the most frequently used ICT device by patients for e-mail (166/190 patients, 94%), to search for information (162/190 patients, 92%), for support (e.g., scheduling, banking and route planning) (137/190 patients, 78%) and social media (104/190, 59%). For physical and mental exercise the PC/ laptop was used by 39 patients (22%), followed by a tablet by 21 patients (24%), a smartphone by 12 patients (11%) and a game console by 8 patients (26%).

	All age	18–36	37–51	52–61	>62
	categories	years	years	years	years
Possession of ICT devices: <sup>b</sup>					
PC/Laptop	176 (93)	46 (98)	37 (88)	47(98)	46 (87)
Tablet	89 (47)	19 (40)	26 (62)	27 (56)	17 (32)
Smartphone	109 (57)	35 (76)	29 (69)	20 (63)	15 (28)
E-reader	27 (14)	5 (11)	9 (21)	8 (17)	5 (9)
Game console	31 (16)	18 (38)	5 (12)	7 (15)	1 (2)
Smart TV	29 (15)	9 (19)	5 (12)	11 (23)	4 (8)
No one of above	5 (3)	1(2)	0 (0)	1 (2)	3 (6)
The frequency of use of any ICT device:					
Less than once a week	2 (1)	0 (0)	1 (2)	0 (0)	1 (2)
1–3 days per week	11 (6)	4 (9)	1 (2)	3 (6)	3 (6)
4–6 days a week	26 (14)	7 (15)	2 (5)	8 (17)	9 (18)
7 days per week	149 (78)	36 (77)	38 (91)	37 (77)	38 (75)

Table 2. Usage of ICT devices among 190 patients in rehabilitation care<sup>a</sup>.
	All age categories	18–36 years	37–51 years	52–61 years	>62 years	
Use of ICT device to search for information	1: <sup>b</sup>					
PC/Laptop	162 (92)	40 (87)	36(87)	44 (94)	42 (91)	
Tablet	73 (82)	11 (58)	23 (86)	25 (93)	14 (82)	
Smartphone	76 (40)	27 (77)	18 (62)	20 (67)	11 (73)	
Use of ICT device for email: <sup>b</sup>						
PC/Laptop	166 (94)	42 (91)	36 (97)	45 (96)	43 (93)	
Tablet	62 (70)	11 (58)	18 (69)	19 (70)	14 (82)	
Smartphone	84 (77)	27 (77)	22 (76)	24 (80)	11 (73)	
Use of ICT device for social media: <sup>b</sup>						
PC/Laptop	104 (59)	37 (80)	26 (70)	24 (51)	17 (37)	
Tablet	47 (53)	14 (74)	10 (39)	13 (48)	10 (59)	
Smartphone	61 (56)	29 (83)	14 (48)	14 (47)	4 (27)	
Use of ICT device for physical and mental	exercise: <sup>b</sup>					
PC/Laptop	39 (22)	12 (26)	8 (22)	13 (28)	6 (13)	
Tablet	21 (24)	6 (32)	5 (19)	6 (22)	4 (24)	
Smartphone	12 (11)	5 (14)	5 (17)	2 (7)	0 (0)	
Game console	8 (26)	5 (14)	2 (7)	0 (0)	1 (2)	
Use of ICT device for support (e.g., schedu	Use of ICT device for support (e.g., scheduling, banking, route planning): <sup>b</sup>					
PC/Laptop	137 (78)	34 (74)	31 (84)	37 (79)	35 (76)	
Tablet	56 (63)	9 (47)	17 (65)	19 (70)	11 (65)	
Smartphone	91 (83)	28 (80)	25 (86)	26 (87)	12 (80)	

#### Table 2. Continued.

<sup>a</sup> Indicated as the number of patients possessing the device (%).

<sup>b</sup> Patients could give more than one answer to each question.

## Usage preferences of ICT devices in future rehabilitation

A top 10 of usage preferences of ICT devices for rehabilitation in the future are shown in Table 3. It was found that patients (highly) prefer to have digital contact with a health professional (mean 3.15, SD 0.79). Second, patients want to have digital access to their personal record in which both the patient and the health professional can make notes (mean, 3.09, SD 0.78). Third, digital scheduling of appointments with a health professional was highly preferred by most patients (mean 3.07, SD 0.85).

About 108 out of 190 patients (58%) agreed they want to fill in digital questionnaires about quality of care (mean 3.03, SD 0.84). Moreover, 93 patients (49%) agreed and 49 patients (26%) highly agreed they want to do exercises at home using a computer (mean 2.97, SD 0.80). 79/190 patients agreed (42%) and 34/190 patients (18%) highly agreed they

want to use ICT for self-measurement of health status (e.g., blood pressure) and forwarding the results to a health professional, while 62 patients (33%) disagreed and 13 patients (7%) highly disagreed. Contact with other patients (peers) was a preference of 90/190 patients (47%), but not for 55/ 190 patients (29%).

Less important user preferences for future rehabilitation were digital participation in group therapy under supervision of a health professional (mean 2.36, SD 0.86), receiving information and latest news from the rehabilitation centre (mean 2.56, SD 0.91) and getting support from health professionals at home (mean 2.61, SD ¼ 0.80).

Fa	ctor	Totally	Disagree	Agree	Totally	Mean (SD)
		disagree	5	5	agree	. ,
1.	Having contact with a health professional	9 (4.7)	19 (10)	95 (50)	65 (34)	3.15 (0.79)
2.	Access to health record to make notes	9 (4.7)	22 (11.6)	101 (53.2)	56 (29.5)	3.09 (0.78)
3.	Schedule appointments with health professional	12 (6.3)	26 (13.7)	87 (45.8)	63 (33.2)	3.07 (0.85)
4.	Fill in questionnaires about quality of care	11 (5.8)	21 (11.1)	108 (56.8)	48 (25.2)	3.03 (0.84)
5.	Exercises to do at home	8 (4.2)	38 (20)	93 (48.9)	49 (25.8)	2.97 (0.80)
6.	Self-measurement and forwarding results to a health professional	13 (6.8)	62 (32.6)	79 (41.6)	34 (17.9)	2.71 (0.84)
7.	Contact with other patients	18 (9.5)	55 (28.9)	90 (47.4)	25 (13.2)	2.65 (0.83)
8.	Support from health professionals at home	15 (7.9)	65 (34.2)	86 (45.3)	22 (11.6)	2.61 (0.80)
9.	Information and latest news from the rehabilitation centre	18 (9.5)	30 (15.8)	52 (27.4)	15 (7.9)	2.56 (0.91)
10	). Participating in group therapy under supervision of a health professional	28 (14.7)	85 (44.7)	55 (28.9)	20 (10.5)	2.36 (0.86)

Table 3. Patients' ranking of usage preferences of ICT devices in future rehabilitation<sup>a</sup>.

<sup>a</sup> Data are presented as the number with percentages (%) unless indicated otherwise.

# Discussion

This cross-sectional survey explored the usage of ICT devices and usage preferences to incorporate ICT devices in rehabilitation treatment among 190 adult rehabilitation patients from a rehabilitation centre in the Netherlands with access to email. We found that more than 90% of the responded patients used at least one ICT device, from which a computer/ laptop most frequently, followed by a smartphone and then a tablet. Younger patients were found to use more devices than older patients, but older patients use their ICT devices with the same frequency as younger patients. Patients used their devices for e-mail, finding information, support (e.g., scheduling, banking, route planning), social media and physical

and mental exercises. Patients' usage preferences of ICT devices in rehabilitation were: having contact with health professionals (telecommunication), have access to their health record and scheduling appointments with health professionals.

Population based studies by the Dutch Central Agency for Statistics (2015) showed that in 2014 80% of the households in The Netherlands were possessing a laptop, 65% a PC, 63% a tablet and 74% a smartphone [27]. Comparing these data to the current study, possession of a computer/PC (93%) is slightly higher, although possession of a tablet (47%) and smartphone (57%) is lower among the responded patients in rehabilitation. Purposes of using ICT devices found in the current study were almost similar compared to the general population [28]. A more recent study amongst patients with multiple sclerosis showed that 86% (44/51) used a mobile phone [29]. From patients with cardiovascular disease, Buys et al. found most patients (97%) had a mobile phone, from which 64% owned a smartphone [30]. In the current study, possession of a smartphone was slightly lower (57%).

A few studies investigated patient preferences for use of ICT in (rehabilitation) health care using a qualitative research design [7,24,25]. Therefore, frequency data found in the current study could not be compared to other literature. First, this study showed that 101 out of 190 patients (53%) highly prefer to have insight in their personal record and also want to use it to make notes for health professionals. Although growing patient demand to online personal health record (PHR) access was already recognized in other studies [25,31–33], it is still not widely adopted. A study among 283 individuals over the age of 18 found that individual factors (satisfaction with provider, belief of the tool to be empowering) and environmental factors (communication tactics, technology characteristics and management support) influence intentions to use a PHR [34]. These aspects should be taken into account with the implementation of PHRs. Moreover, development of such systems should focus on patients and their families as well as on physicians and other healthcare professionals [33].

Second, communication with peers was identified as patient preference among 90/190 patients (47%) and also found in other studies [24–25]. Available evidence suggests that online peer-topeer support interventions might be beneficial for users [35]. More research is needed to further investigate how ICT tools can be used to fulfil to patients' preferences for peer support. Third, we found a group of patients in rehabilitation preferred to use ICT to schedule appointments with their clinicians. This was not identified as a preference in previous studies. Moreover, a sub group of patients wanted to use ICT for self-monitoring and physical exercises, which is in line with preferences of patients with cancer [7] and cardiac patients [30].

Transferability of the findings for usage of devices to other contexts might be impaired, because participants were a subgroup from the general population of patients in rehabilitation and their treatment process might have influenced their preferences for e-health in future rehabilitation. More importantly, participants were from two rehabilitation

centres in one region in one country. There may be large differences in access to and usage of ICT among countries, hampering the generalizability. As an example, the highest proportion of households with internet access in Europe in 2016 was recorded in the Netherlands and Luxembourg (97%). By contrast, the lowest rate was found in Bulgaria (64%) [36].

A limitation of the current study is that only patients with an email address were invited to fill in the electronic questionnaire. However, we aimed to identify usage and preferences in patients who have access to ICT and having an email address suggests the latter. Future studies should also include patients in rehabilitation with low level of access to ICT [10], lack of ICT experience [10,22,37] and personal traits for ICT utilization (e.g., age and health condition) [38] in order to better understand how to enable all patients to benefit from of e-health.

In addition, only 190 out of 714 patients responded (27%) and data about possession and usage of ICT devices is approximately 2.5 years old. However, we compared it with data from 2015 and the availability of data like ours is scarce in health care and rehabilitation in particular. Moreover, to the best of our knowledge, this is one of the few studies investigating the use of ICT devices and usage preferences amongst patients in rehabilitation. Since a quantitative study design was used a high number of patients participated in the study (n ¼ 190).

This study found that the majority of patients in rehabilitation with a registered email address used one or more ICT devices every day of the week (younger patients more often than older patients). The most frequently used devices were a computer/laptop, smartphone and tablet. According to patients, e-health in rehabilitation needs to include online access to their health record, communication with peers and scheduling appointments with health professionals. To better assist patients with e-health in rehabilitation care in the future, further research is needed about how the preferences identified in the current study could be implemented in rehabilitation care by using the most commonly used ICT devices (computer/laptop, smartphone and tablet).

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#### **Disclosure statement**

No potential conflict of interest was reported by the author(s).

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# How to improve eRehabilitation programs in stroke care? A focus group study to identify requirements of end-users.

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# Abstract

**Background:** A user-centered design approach for eHealth interventions improves their effectiveness in stroke rehabilitation. Nevertheless, insight into requirements of end-users (patients/informal caregivers and/or health professionals) for eRehabilitation is lacking. The aim of this study was to identify end-user requirements for a comprehensive eHealth program in stroke rehabilitation.

**Methods:** Eight focus groups were conducted to identify user requirements; six with patients/informal caregivers and two with health professionals involved in stroke rehabilitation (rehabilitation physicians, physiotherapists, occupational therapists, psychologists, team coordinators, speech therapist). The focus groups were audiotaped and transcribed in full. Direct content analysis was used to identify the end-user requirements for stroke eHealth interventions concerning three categories: accessibility, usability and content.

**Results:** In total, 45 requirements for the accessibility, usability and content of a stroke eRehabilitation program emerged from the focus groups. Most requirements concerned content (27 requirements), followed by usability (12 requirements) and accessibility (6 requirements). Patients/informal caregivers and health professionals each identified 37 requirements, respectively, with 29 of them overlapping.

**Conclusions:** Requirements between stroke patients/informal caregivers and health professionals differed on several aspects. Therefore, involving the perspectives of all end users in the design process of stroke eRehabilitation programs is needed to achieve a user-centered design.

**Trial registration:** The study was approved by the Medical Ethical Review Board of the Leiden University Medical Center [P15.281].

# Introduction

Stroke, or a cerebrovascular accident (CVA), often occurs when a clot in the blood vessel blocks the blood flow to the brain cells (ischemic stroke) or when a blood vessel in the brain breaks or ruptures (hemorrhagic stroke). Subsequently, brain cells are deprived of oxygen and glucose, causing damage to the brain tissues. Although stroke mortality rates have decreased in Western countries, the prevalence of stroke is increasing [1].

Stroke survivors can experience lasting impairments with disruption of psychological and social well-being, including activities of daily life, cognitive and emotional functioning and social relationships [2,3]. Therefore, stroke rehabilitation is a comprehensive, multidimensional process including multiple interventions aimed at individual treatment goals in impairment, activity or participation [4], which involves both the patient, their informal caregivers and various health professionals (e.g. physicians, physical and occupational therapists, speech-language pathologists, psychologists) [5].

EHealth is proposed as a useful tool to improve efficiency and quality of rehabilitation care [6,7]. Ehealth is defined as 'the use of Information and Communication Technology (ICT) to improve or support interventions in health care'. Consequently, (the effectiveness of) use of eHealth in rehabilitation, also known as eRehabilitation, after stroke has become a research area of interest [8-12]. Examples of stroke eRehabilitation programs used in studies are serious brain games, virtual reality or telerehabilitation [8,13,14].

Despite widespread agreement about the potentials of eRehabilitation, eHealth interventions often do not match with the requirements of intended users (e.g. patients and health care professionals), impairing their adoption in health care [15]. Therefore, a 'user-centered design approach', in which the requirements/needs of end users are taken into account at each stage of the design of a new product, intervention or service is highly recommended [16-22]. Requirements of end users involved in stroke care (patients, their informal caregivers and different health professionals) can be identified by means of qualitative research (e.g. interviews, focus groups, brainstorm sessions) [23,24].

Studies assessing requirements/needs of intended users of an eRehabilitation program [17, 25-32] found concerning the content, that interventions should be adapted to the patients' own circumstances [25,30,31] (including personal goals [17,27]), should deliver rewarding feedback [32] and need to demonstrate outcomes on training performances [25,27,28,31]. Moreover, eRehabilitation programs must be user-friendly [17,25,28,31] (e.g. size of buttons, colors, information delivery, instructions etc.).

However, requirements should not only be identified for the content and usability of eRehabilitation programs, but also for their accessibility in order to enable successful adoption of eRehabilitation in health care [33,34]. This is important since easy access of eHealth technology (accessibility) allows users to start using it and the extent to which the technology can be used allows users to achieve specified goals (usability) so that users benefit from the services provided (content). Moreover, it is argued that identifying user requirements for eHealth should go beyond functional and technical requirements and also needs to consider requirements for accessibility and acceptability [34,35,46].

In addition, the requirements in these studies mainly addressed only one aspect of stroke recovery (e.g. hand function, upper limb rehabilitation, weight shifting) or one technology tool (e.g. a game, robotica) [25,27-31] and not to a comprehensive eRehabilitation program in which multiple modalities are delivered. Although there have been some studies focusing on this area [37-39], requirements of intended users for comprehensive eRehabilitation that covers multiple aspects of stroke management are rather unknown.

Therefore, the aim of this study was to identify the requirements of end users (patients, their informal caregivers and health professionals) for the content, usability and accessibility of a comprehensive eRehabilitation program in stroke care.

# Methods

# Design

To identify the requirements for eRehabilitation in stroke care, a qualitative focus group study was employed with end users. In this study end users were patients with stroke, their informal caregivers and health professionals involved in stroke care. Focus groups are a useful method to gather information about perceptions of participants and to identify perceived requirements of subgroups [40]. The study took place between January 2016 and March 2016 in two rehabilitation centers in the Netherlands, both providing inpatient and outpatient multidisciplinary stroke care: Rijnlands Rehabilitation Center (RRC) in the city of Leiden and Sophia Rehabilitation (SR) in the area of The Hague.

# **Recruitment and inclusion**

## Patients and informal caregivers

Patients were recruited based on the following criteria: >18 years, diagnosed with stroke, completed rehabilitation which started after June 2011. From a group of circa 2.700 potential participants which are treated in one of the two rehabilitation centers, 200 patients of each rehabilitation center were randomly selected (Figure 1). Those 400 patients received a letter with information about the study and an invitation to participate from their former rehabilitation physician. Invitations to patients were directed to the informal caregiver as well, which could be a partner, child, parent or friend who is involved in the daily life of the patient. In addition, a group of five former stroke patients from SR (innovation partners),

who come together on a regular basis to discuss the newest innovations in rehabilitation, were invited.

The invitation included a self-developed questionnaire concerning marital status (single, married, divorced, widow/widower), daily activities ((un)paid job, household tasks, student), education level (low: up to and including lower technical and vocational training, medium: up to and including secondary technical and vocational training, and high: up to and including higher technical and vocational training and university), impairments as a consequence of stroke (physical, communication, cognition), use of ICT-devices (smartphone, tablet, laptop, pc) and the purpose of this use (applications, email, information, games, exercises). From the patients/informal caregivers that indicated their willingness to participate, we purposively selected both man and women, young (<20 age) and older (>70 age) patients, patients with less (e.g. using a computer only for mail) and more experience with digital devices (e.g. using a smartphone/tablet for applications) and patients with communication, cognitive and physical impairments. Patients with aphasia or severe cognitive problems were asked to bring their informal caregiver in order to help them represent their perspective.

## Health professionals

Health professionals from the two rehabilitation centers (n=56, 29 at Sophia Rehabilitation, 27 at Rijnlands Rehabilitation Centre) were invited to participate by e-mail and selected based on the following criteria: a practiced and certified health professional (rehabilitation physician, physical therapist, occupational therapist, speech therapist and/or a psychologist) with  $\geq$ two years of working experience in multidisciplinary stroke care or working as a coordinator of a multidisciplinary team. A selection was made based on availability and profession, so that each profession was represented.

# Data collection

#### Focus groups

It was planned to execute four focus groups at the two Rehabilitation centers, two with patients/informal caregivers and two with health professionals. Separate groups were organized with patients/informal caregivers vs health professionals in order to allow patients/informal caregivers to speak freely about experiences in the rehabilitation center and professionals to share their opinions about delivery of care. The aimed group size was 6 to 8 participants, although higher invitation rates were used to account for participants who would decline last minute [41].

A moderator (MW; Msc, female), assistant (BB; Msc, female/HB; Msc, female) and observer (SH; physiotherapist, male/PK; MD, female) conducted the focus groups. The assistant contributed with questions, made sure all participants were involved in the discussion

and managed the tape-recorders and time. The observer observed and took notes. The moderator and assistant had no involvement in patient care and a master's degree in Health Sciences/Human Movement Sciences including education about conduct of interviews. The moderator was trained in communication skills (listening, summarizing and disquisition). Patients/informal caregivers received travel costs reimbursement and were rewarded for participating with a gift card of 10 euro.

#### Interview guide

A semi-structured interview guide was developed with open-ended questions concerning three categories of eRehabilitation: accessibility, usability and content. These categories were based on research findings. Existing eHealth frameworks as a theory and guidance for the focus groups were considered by the research team, for instance the 'Technology Acceptance Model' [42], the 'Comprehensive Health Technology Assessment Framework' [43] and the 'Evaluation of e-health services: user's perspective criteria' [44]. However, most frameworks focus on the evaluation process [43-48] instead of the development process of eHealth technologies [49-52], and although the frameworks for development of eHealth admitted user requirements should be identified in an early stage, none of these frameworks described which aspects to explore.

In relation to the focus in this study, accessibility was defined by the research team as "easy access to eRehabilitation for all end users, including patients with disabilities as a consequence of stroke". Usability was defined as "the extent to which the eRehabilitation service can be used by the specified users (patients, informal caregivers and health professionals) to achieve specified goals with effectiveness, efficiency and satisfaction (e.g. recovery after stroke) in a specific context of use (e.g. during their stay in the rehabilitation center and/or at home)" [35]. Content was defined as "everything end users want to include in eRehabilitation (e.g. services, information, applications, etc.) to achieve specified goals for eRehabilitation in their rehabilitation process."

Examples of questions included were: "what ICT devices would you like to use for eRehabilitation?" (accessibility), "what aspects would make eRehabilitation easy to use?" (usability) and "what elements of care should be included in an eRehabilitation program?" (content). Prompts were included in the interview guide (e.g. example of eRehabilitation, pictures, etc.) to facilitate participants in verbalizing thoughts.

The interview guide was tested in a pilot focus group with a group of former stroke patients. No adjustments were made to the interview guide and therefore data from this focus group were included in the analysis. The focus groups lasted two hours, including breaks, and were audiotaped and transcribed in full.

#### **Participants**

Out of the 400 patients and their informal caregivers (200 at RRC/200 at SR) invited to participate in this study, 53 patients (27 at SR/26 at RRC) and 22 informal caregivers (11 at SR/11 at RC) responded. Reasons for non-response were not recorded. Of the 53 responded patients, 32 were invited to participate of whom 27 were present at the focus groups (Figure 1). Five innovation partners were also present, so that a total of 32 patients participated. Of these patients, 15 had an informal caregiver that participated with them in the focus groups. Seven out of these 15 caregivers were required to support a patient with aphasia or severe cognitive problems. In total 56 health professionals (29 at SR/27 at RCC) were invited, from which 22 responded (11 at SR/11 at RRC). Nine professionals were not able to attend the focus groups, so that eventually 13 professionals participated in the study (7 at SR/6 at RRC).

In total, eight focus groups were conducted; six with patients/informal caregivers and two with health professionals. The characteristics of all patients, informal caregivers and health professionals are presented in Table 1.



Figure 1. Flow of inclusion

	Patients	Informal caregivers	Health professionals
Number of participants	321	15	13
Gender, male; number (%)	19 (59)	4 (27)	3 (23)
Age in years; mean (SD)	57 (15)	61 (10)	-
Time since stroke in months; mean (SD)	28 (14)	-	-
Physical impairment; number (%)	20 (63)	-	-
Problems with communication; number (%)	16 (50)	-	-
Cognitive impairment; number (%)	24 (75)	-	-
Using digital devices (laptop, tablet, smartphone) in daily life; number (%)	32 (100)	-	-
Purpose of using digital devices; number (%) <sup>a</sup> :			
Access to email	18 (56)		
Access to applications	15 (47)		
Searching information	10 (31)		
Playing games	14 (44)		
Doing exercises	8 (25)		
Profession; number (%):			
Physiotherapist	-	-	3 (23)
Psychologist	-	-	1 (8)
Occupational therapist	-	-	3 (23)
Speech therapist	-	-	1 (8)
Rehabilitation physician	-	-	4 (31)
Team coordinator	-	-	1 (8)

**Table 1.** Participants of the focus groups, including the pilot focus group, exploring end-user requirements for eRehabilitation in stroke care.

<sup>a</sup> Patients could give more than one answer to each question.

# Ethical issues and approval

Informed consent was obtained from all participants. Participants were informed that all their comments were confidential and would be used to improve rehabilitation treatment. It was explicitly mentioned that participation would not affect future treatment in the rehabilitation center. Collected data were reported in such way that persons could not be identified. Only researchers involved in the data analysis had access to the data. The study was approved by the Medical Ethical Review Board of the Leiden University Medical Center [P15.281]. COREQ guidelines were used for adequate reporting of the study [53].

# Data analysis

The audio-tapes of the focus groups were transcribed in full. Directed content analysis was

used [54], in which the three predetermined categories of the interview guide (accessibility, usability and content) were used as guidance for analyzing the data. First, two (MW, BB) out of four researchers (BB, MW, SH, PK) independently highlighted text that appeared to reflect a requirement for eRehabilitation (codes). These requirements were directly classified in one of the prescribed categories (accessibility, usability or content). Second, researcher MW examined the data to determine whether subcategories were needed and requirements with comparable content were merged (subcategories). A new category was added if one of the three prescribed categories were not sufficient for identified requirements. It was aimed to stop conducting focus groups when no additional categories of user requirements were found, indicating saturation [40]. In each step of the analysis, discrepancies were compared and discussed in order to reach consensus. When the two researchers (BB, MW) still disagreed, a third researcher (JM), made a final decision. The framework and illustrations were discussed with two other researchers (LB, JM). Transcripts and findings were not returned to participants for comments. The 2 software package Excel 2010 was used to organize codes, subcategories and categories.

## Results

#### **User requirements**

In total, 45 user requirements (codes) for a comprehensive eRehabilitation program were identified for the three prescribed categories (accessibility, usability and content). No categories were added, since the three prescribed categories were sufficient for all identified requirements. The requirements were classified into a total number of eleven self-determined subcategories. Most subcategories and requirements were identified for Content (6 subcategories/27 requirements), followed by Usability (4 subcategories/12 requirements) and Accessibility (1 subcategory/6 requirements). The eleven subcategories are presented in Figure 2. An additional table presents the user requirements for eRehabilitation in stroke care for each (sub)category (Table 2).

A total number of 45 requirements were retrieved from the focus groups. Thirtyseven requirements were mentioned by patients/informal caregivers (6 for accessibility, 12 for usability and 19 for content) and 37 by health professionals (6 for accessibility, 9 for usability and 22 for content). Thirty-two requirements were overlapping between patients/informal caregivers and health professionals, 8 requirements were unique for patients/informal caregivers and 8 requirements were only mentioned by health professionals. The results will be further explained in the following sections by a description of the identified user requirements for each category within each category.



**Figure 2.** Subcategories of user requirements for the accessibility, usability and content of a stroke eRehabilitation program.

Categories	Subcategories	Requirements	Patients / caregivers	Professionals
Accessibility:	Access:	No internet connection is required to use eHealth interventions (offline use). (1)	Х	Х
		eHealth interventions are accessible without logging on each time. (2)	Х	Х
		Applicable to most commonly possessed ICT-devices (laptop, tablet and smartphone). (3)	Х	
		Access for health professionals to the electronic patient record to stay informed about training results. (4)	Х	
		Applicable on computers at the rehabilitation center and synchronization with programmes used for the electronic patient record. (5)		Х
		Different eHealth interventions should be brought together in one central dashboard. (6)		Х
Usability:	Product attributes (visual):	Use of pictograms, symbols and graphics. (1)	Х	Х
		Non-flashing and tranquil interface. (2)	Х	Х
		Adjustable lay-out settings (font style, font size, background and colors). (3)	Х	

**Table 2.** Requirements for an eRehabilitation program in stroke care according to patients, informal caregivers and health professionals.

Categories	Subcategories	Requirements	Patients / caregivers	Professionals
Usability:	Product attributes (auditory):	Ability to listen to written text. (4)	Х	Х
		Sounds for alert or as feedback. (5)	Х	
	Product attributes (simplicity):	Limited amount of open webpages as a consequence of using a service. (6)	Х	Х
		Limited amount of information on a single screen. (7)	Х	
		Limited options on a single screen to click further to another screen. (8)	Х	
	Service (support):	Menu with frequently asked questions (FAC). (9)	Х	Х
		Videos with instructions on how to use eRehabilitation. (10)	Х	Х
		Helpdesk. (11)	Х	Х
		Direct assistance at home/ workplace. (12)	Х	
Content	Personalized training	Physical exercises. (1)	Х	Х
	facilities:	Exercises for cognitive functioning. (2)	Х	Х
		Speech exercises. (3)	Х	Х
	Tracking:	Monitor activities in daily living (i.e. what activities and for how long). (4)	Х	Х
		A video system to record exercises at home. (5)	Х	
		Monitor a patients' health status (e.g. body weight, heart rate function, etc.). (6)		Х
	Agenda and reminders:	Insight in the rehabilitation schedule of a patient. (7)	Х	Х
		A reminder function for scheduled appointments. (8)	Х	Х
		Scheduled time to use eRehabilitation (digital training). (9)	Х	Х
		Scheduling appointments with health professionals on the initiative of patients and their informal caregivers. (10)	Х	Х
	Communication:	Contact with peers (patients) to share experiences on how to cope with having a stroke. (11)	Х	Х
		Contact with peers (care givers) to share experiences on how to cope with having a relative with stroke. (12)	Х	Х
		Communication between patients and their informal caregivers and health professionals from a distance (telecommunication). (13)	Х	Х

#### Table 2. Continued.

#### Table 2. Continued.

Categories	Subcategories	Requirements	Patients / caregivers	Professionals
Content	Information:	General information about stroke. (14)	Х	Х
		Hyperlinks to reliable and relevant web pages for patients with stroke and their informal caregivers. (15)	Х	Х
		Information about patient organizations. (16)	Х	Х
		Information on how to cope with consequences of stroke (psycho- education). (17)	Х	Х
		Descriptions on how to perform daily activities (strategy training). (18)	Х	
		Insight in agreements and information discussed during a consult. (19)		Х
		Insight in final reports of a patients' rehabilitation process. (20)		Х
	Goal setting and evaluation:	Setting goals for eRehabilitation. (21)	Х	Х
		Evaluation of goals for eRehabilitation. (22)	Х	Х
		Feedback about training results (i.e. insight in what is trained, the number of completed training sessions and training outcomes). (23)	Х	Х
		Feedback on goals (i.e. when a goal is accomplished). (24)	Х	Х
		Use of clinical assessments for goal setting and goal evaluation. (25)		Х
		Use of valid questionnaires for goal setting and goal evaluation. (26)		Х
		Compare training outcomes of a single patient with those of other patients. (27)		Х

# Accessibility

## Access

Most patients are interested in eRehabilitation, but not all patients want to use it for their recovery, because it is not suitable for them (e.g. lack of computer skills or disabilities impairing use of technology). This was also acknowledged by health professionals. [Professional\_5: *"It is not realistic to strive for every patient to use eHealth. You can offer it to the people who are willing to use it and have the required skills."*].

Easy access is important according to all end users to establish effective eRehabilitation interventions. [Patient\_11: "If getting into the program fails the first time you try, then you will be done with it soon."]. Requirements for easy access were: no internet connection is needed (requirement 1) and logging on is only required once (requirement 2).

Furthermore, patients/informal caregivers want eRehabilitation to be *applicable to most* possessed ICT devices (requirement 3) and that *their health professionals have access to their* electronic patient record to stay informed about training results (requirement 4).

For professionals it was important that eRehabilitation is *applicable on computers at the rehabilitation center and synchronizes with programs used for the electronic patient record* (requirement 5). Moreover, they stated that *different eHealth interventions should be brought together in one central dashboard* (requirement 6). [Professional\_7: "I would like to argue that people only have one account and that all facilities are directly available via one digital environment."].

# Usability

#### **Product attributes (visual)**

Visual disabilities related to stroke were mentioned (e.g. neglect) and resulted in a list of requirements regarding visual attributes, i.e. *use of pictograms, symbols and graphics* (requirement 1) and *a non-flashing and tranquil interface* (requirement 2). [Patient\_18: *"I prefer a light and calm background. Lots of colors and flashing lights onscreen often cause me a headache."*].

In addition, patients/informal caregivers mentioned *lay-out settings should be adjustable* (requirement 3), so that this can be adapted to the patients' own preferences. [Caregiver\_4: *"I have seen so many differences between patients with stroke. No one is the same. So, I can imagine type of letters, colors and so on need to be adjustable."*].

#### Product attributes (auditory)

As a consequence of cognitive and speech disabilities (e.g. aphasia), end users mentioned eRehabilitation interventions would be more suitable for stroke patients when *being able to listen to written text* (e.g. instruction of exercises) (requirement 4). [Caregiver\_12: *"It would be very helpful for my father if he can listen to instructions instead of reading it himself."*].

In addition, *sounds for alerts or as feedback* (requirement 5) was a requirement of patients/ informal caregivers. They prefer alerts as a reminder (e.g. alarm for training) or for fun (direct feedback whilst training). However, some patients also mentioned irritation and fatigue as negative side effects of sounds.

#### Product attributes (simplicity)

End users required simple eRehabilitation interventions to increase usability: *limited options* on a single screen to click further to another screen (requirement 6) and a *limited amount of* information on a single screen (requirement 7).

Patients/informal caregivers also required a limited amount of open webpages as a

consequence of using a service (requirement 8) to prevent patients from getting lost. [Caregiver\_9: "If I look at my husband when he uses the computer, I think it should be very simple. So not too much text, pictures, things you can click on... otherwise he has no idea what he is doing"].

# Service (support)

Support on how to use eRehabilitation was considered crucial for usability according to all end users. Several requirements were mentioned: *menu with frequently asked questions* (requirement 9), *videos with instructions* (requirement 10), *helpdesk* (requirement 11) and *direct support on location* (requirement 12). [Caregiver\_4: "If you're at home and you'll get stuck, you want to be able to ask someone directly for help"].

# Content

# Personalized training facilities

End users want eRehabilitation to include tailored training facilities for recovery after stroke, i.e. *physical* (requirement 1), *cognitive* (requirement 2) and *speech exercises* (requirement 3). [Patient\_19: "*If I came to know one thing, it is that no person who have had a stroke is the same, so you should be able to compose it in a way that it applies to you.*"]. Moreover, training facilities need to deliver constant personalized feedback (e.g. symbols, sounds, etc.) to prevent boredom with training and increase fun and accordingly stimulate training adherence and rehabilitation outcomes.

# Tracking

All end users mentioned activity trackers as an eRehabilitation tool to *monitor daily activities* (requirement 4). [Caregiver\_11: "He forgot to count taking a shower, having breakfast, going up and down the stairs... Then this device measured all activities and he became aware that he actually did a lot. That explained why he was so tired."].

Patient/informal caregivers also mentioned *a video system to record exercises* (requirement 5) and the ability to send these recordings to their health professional for feedback. A requirement of health professionals was *monitoring of a patients' health status (e.g. body weight, heart rate function, etc.)* (requirement 6).

## Agenda and reminders

All end users preferred a digital agenda which includes: *a patients' rehabilitation schedule* (requirement 7), *a reminder function for scheduled appointments* (requirement 8) and *scheduled time to use eRehabilitation (digital training)* (requirement 9). This was found important in case of cognitive impairments and difficulties with time management after

stroke.

Furthermore, patients/informal caregivers want to be *able to make appointments with health professionals on their own initiative* (requirement 10). Professionals required a limit in the number of appointments. [Professional\_2: "I would like if patients can schedule an appointment with me, but only within restrictions. I certainly do not want them to schedule appointments with me every week."].

## Communication

End users required digital communication tools (e.g. chat room, video chat, etc.) in order to facilitate *contact with peers to share experiences on how to cope with having a (relative with) stroke* (requirement 11). [Professional\_5: "There must be a digital function that allows patients and caregivers who have come to know each other in the center, to stay in contact if they want to"]. Moreover, communication tools can provide communication between health professionals and patients and their informal caregivers from a distance (telecommunication) (requirement 12).

## Information

According to all end users provision of information should include: *general information about stroke* (requirement 13), *hyperlinks to reliable and relevant web pages* (requirement 14), *information about patient organizations* (requirement 15) and *information on how to cope with consequences of stroke* (*psycho-education*) (requirement 16).

In addition, patients/informal caregivers required to get *information on how to complete daily activities (strategy training)* (requirement 18). Professionals want patients/informal caregivers to have insight in *agreements and information discussed during a consult* (requirement 19) and *final reports of their rehabilitation* (requirement 20). [Professional\_7: "Patients easily forget what I have discussed with them during a consult. It would be great if they can have access to this information later. To be honest: To me it is quit strange that some information is still not digitally available."].

#### Individual goal setting and evaluation

Requirements mentioned by all end users were: *setting individual goals for eRehabilitation* (requirement 21), *evaluation of these goals* (requirement 22) by getting *feedback about training results* (i.e. insight in what is trained, number of completed training sessions and training outcomes) (requirement 23) and receiving *feedback on goals* (e.g. receiving a digital medal when a goal is accomplished) (requirement 24).

In addition, requirements of health professionals were: *use of clinical assessments to set and evaluate goals* (requirement 25), *use of valid questionnaires to set and evaluate goals* (requirement 26) and *comparing training outcomes of a single patient with those of other* 

patients (requirement 27). However, they find this irrelevant for patients [Professional\_1: "Comparison of scores is especially useful to me, but not for patients. I am thinking of the prognosis and comparison with the average."].

# Discussion

The aim of the study was to identify end-user requirements for the accessibility, usability and content of a comprehensive eRehabilitation program for stroke care. In total 45 user requirements were identified, which were grouped into eleven subcategories. Most requirements of end-users concerned the content of eRehabilitation (27 requirements), followed by usability (12 requirements) and then accessibility (6 requirements).

User requirements were quite similar between patients/informal caregivers and health professionals, but also showed differences in perspectives. For instance, professionals required that eHealth programs are able to run on the computer at their workplace, whereas patients and caregivers mainly want to their smartphone or tablet. This implies that eHealth interventions should be designed in such a way that both requirements are met. Other studies incorporating multiple perspectives [32,56] did not specifically mention differences between end users, impairing comparability of results.

Compared to previous literature, this study identified new requirements for stroke eRehabilitation interventions. For **Accessibility**, it was found that offline eRehabilitation interventions, brought together in one digital dashboard, need to be directly availability after logging on once. To our knowledge, this was the first qualitative study that found requirements concerning accessibility of stroke eRehabilitation programs.

Identified requirements for **Usability** found in the current study that can be added to the literature were: use of icons/symbols, non-flashing and tranquil interface, ability to listen to written text, methods for simplicity (e.g. limited amount of information on a single screen) and support (a helpdesk, video instructions, etc.). Similar to other studies, all patients had different requirements for lay-out [28,31]. Thus, design solutions should be tailored to a range of users or need to include lay-out options that users can choose from according to their preferences.

Identified requirements for **Content** of eRehabilitation that can be added to the literature were: digital agenda, tracking systems, communication tools, provision of information and goal setting and evaluation. This rather broad range of requirements can be explained by the fact that this study aimed to identify user requirements for a comprehensive eRehabilitation program, instead of a single intervention. Similarities with previous studies were found regarding training facilities, i.e. adaptation to patients' own preferences and capabilities [17,25,27,28,30-32] and provision of (rewarding) feedback [25,27,28].

A limitation of the study is participants with a certain interest in technology and eRehabilitation were probably more likely to respond, causing response bias and reduced generalizability. Therefore, we used purposive sampling based on the purpose of the use of ICT-devices to capture a broad range of perspectives. The group of patients that participated in the study (responders) did not significantly differ in age and gender from the group non-responders. Another limitation is that the chosen study methodology does not allow for comparisons between subgroups of focus group participants (e.g. different technological abilities), since requirements were studied on the level of the group (patients/informal caregivers and health professionals) instead of the individual participant. However, it would be interesting to know if there are differences in requirements of subgroups and this should be studied in the future. In addition, we could not aim for data saturation amongst health professionals. Data saturation was reached after six focus groups with patients/informal caregivers, but due to practical considerations this was not possible for health professionals. Differences in results between patients/informal caregivers and health professionals.

In conclusion, user requirements for an eRehabilitation program for stroke care were identified addressing three categories: content, usability and accessibility. Requirements were to some extent different between stroke patients/ informal caregivers and health professionals. Therefore, involving perspectives of all end users in the design process of eHealth is needed to increase their effectiveness in rehabilitation care. The results in the current study can be used in future studies that apply a user-centered design approach to identify requirements for new eHealth interventions for stroke rehabilitation.

# Declarations

*Ethics approval and consent to participate:* All participants gave written informed consent prior to participation. The study was approved by the Medical Ethical Review Board of the Leiden University Medical Center [P15.281].

Consent for publication: Not applicable.

*Availability of data and material:* The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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

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What is important in e-health interventions for stroke rehabilitation? A survey study among patients, informal caregivers and health professionals

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# Abstract

Incorporating user requirements in the design of e-rehabilitation interventions facilitates their implementation. However, insight into requirements for e-rehabilitation after stroke is lacking. This study investigated which user requirements for stroke e-rehabilitation are important to stroke patients, informal caregivers, and health professionals. The methodology consisted of a survey study amongst stroke patients, informal caregivers, and health professionals (physicians, physical therapists and occupational therapists). The survey consisted of statements about requirements regarding accessibility, usability and content of a comprehensive stroke e-health intervention (4-point Likert scale, 1=unimportant/4=important). The mean with standard deviation was the metric used to determine the importance of requirements. Patients (N=125), informal caregivers (N=43), and health professionals (N=105) completed the survey. The mean score of user requirements regarding accessibility, usability and content for stroke e-rehabilitation was 3.1 for patients, 3.4 for informal caregivers are important and should be incorporated into the design of stroke e-rehabilitation to facilitate their implementation.

# Introduction

Stroke is a major health problem in Europe for which the incidence is expected to increase from 1.1 million per year in 2000 to 1.5 million per year in 2025 (Truelsen, et al., 2006). Patients suffering from stroke may experience multiple disabilities and require comprehensive rehabilitation. Overall, an increase is expected in the need for rehabilitation post stroke, not only because of the rising incidence, but also since, due to the improvement of the initial medical treatment, more patients now survive a stroke (Feigin et al., 2016). Comprehensive rehabilitation is delivered by various health professionals from different disciplines (e.g., physical therapists, occupational therapists, speech-language pathologists, psychologists, and social workers), with therapy aimed at individual treatment goals involving the patient and his or her informal caregiver (Winstein et al. 2016).

Due to developments in society and health care, including limited resources for the delivery of comprehensive rehabilitation, Information and Communication Technologies (ICT) play an important role in the delivery of rehabilitation care.'The use of ICT, mostly internet technology, to improve or support health and health care, is known as e-health (Wentzel, Beerlage-de Jong, & Sieverink, 2014). E-rehabilitation refers to the application of e-health in rehabilitation care (e.g., serious brain games, virtual reality and telerehabilitation). Although many e-rehabilitation interventions have been tested regarding their effectiveness, the use of e-rehabilitation by end users remains low (Brewer, McDowell, & Worthen-Chaudharim, 2007; Lum, Reinkensmeyer, Mahoney, Rymer, & Burgar, 2002).

Implementation of e-health is influenced by its complexity, the adaptability of the technology to fit the local context, and its compatibility with existing systems, work practices, and costs (Ross, Stevenson, Lau, & Murray, 2016). End user input in the design and development of e-health technologies (i.e., user-centered design approach) is a way to overcome such barriers (Goldstein et al., 2014; Pagliari 2007; Ross et al., 2016; van Gemert-Pijnen et al., 2011).

Prior qualitative research (via interviews and focus groups) on end users' requirements for stroke e-rehabilitation (Ehn et al., 2015; Lange, Flynn, Proffitt, Chang, & Rizzo, 2010; Mawson et al., 2014; Mountain et al., 2006; Nasr et al., 2016; Parker et al., 2014; Zheng et al., 2006) found that interventions should be tailored (Lange et al., 2010; Nasr et al., 2016; Zheng et al., 2006); need to involve goal setting (Mawson et al., 2014; Sivan et al., 2014); must be easy to use; and should provide feedback about training performances (Mawson et al., 2014; Mountain et al., 2006; Nasr et al., 2016; Parker et al., 2014; Zheng et al., 2014; Mountain et al., 2006; Nasr et al., 2016; Parker et al., 2014; Zheng et al., 2014; Mountain et al., 2006; Nasr et al., 2016; Parker et al., 2014; Zheng et al., 2014; Mountain et al., 2006; Nasr et al., 2016; Parker et al., 2014; Zheng et al., 2006).

However, quantitative studies regarding user requirements for e-rehabilitation after stroke are scarce. Thus far, one study used a quantitative survey among 233 health professionals in stroke care to rank the importance of the requirements that were identified in a previous qualitative study of Lu et al., (2011). However, this study was concerned with

only one aspect of stroke recovery (upper limb rehabilitation), and one technology tool (robot). Moreover, only health professionals, mainly occupational therapists and physical therapists, completed the survey whereas patients and their informal caregivers were not involved.

Thus, it remains unclear what requirements are most important for the comprehensive delivery of e-rehabilitation interventions (e.g., an app with upper limb exercises, brain games and/or telecommunication) including all potential end users, (i.e., patients, informal caregivers and health professionals). Therefore, this study aims to prioritize the requirements for stroke e-rehabilitation according to patients, informal caregivers, and health professionals. This is relevant for the application of user-centered design and accordingly the development and implementation of effective e-health interventions in stroke rehabilitation.

# **Patients and Materials**

# **Design and setting**

This cross-sectional study, involving a one-time, online survey, was conducted in June 2016 among (former) patients who had been admitted to Sophia Rehabilitation Centre (the Hague) and Rijnlands Rehabilitation Centre (Leiden) in The Netherlands, their informal caregivers, and healthcare professionals (rehabilitation physicians, psychologists, physical therapists and managers). The study was approved by the Medical Ethical Review Board of the Leiden University Medical Center [P15.281].

# **Study population**

## Patients and informal caregivers

Patients and informal caregivers were recruited by identifying potentially eligible patients in the electronic patient registries of the two rehabilitation centres, based on the following criteria: older than 18 years, diagnosed with stroke, rehabilitation started after June 2011 and rehabilitation was completed. Four hundred patients (200 in Leiden and 200 in The Hague) were randomly selected by assigning a number to every patient using a random number generator and subsequently selecting the first four-hundred patients and their informal caregivers.

## Health professionals

Health professionals were selected if they were a practicing health professional (i.e., rehabilitation physicians, physical therapists, or psychologists) with at least two years of working experience in a multidisciplinary team for stroke patients. Health professionals

were randomly selected from the Dutch medical address book (which includes most professionals in The Netherlands), the Dutch Association of Rehabilitation Physicians (VRA: Nederlandse Vereniging van Revalidatieartsen) and the Royal Dutch Society of Physical therapy (KNGF: Koninklijk Nederlands Genootschap voor Fysiotherapie). If an email address was missing, other methods (e.g., internet, telephone calls) were used. We aimed to invite at least 300 health professionals.

Patients and health professionals received an email about the study including a digital link to the survey. Informal caregivers (e.g., partner, family member, etc.) were invited to fill in the questionnaire in the email directed to the patients. Thus, it remains unclear whether the patients had an informal caregiver and if so, whether they passed on the invitation. If the invited health professional stated that he or she was not involved in stroke care, they were asked to invite colleagues to fill out the survey. Non-responders received two reminders, each with an in-between period of 1.5 weeks.

## Survey development

The content of the survey was based on a previous qualitative study, in which a framework for end user requirements for e-rehabilitation in stroke care was established (Figure 1). The framework comprises 45 identified requirements, classified into eleven self-determined categories and organized by three self-determined key themes: 'accessibility', 'usability', and 'content'. Accessibility refers to "easy access to e-rehabilitation for all end users, including patients with disabilities as a consequence of stroke." Usability is "the ease with which end users can use e-rehabilitation interventions for recovery after stroke during their stay in the rehabilitation center and/or at home."



Figure 1. Key themes end-user requirements for e-health interventions in stroke rehabilitation.

Content was defined as "everything end users want to include in e-rehabilitation (e.g., services, interventions, information, applications, etc.) to achieve specified goals for e-rehabilitation in their rehabilitation process."

The user requirements identified for patients/ informal caregivers and health professionals were translated into neutral statements for the survey. Each survey consisted of two parts: (1) socio-demographic and disease characteristics, and (2) a list of user requirements for accessibility, usability, and content for patients/ informal caregivers and health professionals. The survey was pilot tested amongst two health professionals and three patients who were undergoing treatment in the rehabilitation center for recovery after stroke. The survey was tested for feasibility, readability and presentation (e.g. perceived question difficulties, response errors, screen layout, etc.). The pilot testing led to minor changes in the wording and format of the final survey.

# Survey content

## Socio-demographic (and disease) characteristics

The age and gender of patients, informal caregivers, and health professionals were recorded. In addition, patients were asked to provide the following information: education level (low [no or only primary education], intermediate [prevocational secondary education, senior secondary vocational training, senior secondary general education, preuniversity education], high [higher professional education or university (bachelor, master, or PhD degree)]); living status (living alone/ living together); employment (paid job/ no paid job); time after stroke (in months); and self-perceived impairments as a consequence of stroke (cognitive, physical, communication). Health professionals were asked about their discipline; region (north, middle, and/or south of the Netherlands); work setting (primary care, rehabilitation centre, general hospital); years of work experience; and estimated average number of new stroke patients per month. Moreover, they were asked whether they used e-health in routine stroke rehabilitation (yes, no).

#### User requirements

Forty-five requirements for the three themes 'accessibility' (8 requirements), 'usability' (12 requirements) and 'content' (25 requirements) of a comprehensive e-health intervention after stroke were identified in the qualitative study and were transformed into neutral statements for the survey. A total of 39/45 requirements were directly transformed and 6/45 requirements were divided into 2 or more statements, resulting in 15 additional statements for the survey (52 statements). The 52 statements were included in the survey for caregivers, resulting in 50 statements in the survey for caregivers. In the survey of health professionals,
a number of 7/52 statements were asked from the perspective of a patient next to their own perspective, resulting in 7 additional statements. There were 11/52 statements derived from the qualitative study were only applicable for patients and caregivers, so eventually 48 statements (52+7-11) were included in the survey of health professionals.

All participants were asked to rate the importance of the given statements on a 4-point Likert scale (1=unimportant, 2=rather unimportant, 3=rather important, 4=important). These scores were used to calculate the mean in order to make a ranking from highest to least important requirements.

#### Analysis

Respondents were included in the analyses if they completed ≥90 percent of survey. Socio-demographic and disease characteristics were analyzed using descriptive statistics and presented as numbers with percentages, means with standard deviations (SD), or medians with ranges (Inter Quartile Range; IQR), i.e., 25th percentile–75th percentile), where appropriate.

To quantify the importance of requirements for accessibility, usability and content of e-rehabilitation interventions as perceived by respondents, descriptive analysis was used. The mean with the standard deviation (SD) for each statement were reported to discriminate between and prioritize the statements used in the survey items. Means provide the most accurate insight in the importance of the requirements. Scores on statements per subgroup (patients, informal caregivers and health professionals) are presented in separate tables for each theme: Accessibility, Usability and Content. In addition, the mean score of all statements were provided per subgroup. All statistical analyses were performed using Statistical Packages for the Social Sciences (IBM SPSS 22.0 for Windows).

#### Ethical issues and approval

Participants filled in the survey anonymously implying that patient's, informal caregiver's and health professional's characteristics were not traceable, (e.g., age instead of date of birth). Immediately after filling in the survey, participants were thanked for their willingness to participate. Participants did not receive results of the study, since they filled in the survey anonymously.

# Results

## Response

Of the 400 invited patients, 32 had no valid email address; the survey was completed by 125 out of 368 invited patients (34%). Additionally, 43 informal caregivers, and 105 health professionals completed the survey (Figure 2). Reasons for nonresponse were not verified.



Figure 2. Flow of inclusion.

# Socio-demographic (and disease) characteristics

The characteristics of the 273 responders are shown in Table 1. Respondents included 72/125 (58%) patients, 16/43 (37%) informal caregivers and 25/105 (24%) health professionals. The mean age of the patients was 58 years (SD 11.4), of the informal caregivers 58 years (SD 12.0) and of the health professionals 42 years (SD 10.5). In total, 41/105 (39%) of the health professionals were physical therapists, 15/105 (14%) were psychologists, 47/105 (45%) were physicians and 2/105 (2%) did not mention their discipline. Seventy-five out of 105 (71%) responding professionals worked in a rehabilitation center.

Characteristics	Patients	Caregivers	Professionals
	(n=125)	(n=43)	(n=105)
Age, years (mean, SD)	58 (11.4)	58 (12.0)	42 (10.5)
Sex, no. male (%)	72 (58)	16 (37)	25 (24)
Education, no. (%)			
Low	21 (17)	-	-
Intermediate	46 (37)	-	-
High	57 (46)	-	-
Living status, no. living alone (%)	22 (18)	5 (12)	-
Employment, no. with a paid job (%)	42 (34)	21 (49)	-
Work region, no. (%)			
North	-	-	20 (20)
Middle	-	-	63 (60)
South	-	-	21 (20)
Health professional discipline, no. (%)			
Physical therapist	-	-	41 (39)
Psychologist	-	-	15 (14)
Physician	-	-	47 (45)
Unknown <sup>a</sup>			2 (2)
Work setting, no. (%)			
Health centre in primary care	-	-	10 (10)
Rehabilitation centre	-	-	75 (71)
General hospital	-	-	34 (32)
Work experience, no. years (%)	-	-	
>0-5	-	-	25 (23.8)
>6-10	-	-	28 (26.7)
>11-15	-	-	14 (13.3)
>15			37 (35.2)
Estimated average number of new stroke	patients per month; n	0. (%)	
>0-5	-	-	47 (46)
>6-10	-	-	33 (32)
>11-15	-	-	11 (11)
>15	-	-	11 (11)
Time after stroke, months (mean, SD)	30.6 (29.2)		

Table 1. Characteristics of participating patients, informal caregivers and health professionals.

Characteristics	Patients (n=125)	Caregivers (n=43)	Professionals (n=105)
Self-perceived impairments, no. yes (%)			
Cognitive impairments	81 (65)		-
Physical impairments	84 (67)		-
Aphasia	48 (38)		-
Use of any device in daily life, no. yes (%)	113 (90)	41 (95)	
Use of device, no. yes (%)			-
Smartphone	85 (68)	33 (77)	-
Tablet	62 (50)	30 (70)	-
Laptop	71 (57)	30 (70)	-
Computer (PC)	54 (43)	20 (47)	
Use of digital rehabilitation tools, no. yes (%)	-	-	40 (38)

#### Table 1. Continued.

<sup>a</sup> Health professionals who did not mention their discipline.

## Requirements

The mean score of all user requirements regarding accessibility, usability and content for stroke e-rehabilitation was 3.1 for patients, 3.4 for informal caregivers and 3.4 for health professionals. For patients, the mean score (SD) for the least important requirement was 2.4 (1.1) and for the most important 3.6 (0.8). For caregivers, the mean score (SD) for the least important 3.8 (0.4). For health professionals, the mean score (SD) for the least important 3.8 (0.4). For health professionals, the mean score (SD) for the least important requirement was 2.4 (1.0) and for the most important 3.9 (0.4).

## Accessibility

Two requirements for accessibility to e-rehabilitation after stroke were found to be the most important according to all end users: *e-rehabilitation is applicable to most commonly possessed ICT-devices, e.g., laptop, tablet and smartphone* (patients: mean 3.5, SD 0.9; informal caregivers: mean 3.5, SD 0.7; professionals: mean 3.6, SD. 0.6) and *access for health professionals to the electronic patient record to stay informed about training results* (patients: mean 3.3, SD 1.0; informal caregivers: mean 3.5, SD 0.7) (see table 2a).

## Usability

Categories for usability were: visual appeal, auditory appeal, simplicity and support. Two requirements regarding the category 'support' were found to be most important according to all end users: *videos with instructions on how to use e-rehabilitation* (patients: mean 3.3, SD 1.0; informal caregivers: mean 3.7, SD 0.9; professionals: mean 3.7, SD 0.6) and *a menu with frequently asked questions for patients* (patients: mean 3.1, SD 1.0; informal caregivers: mean 3.7, SD 0.6) (see table 2b).

Moreover, three requirements showed a mean score higher than the mean score on all statements for both patients and informal caregivers: *limited options on a single screen to click further to another screen* within the category simplicity (patients: mean 3.1, SD 1.1; informal caregivers: mean 3.4, SD 1.0), *non-flashing and tranquil interface* (patients: mean 3.3, SD 0.8; informal caregivers: mean 3.8, SD 0.4) and *adjustable font style and font size settings* (patients: mean 3.0, SD 1.1; informal caregivers: mean 3.6, SD 0.7) within the category visual appeal.

# Content

Categories for content were: training facilities, tracking, agenda/ reminders, communication, information and goal setting/ evaluation. A relatively large number of requirements for content showed higher mean scores than the mean score on all statements by all end users, e.g., *insight in agreements made during a consult* in the category information (patients: mean 3.5, SD 0.9; informal caregivers: mean 3.6, SD 0.8; professionals: mean 3.7, SD 0.6), *insight in final reports of a patients' rehabilitation process* in the category information (patients: mean 3.6, SD 0.7; informal caregivers: mean 3.7, SD 0.8; professionals: mean 3.4, SD 0.8) and *physical exercises* in the category training facilities (patients: mean 3.4, SD 1.0; informal caregivers: mean 3.7, SD 0.6).

Category	Requirement	End user		
		Patients (n=125)	Caregivers (n=43)	Professionals (n=105)
		Mean (SD)	Mean (SD)	Mean (SD)
The mean score of	of all statements per subgroup	3.3	3.5	3.4
Access	Applicable to most commonly possessed	3.5 (0.9)	3.5 (0.7)	3.6 (0.6)
	ICT-devices.			
Access	No internet connection is required to use	3.2 (1.0)	3.5 (1.0)	3.1 (0.9)
	e-health interventions (offline use).			
Access	Different e-health interventions are accessible	3.1 (1.0)	3.3 (0.9)	3.5 (0.8)
	without logging into the system each time.			
Access	Access for health professionals to the	3.3 (1.0)	3.5 (0.9)	3.5 (0.7)
	electronic patient record to stay informed			
	about training results.			

**Table 2a.** Importance of requirements for **accessibility** of stroke e-rehabilitation according to end users (n=273).

**Table 2b.** Importance of requirements for **usability** of stroke e-rehabilitation according to end users (n=273).

Category	Requirement	End user			
		Patients (n=125) <i>Mean (SD)</i>	Caregivers (n=43) Mean (SD)	Professionals (n=105) <i>Mean (SD)</i>	
The mean score of	of all statements per subgroup	2.9	3.4	3.5	
Visual appeal	Adjustable settings: background.	2.6 (1.1)	3.0 (0.1)	-	
Visual appeal	Adjustable settings: colors.	2.5 (1.1)	3.3 (0.1)	-	
Visual appeal	Adjustable settings: page lay-out.	2.7 (1.1)	3.3 (0.9)	-	
Visual appeal	Adjustable settings: font style and font size.	3.0 (1.1)	3.6 (0.7)	-	
Visual appeal	Use of pictograms, symbols and graphics.	2.7 (1.1)	3.3 (1.0)	-	
Visual appeal	Non-flashing and tranquil interface.	3.3 (0.8)	3.8 (0.4)	-	
Auditory appeal	Ability to listen to written text.	2.7 (1.1)	3.4 (1.0)	-	
Auditory appeal	Sounds for alert or as feedback.	2.7 (1.1)	3.3 (0.9)	-	
Simplicity	Limited amount of open webpages as a consequence of using a service.	2.8 (1.0)	3.6 (0.9)	3.5 (0.7)	
Simplicity	Limited amount of information on a single screen.	3.3 (1.0)	Missingª	-	
Simplicity	Limited options on a single screen to click further to another screen.	3.1 (1.1)	3.4 (1.0)	-	
Support	Direct assistance at home.	3.3 (1.08)	3.1 (1.1)	-	
Support	Video for patients with instructions on how to use e-rehabilitation.	3.3 (1.0)	3.7 (0.9)	3.7 (0.6)	
Support	Video for professionals with instructions on how to use e-rehabilitation.	-	-	3.1 (0.8)	
Support	Menu with frequently asked questions for patients (FAQ).	3.1 (1.0)	3.7 (0.9)	3.7 (0.6)	
Support	Menu with frequently asked questions for professionals (FAQ).	-	-	3.3 (0.7)	
Support	A helpdesk for patients.	2.9 (1.1)	3.5 (0.9)	3.9 (0.4)	
Support	A helpdesk for professionals.	-	-	3.5 (0.6)	

<sup>a</sup> This requirement was accidentally missing in the survey for caregivers.

**Table 2c.** Importance of requirements for **content** of stroke e-rehabilitation according to end users (n=273).

Category	Requirement	End user			
		Patients (n=125) <i>Mean (SD)</i>	Caregivers (n=43) <i>Mean (SD)</i>	Professionals (n=105) <i>Mean (SD)</i>	
The mean score of all statements per subgroup		3.0	3.2	3.2	
Training facilities	Exercises for cognitive functioning.	3.6 (0.9)	3.8 (0.4)	3.2 (0.9)	
Training facilities	Physical exercises.	3.4 (1.0)	3.7 (0.8)	3.6 (0.6)	
Training facilities	Speech exercises.	2.9 (1.3)	3.5 (1.0)	3.3 (1.0)	
Tracking	Monitor activities in daily living: Insight in completed activities Duration of completed activities	2.5 (1.1) 3.1 (1.0)	3.1 (1.1) 3.6 (0.7)	3.2 (0.8) 3.3 (0.7)	
Tracking	A video system to record exercises at home.	2.4 (1.1)	2.8 (1.1)	3.1 (0.9)	
Tracking	Monitor a patients' health status: Body weight Heart rate	2.9 (1.1) 2.9 (1.1)	3.2 (1.0) Missingª	2.5 (0.9) 2.5 (0.8)	
Agenda/ reminders	Insight in the rehabilitation schedule of a patient.	3.2 (1.1)	3.4 (1.0)	3.6 (0.7)	
Agenda/ reminders	A reminder function for scheduled appointments.	2.9 (1.0)	3.4 (1.0)	3.7 (0.6)	
Agenda/ reminders	Scheduled time to use e-rehabilitation (digital training).	3.2 (1.1)	3.3 (1.0)	3.3 (0.8)	
Agenda/ reminders	Appointments with healthcare professionals: Make a request for an appointment Schedule an appointment themselves	3.1 (1.0) 3.0 (1.0)	3.3 (1.0) 3.2 (1.0)	2.9 (0.9) 2.5 (1.0)	
Communication	Contact for care givers to share experiences on how to cope with having a relative with stroke.	2.6 (1.1)	2.7 (1.0)	3.6 (0.6)	
Communication	Contact for patients to share experiences on how to cope with having a stroke.	2.8 (1.0)	3.0 (1.0)	3.5 (0.6)	
Communication	Communication between patients/ caregivers and professionals from a distance (telecommunication).	2.5 (1.1)	3.0 (1.0)	2.9 (0.9)	
Information	General information about stroke.	3.4 (0.8)	3.4 (0.9)	3.7 (0.5)	
Information	Hyperlinks to reliable and relevant webpages for patients and caregivers.	3.2 (0.9)	3.4 (0.5)	3.6 (0.5)	
Information	Information about patient organizations.	3.3 (1.0)	3.0 (1.0)	3.7 (0.6)	
Information	Information on how to cope with consequences of stroke (psycho-education).	2.8 (1.0)	3.7 (0.8)	3.6 (0.6)	
Information	Descriptions on how to perform daily activities (strategy training).	2.4 (1.2)	3.1 (0.9)	3.3 (0.7)	
Information	Insight after a consult with a health professional in: Agreements that were made Information that was discussed	3.5 (0.9) 3.5 (0.8)	3.6 (0.8) 3.7 (0.7)	3.7 (0.6) 3.4 (0.8)	
Information	Insight in final reports of a patients' rehabilitation process.	3.6 (0.7)	3.7 (0.8)	3.4 (0.8)	

Category	Requirement	End user			
		Patients (n=125) <i>Mean (SD)</i>	Caregivers (n=43) <i>Mean (SD)</i>	Professionals (n=105) <i>Mean (SD)</i>	
Goal setting/ evaluation	Setting goals for e-rehabilitation (shared decision making).	3.4 (0.9)	3.7 (0.8)	3.4 (0.7)	
Goal setting/ evaluation	Evaluation of goals for e-rehabilitation.	3.4 (0.9)	3.7 (0.7)	3.4 (0.7)	
Goal setting/ evaluation	Feedback about training results for patients: Insight in what is trained The number of completed sessions Training outcomes	3.2 (1.0) 3.1 (0.9) 3.2 (1.0)	3.6 (0.6) 3.6 (0.6) 3.7 (0.5)	2.3 (1.1) 3.5 (0.7) 3.5 (0.7)	
Goal setting/ evaluation	Feedback about training results for professionals: Insight in what is trained The number of completed sessions Training outcomes	- - -	- -	3.2 (0.8) 3.2 (0.8) 3.3 (0.8)	
Goal setting/ evaluation	Feedback on when a goal for e-rehabilitation is accomplished.	3.3 (0.9)	3.6 (0.9)	3.7 (0.6)	
Goal setting/ evaluation	Use of clinical assessments for goal setting and evaluation.	3.5 (0.9)	3.6 (0.7)	3.3 (0.8)	
Goal setting/ evaluation	Use of valid questionnaires for goal setting and evaluation.	3.3 (0.9)	3.5 (0.8)	3.4 (0.8)	
Goal setting/ evaluation	Compare training outcomes of a single patient with those of other patients.	2.4 (1.2)	2.9 (1.0)	2.4 (1.0)	

#### Table 2c. Continued.

<sup>a</sup> This requirement was accidentally missing in the survey for caregivers.

# Discussion

The aim of this study was to make an inventory and prioritize the requirements for stroke e-rehabilitation according to patients, informal caregivers, and health professionals. Relatively large mean scores for user requirements regarding accessibility, usability and content for a comprehensive e-health intervention after stroke were found for each subgroup (patients 3.1, informal caregivers 3.4 and health professionals 3.4). Moreover, similarities and differences were found between the perspectives of patients, informal caregivers, and health professionals about the importance of the requirements.

To our knowledge one previous study used a quantitative survey in stroke care to discover the importance of the requirements that were identified in a previous qualitative study of Lu et al. (2011). Similar to the findings from the perspective of health professionals in this study, provision of feedback for patient and therapist and the tool being useful for stroke patients were found to be important requirements. However, comparison of the findings between both studies is hampered. Lu et al. (2011) focused on the user' requirements regarding a robot for upper limb rehabilitation, while our study was concerning a comprehensive e-health intervention using multiple tools. Moreover, their survey was conducted among 233 health professionals while our study also included other user groups (i.e., patients and their informal caregivers).

Overall, requirements prioritized in this study were both similar and different compared to previous qualitative studies that identified user requirements for an e-health intervention. An important requirement regarding accessibility found in this study was the ability to use e-rehabilitation on multiple digital devices (smartphone, tablet, laptop). This corresponds to requests identified in previous literature that e-health be integrated in familiar and existing tools/applications, (not replacing them) (Matthew-Maich et al., 2016); is available alongside the work of health professionals (Mountain et al., 2006); is easy to set-up (Sivan et al., 2014; Zheng et al., 2006); and is suitable to the constant modification of the environment (Ross et al., 2016).

An important requirement found in this study regarding usability was a non-flashing and tranquil interface. This is in line with a previous study of Parker et al., (2014) that found participants preferred a simpler looking screen without additional background pictures. In contradiction to previous studies in which design settings needed to be changeable for adjustment to a patient's needs (Parker et al., 2014; Zheng et al., 2006), this study found changeable lay-out, background and color settings were less important. It can be added to the literature that incorporation of support for use of e-rehabilitation programmes (e.g., helpdesk, FAQ menu, videos with instructions) are highly important. These requirements should be integrated in e-rehabilitation designs to increase acceptance of e-rehabilitation for stroke patients, who often suffer from disabilities impairing usage.

Regarding content, the following important requirements were similar to previous literature: general information (McKevitt, Redfern, Mold, & Wolfe, 2004; Peoples, Satink, & Steultjens, 2011; Reed, Wood, Harrington, & Paterson, 2012; Salter, Hellings, Foley, & Teasell, 2008); goal setting and evaluation (Lu et al., 2011; McKevitt et al., 2004; Parke et al., 2015); and providing feedback (Hochstenbach-Waelen & Seelen, 2012; Lu et al., 2011; Mawson et al., 2015; Mountain et al., 2006; Nasr et al., 2016; Parker et al., 2014; Zheng et al., 2006). In contradiction, telecommunications in stroke care are rapidly developing worldwide because of their importance (Blacquiere et al., 2017), although this was found a less important requirement in the current study according to all end users. A broad range of requirements regarding content of comprehensive e-health interventions can be added to the literature (e.g., exercises for cognitive and physical functioning, hyperlinks to webpages, a reminder function, etc.), since this study prioritized user requirements for a comprehensive e-health intervention addressing one aspect of stroke recovery with one technology tool.

Furthermore, similarities were found in perspectives of patients, informal caregivers,

and health professionals about the importance of requirements. The requirements of physical exercises, insight in information discussed during a consult, insight in final reports of the rehabilitation process and setting and evaluation of goals for e-rehabilitation were considered relatively important by all end users. However, notable differences were also found between the subgroups. The required exercises for cognitive functioning were important for patients and informal caregivers, whilst this was a less important requirement for health professionals. In addition, health professionals found contact with peers for caregivers and patients important, although patients and informal caregivers found this less important. Moreover, psycho-education was found to be a relatively important requirement by health professionals and informal caregivers, whereas patients seemed to find this less important. Therefore, differences in the importance of user requirements should be identified so that e-health interventions can be designed in such a way that requirements of different users are met.

As to our knowledge, this is the first study that prioritized a set of requirements for e-rehabilitation amongst multiple subgroups (patients, informal caregivers, and health professionals) and in which informal caregivers were treated as a separate group of end users. Differences in the importance of requirements for comprehensive e-health interventions for recovery after stroke between patients, informal caregivers, and professionals were not previously identified in the literature.

A limitation of the study is that selection bias might have occurred since the survey was distributed by mail, and only patients and their informal caregivers with an email address were able to fill in the survey. As a consequence, the perspective of patients and their informal caregivers with least experience with digital devices might be missing. However, we aimed to identify user requirements for e-rehabilitation, so knowledge and understanding of ICT and e-health were desirable. Moreover, informal caregivers of patients were invited to fill in the questionnaire in the invitation mail directed to the patients. If the invited health professional stated that he or she was not involved in stroke care, they were asked to invite colleagues to fill out the survey. Therefore, the actual amount of invited informal caregivers and health professionals and the response rates are unknown.

In summary, we prioritized requirements for accessibility, usability, and content of comprehensive e-health interventions from the perspective of patients, informal caregivers, and health professionals. It was found that a relatively large amount of user requirements were found important by each separate group and by all subgroups. These results can be used by developers, researchers and health professionals to apply user-centered design to develop effective e-health interventions and accordingly to enable their acceptance and adoption in stroke rehabilitation. However, more research is needed to identify which requirements are most important to optimize implementation, usage and adaptation of e-health in stroke rehabilitation.

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Teachers' and students' perceptions about eHealth education in the curriculum of exercise and physical therapy: a focus groups study on barriers and facilitators.

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# Abstract

**Background:** Despite the growing importance of eHealth it is not consistently embedded in the curricula of functional exercise and physical therapy education. Insight in barriers and facilitators for embedding eHealth in education is required for the development of tailored strategies to implement eHealth in curricula. This study aims to identify barriers/facilitators perceived by teachers and students of functional exercise/physical therapy for uptake of eHealth in education.

**Method:** A qualitative study including six focus groups (two with teachers/four with students) was conducted to identify barriers/facilitators. Focus groups were audiotaped and transcribed in full. Reported barriers and facilitators were identified, grouped and classified using a generally accepted framework for implementation comprising levels of: innovation, individual teacher/student, social context, organizational context and political and economic factors.

**Results:** Teachers (n=11) and students (n=24) of functional exercise/physical therapy faculties of two universities of applied sciences in the Netherlands participated in the focus groups. A total of 109 barriers/facilitators were identified during the focus groups. Most found on the level of the innovation (n=26), followed by the individual teacher (n=22) and the organization (n=20). Teachers and students identified similar barriers/facilitators for uptake of eHealth in curricula: e.g. unclear concept of eHealth, lack of quality and evidence for eHealth, (lack of) capabilities of students/teachers on how to use eHealth, negative/ positive attitude of students/teachers towards eHealth.

**Conclusion:** The successful uptake of eHealth in the curriculum of functional exercise/ physical therapists needs a systematic multi-facetted approach considering the barriers and facilitators for uptake identified from the perspective of teachers and students. A relatively large amount of the identified barriers and facilitators were overlapping between teachers and students. Starting points for developing effective implementation strategies can potentially be found in reducing those overlapping barriers and facilitators.

**Registration:** The study protocol was a non-medical research and no registration was required. Participants gave written informed consent.

# Introduction

Information and Communication Technologies (ICT; e.g. home automation, online training and games) are increasingly used to improve or support health and health care (*eHealth*) [1], such as. Physical therapists use eHealth interventions to support patients in maintaining independency in daily functioning but also for health care processes and services (e.g. telemedicine and electronic patient files) [2]. The role of technology in health care is growing and there is an urgent need for future health professionals who are able to work competently and confidently with eHealth.

The availability of technology in health care is growing and there is an urgent need for health professionals who can use eHealth competently and confidently in clinical practice. This means that there is large responsibility for the institutions for the education of future health professionals to ensure that students acquire knowledge, skills and attributes to work with eHealth, and this requires revision of curricula of education [3,4]. Students should be actively taught how to find, understand, apply and appraise eHealth innovations [5] to constantly update their skills and knowledge [2,6,7]. Ideally, students should become early adaptors and lead eHealth initiatives in settings where eHealth adoption is still low [13].

Despite the growing importance of eHealth in the work field, curricula are currently underdeveloped in teaching eHealth in the field of e.g. dietetics, nursing, occupational therapy, physiotherapy, psychology, or social work [5-9]. Therefore, a systematic approach to design, teach, assess or accredit eHealth education in the curriculum is needed. In the literature, a number of barriers for the uptake of eHealth education in curricula were identified: outdated and rigid curricula with narrow focus on technology [7], teachers' limited experience with and knowledge of the emerging field of eHealth [2,9,10] and health care teachers not feeling confident with technology [2,11,12].

There are several gaps in the knowledge of uptake of eHealth education in the curriculum. First, research about eHealth education predominantly comes from the medical and nursing literature [13]. However, the paramedical education for physical and functional exercise therapy, should also equip students to confidently use of eHealth, especially since eHealth innovations are increasingly used in daily practices of the physical and exercise therapist (e.g. Fysiogaming, eExercise, activity tracking, etc.). Since the work and patient groups of physical therapists differ from those of nurses, barriers and facilitators for eHealth education might also differ. Second, there is a need for more in-depth knowledge of barriers and facilitators for the uptake of eHealth in education, in terms of the factors that may critically influence uptake' [18]. Third, studies mainly focused on single groups.

This study aims to provide insight in the barriers and facilitators for uptake of eHealth in the education for physical therapy and functional exercise therapy, more specific to answer

the research question: what are the barriers and facilitators perceived by teachers and students for implementing eHealth in education?

# **Methods and materials**

## Design

A qualitative study was conducted among teachers and students to explore the perceived barriers and facilitators for uptake of eHealth education in the curricula of the education for physical therapy and functional exercise therapy. In this study eHealth was defined as 'the use of new Information and communication technologies (ICT) to improve or support health and health care' [1]. Given this definition, the technology employed in health care varies largely, e.g. web and mobile applications, electronic patient records, health-sensors and wearable devices, telecommunication, home automation and robotics and serious gaming [1]. 'EHealth education' was defined as teaching how to provide treatments using technology.

Focus groups were conducted to collect data that contributes to a better understanding of teachers' and students' attitudes, experiences with and expectations of eHealth in education [Kitzinger, 2006]. Participants were informed that data would remain confidential and would be anonymously used for scientific research and for improvement of eHealth education. The COnsolidated criteria for REporting Qualitative research (COREQ) guidelines were used for adequate reporting of the study [14].

# **Recruitment and inclusion**

Teachers and students were recruited from two departments teaching functional exercise therapy and physical therapy in a four years full-time program, in the Netherlands: (1) Functional Exercise Therapy, Faculty of Health, University of Applied Sciences in Amsterdam (HvA) and (2) Physical Therapy, Division of Health Care, University of Applied Science in Leiden (HSL). Functional Exercise Therapy and Physical Therapy have similarities (both focus on restoring activities of daily life by means of exercises), but also have differences and are seen as two different paramedical health professions in the Netherlands. Two different health care educations from two different universities of applied sciences were included to ensure a diversity in the population of this study to improve the transferability of the findings.

Teachers were able to participate if they have taught for at least 2 years and met one of the following criteria: 1) Teachers from the departments of functional exercise therapy or physical therapy were included if they and were working, 2) OR working as a researcher in the field of eHealth. Students were able to participate if they were in year 3 or 4 of the study

and completed successfully their placement. Thus both teachers and students were able to reflect on the eHealth education in the curriculum as well as on requirements for successful use of eHealth in clinical practice. Teachers and students were invited to participate via the internal web page and a short oral presentation. Those who were willing to participate, received an email with study information, an informed consent form, and were invited for the focus group.

#### **Focus groups**

The focus groups took place in October and November 2016 at the Universities of Applied Sciences in Amsterdam and in Leiden. Separate groups were organized for teachers and students to ensure that both groups could talk freely about their experiences with eHealth in education. Group size was 5-8 participants to include a diversity of opinions and perspectives, and to allow optimal interaction between participants [15]. The focus groups were conducted by 1) a moderator (MW, female), 2) an assistant (student 1, female) who supported the moderator and managed the tape-recorders and time, and 3) an observer (student 2, female) who took notes and made sure every participant was given the opportunity to speak freely. The moderator has a master's degree in Health Sciences and functional exercise therapy and had formal training in conducting focus groups. The moderator was a colleague of some of the participating teachers and a former teacher of some of the participating students. Participants did not receive reimbursement for their participation.

An interview guide was developed based on the implementation model of Grol and Wensing. This model was chosen, since it offers a framework to identify and categorize barriers and facilitators for the uptake of innovations within a specific context, in this case the uptake of eHealth education in the curriculum. The framework includes six levels: Innovation (e.g. advantages, feasibility, accessibility, attractiveness of eHealth), Individual (e.g. motivation, awareness, knowledge, skills and attitude of students and teachers), Social context (e.g. opinion of colleagues, work culture), Organizational context (e.g. organization of the curriculum, capacities, resources, structures) and Political and Economic factors (e.g. financial arrangements, regulations, policies). By including questions according to each level of the framework the research team aimed to contribute to the need for more indepth knowledge of factors (barriers and facilitators) that may critically influence the uptake of eHealth in education [13].

At the beginning of each focus group a brief description of eHealth was given. Openended questions within each level were asked to facilitate interactions and in depth discussion between the participants about eHealth education [16]. Examples of questions are: "What do you need in order to be able to use eHealth in education?" or "Why would you use eHealth in your lessons?". Prompts were used (e.g. pictures expressing emotions) to facilitate participants in verbalizing thoughts. The interview guide was discussed and pilot tested in a group of students. The focus groups were planned to last approximately one hour and were aimed to continue until data saturation was reached (not more than two new subthemes retrieved from the focus groups).

## Ethical issues and approval

All participants gave written informed consent prior to participation. Participants were informed that their statements were confidential, would be used to improve eHealth education and would not affect their position as a teacher or student. Although the study protocol was a non-medical research, we aimed to conduct the study conform the guidelines for 'Good Clinical Practice' (GCP).

#### Data analysis

Focus groups were audiotaped, transcribed in full and analyzed using direct content analysis. The implementation framework of Grol and Wensing (2004) is often used for implementing interventions and innovations in health care. Because the framework is highly structured and generally accepted in the field of implementation it was used in this study to structure and describe barriers and facilitators for implementing eHealth in education form the perspective of both students and teachers [17]. First step in the analyses was to identify barriers and facilitators for each level of the framework (innovation, individual teacher, individual student, social context, organizational context and political and economic factors) by initial coding of guotes. Second, guotes with comparable content for barriers and facilitators were categorized into (sub)themes. These (sub)themes were further analyzed and categorized into main themes. Data analysis was performed by two students who independently coded and categorized the data. Each step of the data analyses was discussed among the students until consensus was reached. The completed analyses was verified by a third researcher [MW]. Again, discrepancies were discussed among students and researcher until consensus was reached. Microsoft Office Excel was used for data analysis.

# Results

#### Participants

Eleven teachers and 26 students indicated their willingness to participate and were invited for the focus groups. Two students were not present, since they had forgotten the appointment. A total of six focus groups was conducted, two with teachers (n=11) and four with students (n=24). Table 1 presents participants' characteristics.

Characteristics	Teachers (n=11)	Students (n=24)
Age, median (range)	38 (29-52)	23 (20-25)
Gender; male, yes (%)	5 (45)	15 (63)
Year in study, number (%) Third year Fourth year	-	13 (54) 11 (46)
Profession, number (%) <sup>a</sup> Exercise therapy Physical therapy Health Sciences / Human Movement Sciences	3 (27) 7 (64) 4 (36)	- - -
Working experience in years, number (%) 2-3 3-4 >4	2 (18) 4 (36) 5 (46)	- - -
Working as a health professional, yes (%)	7 (64)	-
Working as a researcher, yes (%)	4 (36)	-

Table 1. Characteristics of the participants in the focus groups.

<sup>a</sup> Multiple answers possible.

#### Framework

In the first step of the analyses, a total number of 109 barriers and facilitators (codes) were retrieved from the six focus groups with teachers and students, from which 44 were overlapping between teachers and students, 27 were identified by teachers and 38 by students. Next, the barriers/facilitators were organized into 51 subthemes (see Additional file 1) and 14 main themes within the six levels of the framework of Grol and Wensing (see Table 2).

In the following sections, the main themes within each level of the framework will be discussed, first those themes identified by both teachers and students, then those for teachers only and then those for students only.

#### The innovation

Unclear concept of eHealth was mentioned by both teachers and students. Both groups report it is important for students' to learn to motivate what, when and how to use eHealth in the treatment process of a patient, and to learn to match available eHealth with the preferences of a patient and to provide support to patients with using eHealth. Both students and teachers referred to eHealth by mentioning applications, electronic patient records and digital exercises. Other available eHealth applications (e.g. virtual reality, robotics/ house automation) were barely mentioned. When discussing eHealth tools, both teachers and students wondered whether they were aware of all the possibilities.

			Teachers		Students	
Codes (n= 109)	Themes	Level	В	F	В	F
26	Unclear concept of eHealth		Х		Х	
	Lack of a quality mark and evidence for eHealth services.	Innovation	Х		Х	
17	Capabilities of students on how to use eHealth	Individual	Х	Х	Х	Х
	Attitude/behavior of students towards eHealth	student		Х	Х	Х
22	Capabilities of teachers on how to use eHealth	ا م مان بناما ب	Х	Х	Х	
	Attitude/behavior of teachers towards eHealth (education)	teacher	Х	Х	Х	
14	Inefficient use of expertise		Х		Х	
	Communities of practice	- Social context		Х		
	Interprofessional collaboration/education	-	Х	Х	Х	Х
20	(Lack of) a shared vision within the organization	Organizational	Х	Х	-	
	Situational factors (e.g. lack of time, slow curricula changes)	context	Х	Х		
10	Financial aspects (e.g. no reimbursement, time and money investment)		Х		Х	
	Role of the government (e.g. quality mark for eHealth, reimbursement)	Economic and political context		Х		Х
	Role of profession bodies (e.g. provision of education for therapists)					Х

**Table 2.** Results on codes, themes and levels of perceived barriers (B) and facilitators (F) for eHealth education according to teachers and students.

Lack of a quality mark and evidence for eHealth services was reported by both teachers and students. Both groups related the lack of a quality mark (i.e. applicability, usability, content, privacy, safety) and the relative absence of evidence for eHealth interventions to a lack of eHealth in education. "Teacher K: It is tricky. You can never implement something new in education if you waiting for the scientific evidence. The paradox with eHealth is that you are not going to know until you give it a try".

# The individual student

*Capabilities to use eHealth* was rated highly by teachers, since they agreed that current generations of students are in general competent with using technology. However, this does not imply that students are also able to innovate health care through eHealth and apply this in their professional work. *Teacher A1: "Although students are quite skilled in technical issues, I am often disappointed in their innovativeness.*" Students do think they are capable to work with technology and eHealth, but do not use it since they are unfamiliar with the available eHealth services and have a lack of experience of applying it. *Student M1: "I think I could apply eHealth, but in fact I know quite little about the possibilities. For this reason* 

#### I will not use it just now."

Attitude/ behavior towards eHealth towards eHealth differs between individual students, according both teachers and students. Some students are highly interested in technology and choose to get more involved, whereas others do not. When discussing use of eHealth as a (future) health professional, students' expressed it is optional, in terms of having a choice. Student L1: "I think I will not really focus on it. I do want to know what the options are, but personally I will not devote to it for my future". Student J1: "Once you have graduated you can make your own choice and decide whether you use it."

### The individual teacher

*Capabilities to use eHealth*, i.e. the knowledge about eHealth and skills on how to use eHealth, varies widely between individual teachers according to both the teachers and students. Some teachers admitted to having no overview of existing tools and eHealth interventions in their field of work or expressed to barely know how to use a projector, while others found themselves very competent as researchers in the domain of eHealth.

Attitude and behavior towards eHealth were rated positively towards eHealth education in general by teachers. Teacher V1: "As a teacher I want to use eHealth in my lessons to provide 'future proof' education that is innovative and interactive. This makes learning more fun and challenging for students and they would be more enthusiastic about my lessons." However, a barrier is that teachers feel insecure about eHealth education. Teacher K1: "I do not feel that I know enough about eHealth, but that is what I want as a teacher before I use it in my lessons." Students expressed that teachers have a negative attitude/behavior towards eHealth. Student S1: "Teachers often say: find something you like, because you know better than me." Student M2: "If a passionate teacher puts something forward, then I am more open for it. However if a teacher says 'you are the young generation. You surely know of some app, and give it a try', then I am not. And the latter is what I have been told so far."

#### The social context

Inefficient use of expertise of eHealth within the organization was mentioned as a barrier by both teachers and students. Student L1: "Teachers do not collaborate. For example get a lecturer who knows a lot about eHealth to take over the lesson. All should be benefit from it, since the less experienced teacher will catch up." Teacher M2: "More experienced teachers who are doing research in technology or eHealth should share their knowledge with less experienced teachers. A kind of cross-fertilization".

*Communities of practice* were recognized as a facilitator for eHealth education according to teachers. Such communities were seen as mixed groups (teachers, students, researchers and/or the workfield) of people who share their passion and learn how to do it better by interacting regularly. *Teacher A1: "we do quite a bit of research using eHealth. It would be great* 

if we can get an exchange between research, education and practice and in this way create an inspiring environment around eHealth."

Interprofessional collaboration education is, by both teachers and students, regarded as a facilitator for eHealth in education if students of different professions work together (e.g. technology, ICT, media, etc.). Student N1: "I think it would have an enormous added value if you would work on a project on eHealth together with students with an IT background; developing an app for example."

## The organizational context

(Lack of) shared vision/rationale in the university about what students should learn about eHealth is absent according to teachers. Teacher D1: "As a school you have to decide to what degree you want to integrate this in your basic curricula. A choice can be to provide eHealth as a dedicated subject of choice. This can be a choice, but you will have to have an idea." Teachers felt that what students learn about eHealth is too much of a coincidence, depending on a students' own interest in technology, the extent of eHealth experience during their internships/study route and the teachers they had. "There is no clear approach for eHealth in the curricula in which connects to the professional roles (CanMeds) of the care professionals (OT/ PT)." Although there is not (yet) a clear vision about what students should learn, teachers did agree that there is a consensus within the university about the importance of eHealth education.

*Situational factors,* as mentioned by teachers, include the following barriers for eHealth education: lack of time for preparing lessons, failing technology, absence of didactic materials and relative slow curricula changes. Facilitators according to teachers would be: presence of ICT professionals within the organization, direct accessibility to materials (e.g. LivingLabs), (scheduled) time to prepare lessons, special interest group of teachers taking the lead and training for teachers to improve their competences.

## Economic and political context

*Financial aspects* are expressed by both teachers and students in 10 quotes. The lack of reimbursement by health insurance companies in the Netherlands for eHealth interventions results in the absence of incentives to use eHealth in the field of work. Teachers specifically mentioned financial aspects such as the investments in technology and eHealth, needed for eHealth education, are a financial barrier for uptake.

The role of the government is to provide a definition of the future health professionals in relation to eHealth to give direction for eHealth education, according to the teachers. Students expressed that it is the role of the government to manage reimbursements for eHealth interventions and to lower the workload for health professionals. According to the students, this would facilitate health professionals to apply eHealth and consequently students can experience eHealth during internships. Moreover, students want the government to improve the quality of eHealth by a national quality mark or at least a check list to determine quality of eHealth services.

*Role of profession bodies.* Students noticed during their internships eHealth is not yet imbedded in the work field. According to them, their professional organizations should facilitate uptake of eHealth in daily practice, for instance by providing education to health professionals and incorporation of eHealth in practical guidelines.

## Discussion

The aim of this study was to identify barriers and facilitators for eHealth education as perceived by teachers and students of physical therapy and functional exercise therapy. Teachers and students equally contributed to the number of facilitators and barriers for the use of eHealth in professional education identified in this focus group study. Main barriers for the *innovation* were a lack of understanding the full concept of eHealth and a lack of knowledge and skills in critically appraising eHealth. For the *individual users*, the variety in knowledge and skills of individuals was a factor influencing uptake. On the level of the *organization*, identified factors for uptake were the shared sense of importance of implementing eHealth in education, a shared vision about what students should learn about eHealth and didactic materials. *Economical* barriers were seen in the investments in technology and eHealth. Finally, *political* factors were identified in the national government to manage future reimbursements for eHealth interventions and to improve the quality of eHealth by a quality mark.

As expected, and based on the literature, we found unanimous support for implementing eHealth in education in the curricula of two departments in the Netherlands. In line with literature, we found barriers and facilitators on all levels of implementation as described by Grol and Wensing (2014) [17]. The barriers to the uptake of the eHealth *innovation* found in our study are in line with previous research: limited skills and knowledge about the eHealth intervention in both teachers and students [5,10,11,13,18], limited confidence in working with technology in health practice [6,11,13] and critically appraising and applying technique [5]. Lam (2016) mentioned: 'while students demonstrated the technical skills that would potentially enable them to engage in eHealth, they displayed a lack of understanding how these skills could be applied to professional health contexts' [13]. On the level of the *individual user*, there is a marked diversity in knowledge and skills in both teachers and students, which is in line with previous studies [5,13], and might hinder uptake of eHealth in the curricula.

On the level of organization, barriers and facilitators identified in our study add to the

growing consensus that the uptake of eHealth needs a multi-facetted approach and not just 'writing a new module'. In literature, static curricula with narrow focus on technology were reported as important barriers [7], and a clear need for a shared vision/rationale about what students should learn about eHealth and need didactic materials which is also reflected in literature [9]. *Political and economic* factors, i.e. the influential role of government, policies and professional bodies on uptake of eHealth in education, found in this study, were also reported elsewhere: this was phrased by Hilberts and Gray (2014) as the need for 'an education infrastructure in large-scale eHealth strategies' [18].

Strength of this study is that research in this field amongst physical therapists is relatively scare. Another strength is the structured use of the model of Grol and Wensing to gain a more in-depth knowledge of barriers and facilitators for the uptake of eHealth in education and to enable comparison between the perspectives of teachers and students. EHealth is a relatively new and emerging field and, as a consequence, so is the implementation in education. There is surprisingly little evidence for the effectiveness of education focusing on the use eHealth [18]. Last but not least, a strength is that both teachers' and students' perspectives were included, whilst most studies focused on single groups of teachers, students or professionals. Limitations of this study are the professional relationship of the first author with some of the teachers and students. For that reason it was made very clear to the participants that their statements were confidential and not affected their position as a teacher/student. However, some bias in their responses cannot be ruled out entirely. Moreover, further focus groups might add to the data-saturation to some degree.

For uptake of eHealth in the curricula of physical and functional exercise therapy it is eminent to recognize the multi-level character of it. This study highlighted the need for a vision on eHealth at a faculty level. Besides a generally limited understanding of the width of eHealth and the expected impact of eHealth in clinical practice, this study showed that both the lack of skill in critically appraising the quality and usefulness of eHealth and the diversity in background knowledge and skills in technology need to be a point of engagement in future uptake plans. Moreover, the 'higher order' influences on both education and professional practice need to be addressed in eHealth education, i.e. the role of government, policies and professional bodies. In addition, to further enhance uptake it is strongly advised to take a structured approach by addressing the levels of uptake [17]. Using 'a clear rationale for teaching clinical informatics and a detailed list of desired competencies are an important start' [9], and keeping in mind that 'there is surprisingly little evidence about what works and doesn't work with regard to the eHealth education' [18]. Finally, more tools should be provided by the organizations itself, such as didactic materials and eHealth facilities.

This study provides insights into the many factors which influence the successful uptake of eHealth in the curricula of functional exercise and physical therapy education. This is highly important given the fact that the application of eHealth is irreversible and health professionals do not seem to be fully equipped to work with eHealth. Uptake of eHealth needs a systematic multi-facetted approach considering factors on the level of the innovation, individual users, organization and political and economic levels. Important starting points for developing uptake strategies, for both teachers and students, are a limited knowledge of eHealth, a large diversity in eHealth skills, a lack of skills in critically appraising eHealth and to development of a clear rationale for teaching eHealth. A recommendation for further research is to re-examine the study in other health professions for a good comparison of perceived barriers and facilitators for eHealth education. Moreover, future research should provide evidence for what works and doesn't work with regard to the eHealth education.

# Declarations

*Ethicsapprovalandconsenttoparticipate:* All participants gave written informed consent prior to participation. The study protocol was a non-medical research and no registration was required. *Consent for publication:* Not applicable.

*Availability of data and material:* The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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

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# Summary & general discussion

# SUMMARY

# Aims of this thesis

eHealth is increasingly used in rehabilitation (eRehabilitation), yet evaluations of its effectiveness, the process of delivery and the perceptions of patients, their caregivers and health care providers are relatively scarce. This thesis aimed to:

- I. Evaluate the outcome and process of an eHealth intervention for cognitive stroke rehabilitation.
- II. Explore the (readiness for) use of eHealth among patients in rehabilitation.
- III. Investigate the requirements of patients, informal caregivers, health professionals, teachers and students regarding the use of eHealth interventions in stroke rehabilitation.

## **Main findings**

The outcome and process of an eHealth intervention for cognitive stroke rehabilitation were addressed in Chapters 2 and 3.

**Chapter 2** concerned a Randomized Controlled Trial (RCT) to evaluate the effect of an online serious brain training programme on multiple aspects of cognitive functioning, quality of life (QoL) and self-efficacy in comparison to a control intervention in stroke patients with self-perceived cognitive impairments. 110 stroke patients with self-perceived cognitive impairment 12–36 months after stroke were randomly allocated to the intervention (n=53) or control group (n=57). The intervention consisted of an 8-week brain training programme (Lumosity Inc.®). The control group received general information about the brain weekly. Assessments consisted of a set of neuropsychological tests and questionnaires on cognitive functioning, QoL and self-efficacy. After 8 and 16 weeks, no significant effect of the intervention was found on cognitive functioning, QoL or self-efficacy as compared to the control condition, except for small, yet statistically significant, effects on working memory and speed (mixed model analysis).

In **Chapter 3** the adherence of patients with the above mentioned 8-week brain training programme (intended use a minimum of 600 minutes of playtime) was described, with a focus on the role of health professionals' supervision. This study was part of the RCT described in Chapter 2 and used data from patients in the original intervention group (n=53) and the patients in the control group who accepted the offer to use the brain training programme after the initial trial period (n=52). Patients in the original intervention group

received supervision eight times during the training period (group 1), whereas patients in the original control group were only supervised twice (group 2). It was found that patients experienced several difficulties with tasks and conditions required to participate in the brain training (e.g. not able to cope with flashing screens, etc.). Only 24 out of the 105 patients (23%) were able to complete the intended dose of 600 minutes brain training over a period of 8 weeks, with the median playtime being 424 minutes (27-2162). The median playtime was significantly higher in group 1 (562 minutes, range 63-1264) than in group 2 (193 minutes, range 27-2162) (p < 0.001, Mann Whitney U). A possible explanation could be that excitement for the study waned for patients in group 2 who had to wait 16 weeks after the randomisation, whilst patients in group 1 started the training straight away after inclusion. Nevertheless, the findings may indicate that the frequency of the interaction with a supervisor can increase stroke patients' adherence with a brain training programme at home.

Given the suboptimal use of the brain training programme in Chapters 2 and 3, a descriptive study in **Chapter 4** explored the (readiness for) use of information and communication technology (ICT) devices (e.g. personal computer (PC), laptop, tablet, smartphone) among patients who were or had been admitted for rehabilitation. It also aimed to investigate patients' preferences to incorporate this technology in their rehabilitation process. For this study a cross-sectional design with a self-developed online guestionnaire was used. The guestionnaire comprised 61 guestions about current possession and use of ICT devices, desired usage of ICT devices in the rehabilitation process in the future and sociodemographics and disease characteristics. Open answers, multiple choice and a 4-point Likert scale (1-4: totally disagree-totally agree) were used to examine current possession and user preferences. 190 out of 714 invited patients admitted for inpatient and/or outpatient rehabilitation and registered with an e-mail address, completed the guestionnaire. 94 (49%) were women and 96 (51%) were men. The mean age of the participants was 49 (SD16) years. 149 out of 190 patients (78%) used one or more devices every day of the week. The most frequently used devices were: PC/laptop (93%), smartphone (57%) and tablet (47%). Most of the patients were willing to incorporate ICT devices in their rehabilitation process. The most frequently mentioned potential purposes for use in rehabilitation included: having insight in the medical health record, communication with peers and scheduled appointments with health professionals.

Chapter 4 provided insight in current and desired use of ICT devices in rehabilitation in general, but the perspectives of intended users regarding eRehabilitation after stroke are not yet explored. Therefore, requirements for use of stroke eRehabilitation were investigated and prioritized in chapters 5 and 6. **Chapter 5** describes the requirements for the accessibility, usability and content of comprehensive eRehabilitation after stroke as perceived by

patients with stroke, their informal caregivers and health professionals, as identified by a qualitative (focus group) study. In total, eight focus groups were conducted to identify user requirements; six with patients/caregivers and two with health care professionals involved in stroke rehabilitation (rehabilitation physicians, physiotherapists, occupational therapists, psychologists, team coordinators). Direct content analysis was used to identify the user requirements concerning three predefined categories: accessibility, usability and content. In total, 45 requirements emerged from the focus groups. It was concluded that the majority of requirements of patients, informal caregivers and health professionals concerned content (25 requirements), followed by usability (12 requirements) and accessibility (8 requirements). Moreover, requirements between stroke patients/informal caregivers and health care professionals differed on several aspects. For instance, a requirement of health professionals was that eRehabilitation programmes can be accessed by the computer in the rehabilitation center, whereas patients and caregivers preferred to use a smartphone or tablet.

**Chapter 6** provides an overview of the most important requirements for comprehensive eRehabilitation after stroke according to larger groups of patients with stroke, their informal caregivers and health professionals (physicians, psychologists and physical therapists), as based on a quantitative (survey) study. In order to determine the importance of requirements, a questionnaire with a 4-point Likert scale (1-4; unimportant-important) was developed with statements regarding accessibility, usability and content of comprehensive eRehabilitation after stroke. 125 patients, 43 informal caregivers and 105 health professionals completed the survey. The most important requirements as perceived by the majority of all stakeholder groups were: applicability of eRehabilitation to possessed ICT-devices (e.g. tablet, smartphone, computer in rehabilitation center), support with usage (i.e. instruction videos, menu with frequently asked questions), physical exercises, general information about stroke, insight in the rehabilitation process (i.e. feedback about training results, final reports) and setting and evaluation of goals. Notable differences were also found between the stakeholder groups, for instance exercises for cognitive functioning were important for patients and informal caregivers, whilst this was a less important requirement for health professionals.

Except for matching eHealth interventions with the requirements of its users, successful adoption in stroke rehabilitation also depends on how well health professionals are prepared to use eHealth in daily practice. This readiness starts with educating health professionals to work competently and confidently with eHealth.

Chapter 8

**Chapter 7** describes the barriers and facilitators for eHealth education as perceived by teachers and students involved in the education of exercise/physical therapists. A qualitative study including six focus groups was conducted: two with teachers (n=11) and four with students (n=24), all selected from two universities of applied sciences in the Netherlands. Reported barriers and facilitators were identified, grouped and classified according to the levels of a generally accepted framework for implementation (innovation, individual teacher, individual student, social context, organizational context and political and economic factors). More barriers than facilitators were perceived for the uptake of eHealth education in the curriculum, by both educators and students. Most barriers and facilitators were identified on the level of the Innovation (eHealth, e.g. unclear concept) (n=26), followed by the Individual teacher (e.g. capabilities on how to use eHealth) (n=22) and the Organizational context (e.g. didactic materials) (n=20). Starting points for developing implementation strategies of eHealth (education) in the curriculum, for both teachers and students, can be found in reducing the barriers (e.g. limited knowledge of eHealth, lack of skills in critically appraising eHealth) and by using the facilitators (e.g. shared sense of importance of implementing eHealth in education, passionate teachers, didactic materials).
## DISCUSSION

### Focus of this thesis

This thesis focused on the evaluation of an eHealth intervention for cognitive stroke rehabilitation and the perspectives of different stakeholders on the uptake of eRehabilitation in general.

The studies included in this thesis showed that there was no overall effect of an online brain training programme on cognitive functioning of patients with stroke. Only performances on cognitive function tests that were similar to the games included in the intervention improved, no near transfer effect was found. Moreover, usage of the training was suboptimal and not all of the patients were able to complete it. In order to improve daily activities of stroke patients, computer tasks need to be closely related to the impaired task itself. Thus, computer-based cognitive rehabilitation (CBCR) needs to be tailored and adapted to each patient's individual profile. It would appear important to support stroke patients with CBCR training, since training is not well used by all patients. It is possible patients benefit more when they learn how to use strategies in their training and when motivated by clinicians.

However, regarding patients' ICT readiness, wishes and requirements it was also found that a relatively large amount of patients in rehabilitation wish to incorporate ICT in their rehabilitation treatment and that patients with a stroke have specific requirements regarding the accessibility, usability and content of eRehabilitation. The requirements of patients were not entirely similar to those of informal caregivers and health professionals, indicating that all perspectives of all stakeholders should be taken into account. In addition, developing tailored implementation strategies to implement eHealth in the bachelor curriculum of health professionals, based on the identified barriers and facilitators in this thesis is highly relevant to make sure that future health professionals are able to work with eHealth.

Given the abovementioned findings, this Discussion focuses on conditions that can facilitate the effect and uptake of eRehabilitation, with emphasis on rehabilitation of patients after stroke.

# Part I. Evaluation of an eRehabilitation programme after stroke: outcome, process and study design.

#### Evidence for the effectiveness of cognitive eRehabilitation after stroke

Our finding (chapter 2 and 3) is in line with the suggesting that the evidence for the effectiveness of cognitive eRehabilitation in stroke is scanty [1-6].

A recent systematic review by Laver et al. concluded that the effect of cognitive

eRehabilitation through virtual reality on cognitive functioning in stroke patients is still unclear because of a lack of trials [2]. A recently performed RCT also found that a brain training programme, which was comparable to the training used in our study, did not improve cognitive functions, subjective cognitive functioning or quality of life in patients in the chronic phase after stroke compared to a control group (waiting list) [7]. The literature is however conflicting, as some studies have also found positive effects in patients with stroke or other acquired brain injury after brain training [8-17]. It should be noted though that effects were mostly seen for tasks (outcomes) similar to tasks in the training process (i.e. near transfer effect), rather than tasks that are dissimilar to the training (i.e. far transfer effects) [15-21]. In other words, outcomes in terms of tasks that are similar to the training are less likely to contribute to improvements in daily living than outcomes that are directly linked to activities done in daily life [6]. It is possible that cognitive eRehabilitation interventions in which the tasks are closely related to the cognitive tasks in daily life, are more effective to stimulate cognitive functioning after stroke than playing games. This is supported by a RCT of Faria et al. (2016). In this study the potential benefits of virtual reality based cognitive rehabilitation after stroke through simulated activities of daily living were compared to conventional therapy only [22]. The intervention involved a virtual simulation of a city where memory, attention, visuo-spatial abilities and executive functions tasks were integrated in the performance of several daily routines. A between groups analysis showed significantly greater improvements in global cognitive functioning, attention and executive functions in patients with stroke when comparing virtual reality to conventional therapy.

Except for the scarcity of trials on the effectiveness of stroke eRehabilitation, according to the previously mentioned systematic reviews the methodology and reporting is poor in many cases, hampering the interpretation of their findings [2;23-28].

### The process of cognitive eRehabilitation programme after stroke

The RCT described in this thesis showed that only 24 out of 105 patients (23%) were able to complete the desired total number of 600 minutes of brain training over a period of 8 weeks. This is in line with other studies that concluded that intensive (eHealth)-exercise regimes after stroke are difficult to perform for stroke patients [29-32].

During the execution of the trial, patients experienced several difficulties with tasks and conditions required to participate in the brain training (e.g. no possession of the required operating system to run games on their computer, incompetency with technology, not able to cope with flashing screens, etc.). These barriers might have contributed to the relatively low usage. Other barriers were identified by Pugliese et al. for mobile tablet-based care in patients with stroke (e.g. complexity of therapy instructions, fine-motor requirements, and unreliability of internet or cellular connections) [33].

To allow successful uptake of eRehabilitation it is recommended to identify methods that

can minimize the barriers for the use of eRehabilitation and support maximize adherence of patients with stroke [33]. One of these methods, explored in this thesis, was the delivery of supervision during the eRehabilitation intervention. Two intensities of supervision offered by a health professional were compared, showing that more frequent supervision (weekly) resulted in significantly higher adherence levels than low frequent (4-weekly) supervision. This is in line with a review by Kelders et al. (2012), concluding that the frequency of interaction with a counselor was a significant predictor for adherence with web-based health interventions in different patient groups [34]. Therefore, regular interaction with a supervisor is important to increase stroke patients' adherence with eRehabilitation interventions and supports the importance of offering eHealth by means of a blended care strategy.

### Study strategies to evaluate a cognitive eRehabilitation programme after stroke

Although effects of eRehabilitation interventions are often evaluated in conventionally designed clinical trials, as was done in the RCT presented in this thesis, these designs are not always appropriate to evaluate effects of eHealth [35-38]. For example, an RCT does not always represent daily health care practice because of its sometimes very strict inclusion and exclusion criteria [38]. Consequently, when the effectiveness of eHealth has been established in a "laboratory setting", the results may not be replicated in a different context, where e.g. patients with less digital skills or cognitive impairments are offered the intervention.

Another drawback of traditional research designs is that their time cycle is much longer than the speed at which eHealth develops and evolves. This can make (parts of) the innovation under study already outdated by the time the results of the RCT are published [39]. Moreover, 'early adopters' among patients and health professionals may use an eHealth innovation before the evidence is available [38], decreasing the contrast between intervention and control conditions.

All of the abovementioned aspects have implications for the design of future eRehabilitation research. First, alternative research designs than the traditional RCT are recommended in order to provide information about how an eHealth intervention works in health care practice and to make experiences of users more visible. The following (research) strategies can be considered for research in eRehabilitation:

- 1) Multiple evaluations and use of clinically meaningful outcome measures that are highly sensitive and quickly responsive to the effects being evaluated [39];
- 2) Using alternative resources to generate information, e.g. digital self-measurements, social media, online databases or personal health files, big data analysis [36;40];
- 3) Qualitative research into the experiences of patients; and
- 4) Action research. Action research, often led by a group of professionals as part of

a community of practice, is initiated to solve an immediate problem identified by professionals [41]. The goal is to investigate and solve the problem, for instance by developing guidelines, strategies and knowledge in order to improve the communities' work practices. This is done by active participation of the community of professionals itself (e.g. teachers, students, researchers, patients, health care professionals). After investigation of the problem, the group makes decisions, observes and keeps note of the consequences of changing the particular situation. So, the group participates in a change situation, whilst research is conducted simultaneously, alongside the iterative process of adapting, testing and evaluating the innovation.

To conclude with, it should be noted that the development, evaluation and implementation of stroke eRehabilitation interventions and associated research must be executed in collaboration with all relevant stakeholders to make eRehabilitation relevant and feasible for the intended users in health care [42;43]. An example of such a collaboration is a so called "Living Lab", where various stakeholders (e.g. knowledge institutions, health care organizations, practitioners, patients, financiers, innovators, established companies, startups, researchers, etc.) work together to develop, evaluate and implement eHealth. In a medical specialist rehabilitation center, Basalt rehabilitation, such a Living Lab, the SmartLab, is instituted. Here, a stepwise procedure is used to test innovations in rehabilitation for their potential added value and usability (www.medicaldeltalivinglab.nl; (http://www.basaltrevalidatie.nl/onderzoek-innovatie/smartlab/). Subsequent steps involve research to systematically evaluate the effectiveness, experiences and costs, and implementation when appropriate.

# Part II. Readiness and requirements for eRehabilitation after stroke: implications for the uptake, health care practice and education.

## Incorporating perspectives of stakeholders in the development of stroke eRehabilitation

This thesis includes a number of studies aiming to identify the readiness and requirements for stroke eRehabilitation among stakeholders involved in stroke care. A survey study found that the possession and usage of ICT devices was relatively high among patients in rehabilitation and that most patients wished to use those devices during the rehabilitation process. Moreover, a focus group study showed that stroke patients, informal caregivers and health professionals had very specific requirements for stroke eRehabilitation, e.g. doing physical exercises, information about stroke and outcomes of rehabilitation and scheduling appointments with health professionals. These findings suggest that preferably, eHealth services should be developed where diverse purposes (e.g. telecommunication, training facilities, information, agenda, etc.) are combined in one digital platform to allow easy

access and use. Partly based on the outcomes of this qualitative study a comprehensive eRehabilitation platform for stroke was built and is currently evaluated in the Fit After Stroke 'Fast@Home' project (www.fastathome.org).

Moreover, our focus group study showed that eRehabilitation training facilities and feedback should both be adapted to patients' preferences and capabilities (tailored care) [44-50]. Offering support with daily use of an eRehabilitation programme (i.e. direct assistance, a helpdesk, videos with instructions and/or a menu with frequently asked questions) was considered a crucial element as well. These findings may imply that to develop stroke eRehabilitation programmes that match with the needs of the intended users, it is essential that eRehabilitation programmes are designed in co-creation with all relevant stakeholders (co-design'). Requirements of patients, informal caregivers and health professionals should be incorporated in each step of the design process ('user-centered design'). This is especially important since this thesis showed that different types of stakeholders have different requirements to optimize usage of eRehabilitation. The aforementioned community of practice is a good method to establish active participation of all relevant stakeholders and thereby enhances co-creation and user-centered design in eRehabilitation.

### The uptake of eRehabilitation in stroke care

The impact of a stroke varies widely among individuals with the optimal treatment depending on abilities, preferences and goals of both the patient and his or her caregiver(s) [51]. Health professionals can play a central role in this patient-centered delivery of eRehabilitation (e.g. adjustment of training facilities according to progression, feedback and motivation). They are able to link the patient to effective eRehabilitation interventions and can provide guidance with using a new eHealth service. It is recommended to further implement living labs, Communities of Practice, involvement of end-users (patient, caregiver, professional, students, designers, researchers, etc.) and co-create in ideation, testing, implementation, evaluation and upscaling.

In a qualitative study aiming to identify user requirements for stroke eRehabilitation by means of focus groups, the participating healthcare providers (rehabilitation physicians, physiotherapists, occupational therapists, psychologists, team coordinators and speech therapist) also acknowledged the importance of their role in the uptake of eRehabilitation in stroke care. Health professionals are often not aware of the opportunities of eHealth and poorly informed about available eHealth interventions [37]. It is often unclear to health practitioners how eRehabilitation can be effectively used for patients [52]. If evidence from research is available, it may not be suitable to directly support health practitioners in making clinical decisions [37;38]. Virtual reality, for instance, has emerged as a therapeutic tool facilitating motor learning for balance and gait rehabilitation in stroke patients [2]. The evidence, however, has not yet resulted in protocols or standardized guidelines and/

or a consensus regarding optimal intervention programmes (e.g. dosage and tasks) [52]. Furthermore, it is complex to integrate effective eHealth interventions in existing work processes.

Therefore, health professionals need to be supported with protocols and guidelines that provide insight which type of stroke eRehabilitation works for whom [37;53]. Moreover, an overview of applicable eHealth interventions in stroke rehabilitation should be developed based on different resources, such as evidence, experiences of users and patient consumer organizations and professional organizations [37]. Therefore, the above mentioned SmartLab is linked with the National eHealth Living Lab (NeLL), an eHealth community (patients, consumers, professionals, scientists, students, organisations) aiming to create the best eHealth solutions by sharing knowledge, contacts and experiences with each other (https://nell.eu).

Furthermore, this thesis showed that applicable eHealth needs to be integrated into working routines. A major challenge is realizing an integrated digital infrastructure, with patients, caregivers and healthcare providers connected in a safe, dynamic and efficient system.

### eHealth in health professionals' education

Future health professionals should be able to competently and confidently work with eHealth [54;55]. However, education in eHealth is currently underrepresented in the curricula of health professions'education (e.g. dietetics, nursing, occupational therapy, physiotherapy, psychology or social work) [56-59]. In this thesis a focus group study among teachers and bachelor physical and exercise therapy students was conducted to identify barriers and facilitators for the uptake of eHealth education in the curriculum. Better integration of eHealth in the curriculum was considered important by both students and teachers who participated in the focus groups and they demonstrated their willingness to use eHealth. Nevertheless, in line with other studies in the field, their understanding of eHealth was limited [60]. Moreover, they expressed a lack of skills for critically appraising eHealth and the absence of a clear rationale for teaching eHealth. To enhance implementation in the curriculum of health care education clinical reasoning' will be the driver of the toolkit eHealth that is currently developed, based on our findings and in collaboration between three Universities of Applied Sciences.

A facilitator for the uptake of eHealth education identified in the focus groups was the optimal use of communities of practices. As described previously, in a community of practice, a mixed group (teachers, students, researchers and/or the work field) shares a passion and constantly innovates, in this case eHealth, by interacting regularly in a process of action research with all stakeholders [61]. Participation in such a community of practice benefits both teachers and students in their teaching and learning about eHealth [62]. In addition,

literature suggests that real-life experimentation of eHealth innovations in a realistic context with active user involvement (LivingLabs) are stimulating learning environments [63]. Other identified facilitators, which can be used in strategies for implementation, are the shared sense of importance of eHealth education, passionate teachers, didactic materials, collaboration with ICT professionals, direct accessibility to materials (lab with technology and eHealth), (scheduled) time for teachers to prepare lessons, special interest groups of teachers taking the lead and a national benchmark for the quality of eHealth.

In general, it is advised that eHealth education should be integrated in basic courses so that future healthcare professionals are already familiar with it, but also in postgraduate education to facilitate current use in daily practice [37].

## Conclusion

In this thesis conditions that can facilitate the effect and uptake of eRehabilitation were described, with emphasis on stroke patients. The use of eRehabilitation after stroke is promising, but adoption of eRehabilitation in stroke care falls behind and their evidence regarding its effectiveness is scanty. More research is needed using appropriate study designs for evaluation of the outcomes and processes of eHealth. Moreover, development should be done in co-creation based on user requirements in order to increase the uptake in stroke care. To minimize barriers with usage, both patients and health professionals, should be supported in using eHealth and eHealth (education) needs to be integrated in the curriculum of (allied) health professions of universities for applied sciences.

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# Appendix

Samenvatting en discussie Publications Curriculum Vitae Dankwoord

# SAMENVATTING

eHealth wordt steeds meer gebruikt in de revalidatie (eRevalidatie). Wetenschappelijk onderzoek naar de effectiviteit en de implementatie van eRevalidatie is echter relatief schaars. Dit proefschrift richt zich op:

- I. Een evaluatie van het effect en het proces van een eHealth interventie in de cognitieve revalidatie na een CVA.
- II. Het gebruik van eHealth door patiënten in de revalidatie.
- III. Het inventariseren van randvoorwaarden van patiënten, mantelzorgers, zorgprofessionals, docenten en studenten met betrekking tot het gebruik van eHealth interventies in de revalidatie na een CVA.

## Algemene bevindingen

Een aanzienlijk deel van de mensen met een CVA ondervindt cognitieve klachten. zoals problemen met het geheugen, initiatief nemen of het oplossen van problemen. Hoofdstuk 2 beschrijft een Randomized Controlled Trial (RCT) om de effectiviteit van een online cognitieve training te onderzoeken. Honderdtien patiënten die 12-36 maanden na een CVA beperkingen hadden in het cognitief functioneren werden toegewezen aan de interventie- (n=53) of controlegroep (n=57). De interventiegroep doorliep een 8 weken durende, online cognitieve training (Lumosity Inc.®). De controlegroep ontving wekelijks algemene informatie over cognitieve functies. De metingen werden uitgevoerd na afloop van de training (8 weken) en 8 weken daarna (16 weken). De metingen bestonden uit een set van neuropsychologische tests (werkgeheugen, aandacht, flexibiliteit in denken, reactiesnelheid en vloeibare intelligentie) en vragenlijsten die betrekking hadden op het cognitief functioneren, de kwaliteit van leven en de 'self-efficacy' (het vertrouwen dat mensen hebben in hun eigen vermogen om specifiek gedrag in verschillende omstandigheden uit te voeren). Na 8 en 16 weken werden kleine, statistisch significante effecten op werkgeheugen en reactiesnelheid gevonden. Er waren geen effecten van de cognitieve training op andere belangrijke aspecten van cognitief functioneren (aandacht, flexibiliteit), kwaliteit van leven of de self-efficacy in vergelijking met de controle interventie.

**Hoofdstuk 3** beschrijft de procesevaluatie van de RCT die beschreven is in hoofdstuk 2. Er werden gegevens gebruikt van patiënten uit de oorspronkelijke interventiegroep (n=53, groep 1), aangevuld met gegevens van patiënten uit de controlegroep, die na afloop van de RCT de 8-weekse training alsnog volgden (n=52, groep 2). Patiënten in de oorspronkelijke interventiegroep kregen gedurende de trainingsperiode 8 keer supervisie door een zorgverlener, terwijl patiënten in de oorspronkelijke controlegroep slechts twee keer supervisie hadden.

Uit het contact met de zorgprofessionals bleek dat patiënten diverse problemen ondervonden bij deelname aan de cognitieve training, zoals bijvoorbeeld overprikkeling door flikkeringen op het beeldscherm. Slechts 24 van de 105 patiënten (23%) waren in staat om de beoogde 600 speelminuten over een periode van 8 weken te voltooien. De mediane speeltijd was 424 minuten (range van 27 tot 2162 minuten) en was statistisch significant hoger in groep 1 (562 minuten, range 63 tot 1264 minuten) dan in groep 2 (193 minuten, range 27 tot 2162 minuten). Dit verschil kan mogelijk verklaard worden door een intensievere begeleiding in groep 1. De verschillen kunnen ook mede veroorzaakt zijn door de lange wachttijd voor patiënten in groep 2, die tot 16 weken na de randomisatie moesten wachten om de training te kunnen volgen. Desalniettemin lijken de bevindingen uit deze studie erop te wijzen dat interactie met een zorgverlener het gebruik van een cognitieve training door CVA-patiënten kan verhogen.

Vanwege het suboptimale gebruik van de cognitieve training werd in een beschrijvende studie in **hoofdstuk 4** het gebruik van informatie- en communicatietechnologie (ICT) onderzocht bij patiënten die waren opgenomen in een revalidatiecentrum. Ook werden hun voorkeuren voor het gebruik van ICT in het eigen revalidatieproces geïnventariseerd. Deze inventarisatie bestond uit eenmalige afname van een zelfontwikkelde online vragenlijst. De vragenlijst bestond uit 61 vragen over het bezit en gebruik van ICT middelen, het gewenste gebruik van ICT in het revalidatieproces en enkele sociaal-demografische kenmerken.

714 patiënten die klinisch of poliklinisch hadden gerevalideerd en van wie het e-mailadres bekend was werden uitgenodigd voor het onderzoek. Honderdnegentig van de 714 patiënten vulden de vragenlijst in (27%); 94 (49%) vrouwen en 96 (51%) mannen, met een gemiddelde leeftijd van 49 (Standaard Deviatie (SD) 16) jaar. Uit de resultaten bleek dat 149 van de 190 patiënten (78%) dagelijks één of meer ICT-toepassingen gebruikten. De meest gebruikte apparaten hierbij waren een: personal computer (PC)/laptop (93%), smartphone (57%) en tablet (47%). Het overgrote deel van de patiënten was bereid om ICT in het eigen revalidatieproces te gebruiken. De meest voorkomende redenen hiervoor waren: inzicht in het eigen medische dossier, contact met lotgenoten en afspraken plannen met behandelaars.

Terwijl Hoofdstuk 4 inzicht geeft in gebruik van ICT in de revalidatie in het algemeen, werden de wensen en eisen voor de inhoud en het gebruik van eRevalidatie specifiek na een CVA systematisch onderzocht in hoofdstukken 5 en 6.

**Hoofdstuk 5** beschrijft de eisen die patiënten met een CVA, hun mantelzorgers en behandelaars stellen aan de toegankelijkheid, bruikbaarheid en inhoud van eRevalidatie. Deze werden onderzocht in een kwalitatieve focusgroep studie (n=60). Er werden 8 focusgroepen uitgevoerd; 6 met patiënten/mantelzorgers en 2 met zorgprofessionals die betrokken zijn bij de revalidatie na een CVA (revalidatieartsen, fysiotherapeuten, ergotherapeuten, psychologen, teamcoördinatoren). De gebruikersvereisten werden ingedeeld in 3 categorieën: 1) *toegankelijkheid*, 2) *bruikbaarheid* en 3) *inhoud*.

In totaal werden er 45 vereisten benoemd in de focusgroepen. De meeste eisen van patiënten, mantelzorgers en zorgprofessionals hadden betrekking op *inhoud* (25 vereisten), gevolgd door *bruikbaarheid* (12 vereisten) en *toegankelijkheid* (8 vereisten). De eisen van patiënten/mantelzorgers en zorgprofessionals verschilden op een aantal punten van elkaar. Zo was een vereiste van zorgprofessionals dat eRevalidatie toegankelijk moet zijn via een computer in het revalidatiecentrum, terwijl patiënten en mantelzorgers de voorkeur gaven aan het gebruik via smartphone of tablet.

Aan een kwalitatief onderzoek kunnen slechts een beperkt aantal vertegenwoordigers van patiënten, mantelzorgers en behandelaars meewerken. Om een grotere groep te kunnen bereiken werd vervolgens nog een kwantitatieve studie uitgevoerd. **Hoofdstuk 6** geeft een overzicht van de belangrijkste vereisten voor eRevalidatie na een CVA zoals vastgesteld in een grotere groep patiënten met een CVA, hun mantelzorgers en zorgverleners (revalidatieartsen, psychologen en fysiotherapeuten). Hiertoe werden de verschillende eisen voortkomend uit de kwalitatieve studie (hoofdstuk 5) verwerkt in een vragenlijst, waarbij respondenten het belang van uitspraken over de toegankelijkheid, bruikbaarheid en inhoud van eRevalidatie na een CVA scoorden op een 4-puntsschaal (1-4; onbelangrijk).

125 patiënten, 43 mantelzorgers en 105 behandelaars vulden de vragenlijst in. De vereisten voor eRevalidatie die zowel door patiënten, mantelzorgers als behandelaars belangrijk gevonden werden waren: het kunnen gebruiken van interventies op de meest gebruikte ICT-apparaten (bijv. tablet, smartphone, computer in revalidatiecentrum), ondersteuning bij het gebruik (bijv. instructievideo's, menu met veel gestelde vragen), begeleiding bieden bij het fysiek oefenen, algemene informatie over een CVA, inzicht in het revalidatieproces (bijv. feedback op trainingsresultaten, eindrapportages over het revalidatieproces) en het vaststellen en evalueren van revalidatiedoelen. Er waren ook opvallende verschillen tussen de groepen; zo werden oefeningen voor cognitief functioneren als zeer belangrijk aangemerkt door patiënten en mantelzorgers, terwijl behandelaars dit juist minder belangrijk vonden.

Naast de afstemming van eRevalidatie na een CVA op de wensen en behoeften van gebruikers, hangt succesvol gebruik ook af van de bereidheid, het vertrouwen en de

Appendix

vaardigheden van behandelaars om eHealth in hun dagelijkse praktijk te gebruiken. De basis hiervoor wordt gelegd bij het opleiden van zorgprofessionals. Om die reden beschrijft Hoofdstuk 7 de belemmerende en bevorderende factoren voor het gebruik van eHealth in het onderwijs vanuit het perspectief van docenten en studenten van opleidingen Oefentherapie Mensendieck en Fysiotherapie. Hiervoor werd een kwalitatieve focusgroep studie met zes focusaroepsessies uitaevoerd: twee met docenten (n=11) en vier met studenten (n=24), van twee hogescholen in Nederland (Hogeschool van Amsterdam en Hogeschool Leiden). De in de focusaroepen genoemde bevorderende en belemmerende factoren werden aan de hand van het model voor implementatie van Grol en Wensing als volgt geclassificeerd: innovatie, individuele docent, individuele student, sociale context, organisatorische context en politieke & economische factoren. Uit de resultaten bleek dat, door zowel docenten als studenten, meer belemmerende dan bevorderende factoren werden. gevonden voor toepassing van eHealth in het curriculum. De meeste factoren hadden betrekking op de innovatie bijv. onduidelijkheid rondom het concept eHealth (n=26), gevolgd door de individuele docent (bijv. vaardigheid in het gebruik van eHealth) (n=22) en de oraanisatorische context (bijv. beschikbaarheid van lesmateriaal en technologie) (n=20). Deze bevindingen vormen de basis voor implementatiestrategieën die gericht zijn op zowel het wegnemen van belemmeringen (bijv. gebrek aan kennis en vaardigheden op het gebied van eHealth) als het benutten van bevorderende factoren (bijv. beschikbare eHealth materialen)

## **ALGEMENE DISCUSSIE**

## Focus van dit proefschrift

Dit proefschrift richtte zich op de evaluatie van een eHealth interventie voor cognitieve revalidatie na een CVA (eRevalidatie) en de perspectieven van verschillende betrokkenen over de inzet van eRevalidatie in het algemeen, maar in het bijzonder na een CVA.

De studies in dit proefschrift laten zien dat er vrijwel geen effect was van een online cognitieve training op het cognitief functioneren van patiënten met een CVA. Hoewel een verbetering gevonden werd op cognitieve taken die vergelijkbaar waren met de spellen in het trainingsprogramma werd geen effect op taken anders dan de getrainde taak en de kwaliteit van leven gevonden. Dit suggereert dat computertaken in online cognitieve training nauw verband moeten houden met de daadwerkelijke problemen die patiënten na een CVA ondervinden tijdens dagelijkse activiteiten. Omdat patiënten na een CVA heel diverse cognitieve beperkingen kunnen hebben vraagt dit om het 'op maat maken' van een cognitieve training voor elke patiënt.

Een andere bevinding in dit proefschrift was dat het gebruik van de cognitieve training tegenviel en flink varieerde tussen patiënten. Een deel gebruikte de training niet, anderen waren niet in staat om de vereiste trainingsduur te bereiken. Dit kan samenhangen met specifieke eisen van CVA-patiënten met betrekking tot de toegankelijkheid, bruikbaarheid en inhoud van eRevalidatie. Het bleek echter ook belangrijk dat patiënten goed ondersteund worden door zorgprofessionals bij het gebruik van cognitieve eHealth interventies. Om dat te kunnen doen is het essentieel dat ook het perspectief van behandelaars wordt meegenomen in de ontwikkeling van eHealth. Naast het betrekken van professionals in het werkveld is het evenzo belangrijk om ervoor te zorgen dat toekomstige zorgprofessionals adequaat kunnen werken met eHealth en in staat zijn de beroepspraktijk te innoveren. Hiervoor zijn aanpassingen van het curriculum nodig, gebaseerd op door docenten en studenten ervaren belemmerende en bevorderende factoren, zoals beschreven in dit proefschrift.

# Deel I. Evaluatie van een eRevalidatie programma na een CVA: resultaat, proces en onderzoekstrategie.

## Bewijs voor de effectiviteit van cognitieve eRevalidatie na een CVA

Onze bevindingen (hoofdstuk 2 en 3) komen overeen met de constatering dat het bewijs voor de effectiviteit van cognitieve eRevalidatie na een beroerte schaars is [1-6]. Zo concludeerde een recente systematische review dat het effect van eRevalidatie op cognitief functioneren middels virtual reality bij patiënten na een CVA nog steeds onduidelijk is, niet alleen door een gebrek aan studies, maar ook door de matige kwaliteit ervan [2]. Onderzoek dat wel voorhanden is laat tegenstrijdige resultaten zien. Een recent uitgevoerde RCT concludeerde dat na een cognitieve training, vergelijkbaar met de training die in onze studie werd gebruikt, de cognitieve functies, het subjectieve cognitieve functioneren en de kwaliteit van leven bij patiënten in de chronische fase na een beroerte niet verbeterde in vergelijking met een controlegroep [7]. Sommige studies vonden wel positieve effecten van cognitieve training bij patiënten met een CVA of ander hersenletsel [8-17]. Echter, deze effecten werden meestal gezien voor taken (uitkomsten) die vergelijkbaar waren met taken in de training (d.w.z. 'near transfer of learning') [15-21].

Het is mogelijk dat cognitieve eRevalidatie interventies waarbij de taken nauw verband houden met de cognitieve taken in het dagelijks leven effectiever zijn om het cognitief functioneren na een CVA te verbeteren dan het spelen van braingames, zoals gebruikt werden in ons onderzoek. Dit wordt ondersteund door een RCT van Faria et al. (2016). In deze studie werd het effect van virtual reality met gesimuleerde dagelijkse activiteiten op de uitvoer van cognitieve taken vergeleken met traditionele therapie [22]. De interventie betrof een virtuele simulatie van een stad waar geheugen, aandacht, visuo-ruimtelijke capaciteiten en uitvoerende functionele taken werden geïntegreerd in de uitvoering van verschillende dagelijkse routines. Analyse tussen de groepen toonde aanzienlijk grotere verbeteringen van de virtual reality training op globaal cognitief functioneren, aandacht en executieve functies bij CVA-patiënten in vergelijking met traditionele therapie.

## Het proces van een cognitief eRevalidatie programma na een CVA

De RCT in dit proefschrift liet zien dat slechts 24 van de 105 patiënten (23%) het gewenste aantal van 600 minuten cognitieve training in een periode van 8 weken volbrachten. Dit enigszins teleurstellende resultaat komt overeen met andere studies die concludeerden dat intensieve (eHealth) trainingsregimes na een CVA moeilijk zijn vol te houden voor patiënten [29-32]. Tijdens de uitvoering van de training in onze studie ondervonden patiënten verschillende problemen, zoals te weinig ICT-vaardigheden, een ongeschikt besturingssysteem op de computer of overprikkeling door flikkeringen op het beeldscherm.

Dergelijke belemmeringen werden ook gevonden in een andere studie, waarin CVApatiënten diverse problemen ervaarden bij gebruik van een applicatie op een tablet, o.a. door de complexiteit van instructies, het gebrek aan fijn motorische vaardigheden voor het gebruik en de onbetrouwbaarheid van internetverbindingen [33]. Om dergelijke belemmeringen zoveel mogelijk weg te nemen is adequate ondersteuning van belang. Uit een studie in dit proefschrift bleek dat hoogfrequente supervisie (wekelijks) resulteerde in significant hogere therapietrouw dan laagfrequente supervisie (4-wekelijks). Dit komt overeen met de bevindingen in een review van Kelders et al. (2012), waarin de frequentie van interactie met een behandelaar een significante voorspeller was voor therapietrouw met online gezondheidsinterventies in verschillende patiëntengroepen [34]. Samenvattend lijkt regelmatige interactie met een behandelaar belangrijk om het gebruik van eRevalidatie bij CVA-patiënten te vergroten. In ons focusgroep onderzoek naar vereisten voor eRevalidatie erkenden de deelnemende zorgprofessionals (revalidatieartsen, fysiotherapeuten, ergotherapeuten, psychologen, teamcoördinatoren en logopedisten) het belang van hun rol bij het introduceren en superviseren van eRevalidatie in de behandeling van CVA.

## Onderzoeksstrategieën voor het evalueren van eRevalidatie na een CVA

De effecten van eRevalidatie interventies worden vaak geëvalueerd door middel van traditionele klinische studies. Een voorbeeld hiervan is de RCT die in dit proefschrift is opgenomen. Dergelijke onderzoekdesigns zijn echter niet altijd geschikt om de effecten van eHealth te evalueren [35-38]. Deelnemers aan een RCT vormen bijvoorbeeld niet altijd een goede afspiegeling van de patiëntenpopulatie in de dagelijkse praktijk, o.a. door het hanteren van specifieke selectiecriteria [38]. Wanneer de effectiviteit van eHealth is vastgesteld in een 'laboratoriumomgeving', worden dezelfde positieve resultaten dan ook niet altijd gevonden in een andere context, bijvoorbeeld wanneer de interventie wordt aangeboden aan patiënten met minder ICT-vaardigheden of minder goed getrainde professionals.

Een ander nadeel van de conventionele RCT is, dat de tijd die het duurt om deze voor te bereiden, uit te voeren en te rapporteren meestal veel langer is dan de snelheid waarmee eHealth zich ontwikkelt. Dit kan ervoor zorgen dat (delen van) de onderzochte interventie al verouderd zijn tegen de tijd dat de resultaten van de RCT worden gepubliceerd [39]. Bovendien kunnen 'early adopters' onder patiënten en zorgprofessionals een eHealth innovatie al gebruiken voordat er bewijs beschikbaar is [38], waardoor in sommige gevallen het contrast tussen interventie- en controlecondities kan vervagen. Om deze redenen kunnen andere onderzoekstrategieën worden overwogen, zoals actie-onderzoek. Deze vorm van onderzoek, vaak gecoördineerd door een groep professionals als onderdeel van een zogenaamde 'community of practice', is ontstaan om een actueel probleem in de zorgpraktijk op te lossen [41]. Hierin participeren patiënten, zorgprofessionals, ontwerpers, onderzoekers, docenten en studenten op een actieve manier. Na onderzoek van het probleem neemt de groep beslissingen, observeert en evalueert de gevolgen van de aanpassing voor die specifieke situatie. De groep neemt dus deel aan een veranderproces, waarbij naast het continu aanpassen, testen en evalueren tegelijkertijd onderzoek naar de innovatie wordt uitgevoerd.

Tot slot moet worden opgemerkt dat de ontwikkeling, evaluatie en implementatie van eRevalidatie na een CVA en bijbehorend onderzoek moeten worden uitgevoerd in samenwerking met alle relevante betrokkenen om eRevalidatie relevant en haalbaar te maken voor de beoogde gebruikers in de gezondheidszorg [42;43]. Dit zijn, naast patiënten, mantelzorgers, zorgprofessionals, ontwerpers, onderzoekers, financiers, docenten en studenten.

# Deel II. Gereedheid en vereisten voor eRevalidatie na een CVA: implicaties voor de opname in de gezondheidszorgpraktijk en het onderwijs.

## Integreren van gebruikersperspectieven bij de ontwikkeling van eRevalidatie

Dit proefschrift bevat een aantal onderzoeken die gericht zijn op het bepalen van het gebruik van en vereisten voor eRevalidatie onder betrokkenen in de zorg na een CVA. Uit een enquêteonderzoek bleek dat het bezit en gebruik van ICT-apparaten relatief hoog was bij revaliderende patiënten en dat de meeste patiënten hun eigen apparatuur ook ten behoeve van hun revalidatieproces wilden gebruiken. Bovendien toonde een focusgroepstudie aan dat CVA-patiënten, mantelzorgers en behandelaars specifieke wensen hadden ten aanzien van de gewenste functionaliteiten, zoals ondersteuning van de uitvoering van fysieke oefeningen, informatie over CVA, uitkomsten van de revalidatie en het plannen van afspraken met behandelaars. Deze bevindingen suggereren dat bij voorkeur interventies moeten worden ontwikkeld waarin uiteenlopende functionaliteiten (bijv. communicatiefunctie, fysieke oefenen, informatie over zorg en aandoening, agendafunctie, enz.) worden gecombineerd in één digitaal platform. Mede op basis van de uitkomsten van dit kwalitatief onderzoek werd een uitgebreid eRevalidatie platform gebouwd gericht op het herstel na een beroerte. Dit platform wordt momenteel geëvalueerd in het Fit After Stroke @Home project (FAST@Home).

Daarnaast kwam uit onze focusgroep studie onder gebruikers in de revalidatie en uit literatuur naar voren dat digitale trainingsfaciliteiten, zoals oefeningen gericht op fysiek en cognitief functioneren en spraak, moeten worden aangepast aan de voorkeuren en mogelijkheden van individuele patiënten [44-50]. Ook het bieden van ondersteuning bij dagelijks gebruik van eRevalidatie (d.w.z. directe hulp, een helpdesk, video's met instructies en/of een menu met veel gestelde vragen) werd als een cruciaal element beschouwd. Deze bevindingen impliceren dat het ontwerpen van eRevalidatie programma's in cocreatie met alle relevante betrokkenen moet worden gedaan ('co-design'). Door vereisten van patiënten, mantelzorgers en behandelaars mee te nemen in elke stap van het ontwerpproces ('user-centered design') sluit eRevalidatie beter aan bij de behoeften van de beoogde gebruikers. Dit is vooral belangrijk omdat dit proefschrift heeft aangetoond dat verschillende gebruikersgroepen verschillende eisen hebben. Een manier om alle partijen bij elkaar te brengen is samenwerking in een zogenaamd "Living Lab". Hierin werken verschillende belanghebbenden (bijv. kennisinstellingen, gezondheidszorgorganisaties, zorgverleners, patiënten, financiers, innovators, gevestigde bedrijven, startups, onderzoekers, enz.) samen. In een medisch specialistisch revalidatiecentrum, Basalt revalidatie, is een dergelijk Living Lab (SmartLab) opgericht. Hier wordt een stapsgewijze procedure gebruikt om innovaties in revalidatie te testen op hun potentiële toegevoegde waarde en bruikbaarheid (http:// www.basaltrevalidatie.nl/onderzoek-innovatie/smartlab, www.medicaldeltalivinglab.nl). De vervolgstappen omvatten systematisch evaluaties van de effectiviteit, ervaringen, kosten en implementatie van eHealth in de revalidatiebehandeling.

### Gebruik van eHealth in de revalidatiezorg na een CVA

De impact van een CVA varieert sterk per persoon, en welke behandeling optimaal is hangt af van de mogelijkheden, voorkeuren en doelen van zowel de patiënt als zijn/haar naaste(n) [51]. Zorgprofessionals kunnen een centrale rol spelen in het op de patiënt afgestemde aanbod van eRevalidatie, bijvoorbeeld door aanpassing van het oefenprogramma op basis van vooruitgang, feedback en motivatie. Daarnaast kunnen ze bepalen welke bewezen effectieve eRevalidatie interventies geschikt zijn voor een patiënt en begeleiding bieden bij het gebruik.

Behandelaars zijn zich echter niet altijd bewust van alle mogelijkheden die eHealth interventies bieden en hoe en wanneer zij het moeten inzetten [37;52]. Resultaten van onderzoek naar eHealth zijn vaak niet direct bruikbaar voor zorgverleners in de dagelijkse praktijk [37;38]. Zo is uit onderzoek gebleken dat virtual reality voor het verbeteren van het evenwicht en looppatroon als therapeutisch hulpmiddel kan dienen om herstel van balans en lopen bij patiënten met een CVA te bevorderen [2;52]. Deze bevindingen hebben echter hun weg nog niet gevonden naar de praktijk. Daarvoor is ten eerste een overzicht van bruikbare eHealth interventies voor herstel na een CVA nodig, gebaseerd op resultaten van wetenschappelijk onderzoek, ervaringen van gebruikers, patiëntenverenigingen en beroepsorganisaties [37]. Daarnaast moet de beschikbare kennis worden verwerkt in protocollen, praktijk richtlijnen of andere handvatten die inzicht geven in welk type eRevalidatie werkt voor wie [37;52;53]. Om deze doelen te bereiken is het eerdergenoemde SmartLab verbonden met het National eHealth Living Lab (NeLL), een eHealth-community (patiënten, consumenten, professionals, wetenschappers, studenten, organisaties) die

streeft naar het creëren van de beste eHealth oplossingen door kennis, contacten en ervaringen met elkaar te delen (https://nell.eu). Bovendien toonde dit proefschrift aan dat voor een optimale toepasbaarheid van eHealth interventies deze in werkroutines van zorgverleners moet kunnen worden geïntegreerd.

### eHealth in het onderwijs van zorgopleidingen

Toekomstige zorgverleners moeten vakkundig en vol vertrouwen kunnen werken met eHealth [54;55]. eHealth komt echter maar mondjesmaat aan bod in de curricula van het hoger beroepsonderwijs die opleiden tot zorgberoepen (bijv. voedingsleer, verpleegkunde, fysiotherapie, psychologie of maatschappelijk werk) [56-59]. In dit proefschrift is een focusgroep studie beschreven waarin docenten en studenten aangaven dat zij een betere integratie van eHealth in het curriculum belangrijk vonden, en zeker bereid waren om eHealth te gebruiken. Desalniettemin was, in overeenstemming met andere studies in het veld, hun begrip van het concept eHealth beperkt [60]. Bovendien hadden docenten en studenten behoefte aan vaardigheden om eHealth interventies kritisch te kunnen beoordelen. Om de implementatie van eHealth in het curriculum te verbeteren wordt in het FAST@Home project momenteel de 'toolkit eHealth' ontwikkeld, in een samenwerkingsverband van drie hogescholen (Haagse Hogeschool, Hogeschool Leiden, Hogeschool van Amsterdam).

Een bevorderende factor voor het gebruik van eHealth in het onderwijs, die ook naar voren kwam in de focusgroepen, was het optimaal benutten van de al eerder beschreven zogenaamde 'communities of practices' [61]. Deelname aan een dergelijke praktijk(leer) gemeenschap stimuleert en ondersteunt zowel docenten als studenten in het onderwijzen van en leren over eHealth [62]. Daarnaast suggereert de literatuur dat het uitproberen van eHealth innovaties in een realistische context met actieve betrokkenheid van gebruikers (LivingLabs) stimulerende leeromgevingen zijn [63]. Het is dus raadzaam studenten en docenten hierin te betrekken. Daarnaast is het belangrijk dat ook artsen beter met eHealth om kunnen gaan. Opgedane kennis in het hoger onderwijs is mogelijk ook toepasbaar in het geneeskunde curriculum.

Tot slot moet eHealth niet alleen in het curriculum van de bacheloropleidingen een belangrijke plaats krijgen, maar ook in het postacademisch onderwijs, aansluitend op de visie 'leven lang leren' en met het doel het huidige gebruik in de dagelijkse zorgpraktijk te vergemakkelijken [37].

# Conclusie

eRevalidatie biedt veel mogelijkheden om het herstel na een beroerte te bevorderen. Desondanks valt het gebruik van eHealth in de revalidatiepraktijk nog altijd tegen. Dit komt onder andere door gebrek aan bewijs voor de effectiviteit ervan. Het aantal methodologisch goed uitgevoerde studies is schaars, en de resultaten wisselend. Mogelijk zijn traditionele onderzoekdesigns niet altijd even geschikt om snel ontwikkelende interventies te evalueren. Alternatieve onderzoeksstrategieën, bijvoorbeeld actieonderzoek, zijn mogelijk passender om de effectiviteit van eHealth innovaties inzichtelijk te maken. Om eHealth interventies haalbaar te maken voor de dagelijkse zorgpraktijk is het van belang dat de ontwikkeling ervan plaatsvindt in samenwerking met alle betrokkenen ('co-creatie') en op basis van de wensen van de gebruikers. Voor de implementatie van eHealth in het zorgproces is het daarnaast essentieel om patiënten en behandelaars te ondersteunen bij gebruik en ICT een prominentere plek te geven in het curriculum van zorgopleidingen.

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# **Curriculum Vitae**

Manon Maria Wentink werd geboren op 10 april 1987 in de gemeente Noorder-Koggenland en is opgegroeid in Midwoud. In 2005 voltooide zij het Hoger Algemeen Voortgezet Onderwijs aan de Openbare Scholengemeenschap in Hoorn. In datzelfde jaar startte zij met de opleiding Oefentherapie Mensendieck aan de Hogeschool van Amsterdam. In 2009 studeerde zij af als oefentherapeut. In 2011 behaalde Manon haar Master of Health Sciences aan de Vrije Universiteit van Amsterdam.

### Zorgpraktijk

Na haar studie oefentherapie begon Manon als waarnemend oefentherapeut in diverse settingen. Van 2010 tot 2017 was zij, samen met een oud-studiegenoot, eigenaar van de praktijk voor oefentherapie Mensendieck in Haarlem. Als praktiserend oefentherapeut ontwikkelde zij een wetenschappelijk onderbouwde interventie voor mensen met slapeloosheid. In 2012 richtte zij de onderneming SlaapSlim op en vanaf 2013 tot heden geeft zij geaccrediteerde scholingen aan zorgprofessionals over (de behandeling van) slaapproblemen.

### Onderzoek

In 2012 begon zij, naast haar werkzaamheden als oefentherapeut, als onderzoeksassistent bij de afdeling Kwaliteit van Zorg in het Leids Universitair Medisch Centrum (LUMC). Daar werkte zij mee aan de Lisboa studie en de DISC studie. In 2013 startte Manon onder begeleiding van prof. Dr. Thea Vliet Vlieland als promovenda in onderzoeksproject Spelenderwijs, een samenwerking tussen Basalt (destijds Sophia Revalidatie en het Rijnlands Revalidatie Centrum), het LUMC en de Haagse Hogeschool. Later werkte zij mee aan meerdere onderzoeken waaronder het project Fast@Home, waarvan een deel van de resultaten beschreven staan in dit proefschrift.

#### Onderwijs

Vanaf 2014 tot heden is Manon werkzaam als docentonderzoeker voor de opleiding Oefentherapie Mensendieck aan de faculteit Gezondheid van de Hogeschool van Amsterdam. Sinds 2017 vervult zij hier ook de functie als Hoofddocent Onderzoek met als doel de verbinding tussen onderwijs en onderzoek te versterken.

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