# Value-based stroke rehabilitation: feasibility and results of patient-reported outcome measures in the first year after stroke

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# Value-Based Stroke Rehabilitation: Feasibility and Results of Patient-Reported Outcome Measures in the First Year After Stroke

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*Purpose:* Structured application of patient-reported outcome measures (PROMs) is a key element in Value Based Healthcare. This study aimed to evaluate the feasibility of a broad set of PROMs reflecting similar patient reported health domains as proposed within the International Standard Set of Patient-Centered Outcome Measures After Stroke within the first year after stroke. *Methods:* The study included consecutive stroke patients admitted to inpatient or outpatient specialized rehabilitation. PROMs were administered upon admission, discharge (inpatients only), and at 3, 6, and 12 months. PROMs included: EuroQol 5 Dimensions (EQ-5D), Stroke Impact Scale (SIS), Stroke and Aphasia Quality of Life Scale (SAQOL-39NL), Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P), Hospital Anxiety and Depression Scale (HADS), and Fatigue Severity Scale (FSS). Feasibility was defined as participation, retention, and response rates. Paired *t* tests were conducted to analyze their changes over time. *Results:* Of 485 inpatients and 189 outpatients who were invited, 291 (60.0%) and 82 (43.3%) participated, of whom 45 (15.5%) and 7 (8.5%) dropped out before 12 months, respectively. Two hundred seven (71.1%) and 71 (86.6%) of the inpatients and outpatients returned the questionnaires on all or all but one time points, respectively. Between admission and 12 months statistically significant improvements of PROMs addressing general health and quality of life (EQ-5D), psychiatric functioning (HADS), motor functioning (SIS mobility), and social functioning (USER-P, SIS communication) were seen. The SIS memory scale, the SAQOL-39NL and the FSS did not show any changes. *Conclusions:* Participation, retention, and response rates for a comprehensive set of PROMS for stroke in patients in rehabilitation were moderate to good, with clinical improvements seen until 1 year post stroke. The SAQOL-39NL and FSS did not demonstrate changes over time and cannot be recommended for repetitive measurements in this setting. By simplifying the set of questionnaires, participation and response rates may be further enhanced.

**Key Words:** Stroke—stroke rehabilitation—patient reported outcome measures—feasibility studies—value-based healthcare



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## Introduction

Worldwide, stroke is one of the leading causes of disability and mortality.[1] Stroke can have severe consequences for health, including impairments in physical functioning,[2] memory, and speech/language,[3,4] limitations in activities, and restrictions in participation. Additional health problems such as fatigue,[5] anxiety,[6,7] and depression[8] may arise over time. Health-related quality of life (HRQOL) often declines.[9]

In the Netherlands, approximately 9,000 (~25%) of hospitalized stroke patients are referred to specialised medical rehabilitation in a rehabilitation facility yearly,[10] of whom approximately a third starts as an inpatient.[11,12] In a rehabilitation facility, multidisciplinary rehabilitation treatment is provided by a team of physiotherapists, occupational therapists, speech-language therapists, psychologists, social workers, and rehabilitation physicians.[13-15] The effects of rehabilitation treatment on health outcomes have been described in numerous studies,[16,17] which usually focus on a specific health domain. Observational studies measuring multiple health domains on fixed and repeated points in time are scarce. Such studies are needed to evaluate the changes in health, the sustainability of these changes over a longer period, and the areas of health in which changes are most apparent. Structured assessments of patient-reported outcome measures (PROMs) can help critically appraise healthcare, contributing to the delivery of value-based health care (VBHC).[17]

The concept of VBHC was developed by Michael Porter and Elisabeth Olmsted Teisberg (2006), who stated that "achieving high value for patients must become the overarching goal of health care delivery, with value defined as the health outcomes achieved per dollar spent."[18,19] According to their model, survival, health status achieved, process of recovery, and sustainability of health (Fig 1) all need to be taken into account. Rehabilitation is a medical specialty that particularly fits into this model. One of the strategic imperatives for achievement of VBHC is to repeatedly measure the outcomes of care. Accordingly, the International Consortium for Health Outcomes Measurement (ICHOM) was founded, which develops standard sets of outcomes for various (chronic) diseases, to compare performance globally.[20] For stroke research and practice, the ICHOM International Standard Set of Patient-Centered Outcome Measures was proposed.[21] Although the domains of health addressed by that standard set are comprehensive, it is advised only to collect PROMs data at discharge from hospital and at 90 days after admission or the index event. For rehabilitation purposes, where improvements of activities and participation also on the longer term (after 90 days) are aimed for in many patients, the recommendations of the ICHOM may not be sufficient. Moreover, concerning the content of the Standard Set, the proposed PROMs in the Standard Set comprise the Patient Reported Outcomes Measurement Information System (PROMIS)-10, the modified Rankin Scale Questionnaire and a limited number of questions on functional independence and communication. With the clinical and research experience with PROMIS-10 in stroke patients being limited, the proposed set may not be completely in concordance with the recommendation by Porter et al, suggesting to assess health outcomes more extensively and using different measures: "at minimum, and to the extent possible, providers should collect all the outcome measures that are validated in clinical studies."[22]

Currently, a prospective observational study is ongoing in 2 Dutch rehabilitation facilities, with repetitive measurements of a broad range of PROMs up to 12 months after stroke. Although the outcome measures used in that study are different, they cover similar domains of health as in the ICHOM stroke Standard Set. Determining how these different domains of health are sensitive to changes over time in the subgroup of stroke patients in rehabilitation contributes to the knowledge on the optimal set of outcomes for the rehabilitation setting, which is yet to be established. The aim of this study was to evaluate the feasibility of measuring a broad set of PROMs until 12 months after stroke.

## Materials and Methods

### *Design and Setting*

The ongoing observational Stroke Cohort Outcomes of REhabilitation (SCORE) study (Dutch Trial Register 4293)[23] takes place in one large-sized and one medium-sized rehabilitation facility in the west of the Netherlands. These facilities offer inpatient and outpatient rehabilitation to stroke patients between 18 and 85 years old with multiple and complex impairments. Data collection started March 10, 2014 and current analyses comprise patients included until August 31, 2016. The study was approved by the Ethics Board of the Leiden University Medical Center and conducted in compliance with the Declaration of Helsinki.[24] The methods and results of this study are reported in accordance with the STrengthening the Reporting of OBservational studies in Epidemiology guidelines.[25]

### *Patient Population*

Stroke patients who commenced with inpatient rehabilitation were invited to participate in the study by the rehabilitation physician within the first 2 weeks after admission. Patients who underwent outpatient rehabilitation were invited by the rehabilitation physician shortly before the start of their rehabilitation trajectory. The majority of the outpatients had returned home after their hospital admission, whereas some had completed an inpatient rehabilitation trajectory. Inclusion criteria for the study were: Aged greater than or equal to 18 years; first or recurrent stroke less than 6 months ago. Exclusion criteria were: Dementia or psychiatric disorder; unable to

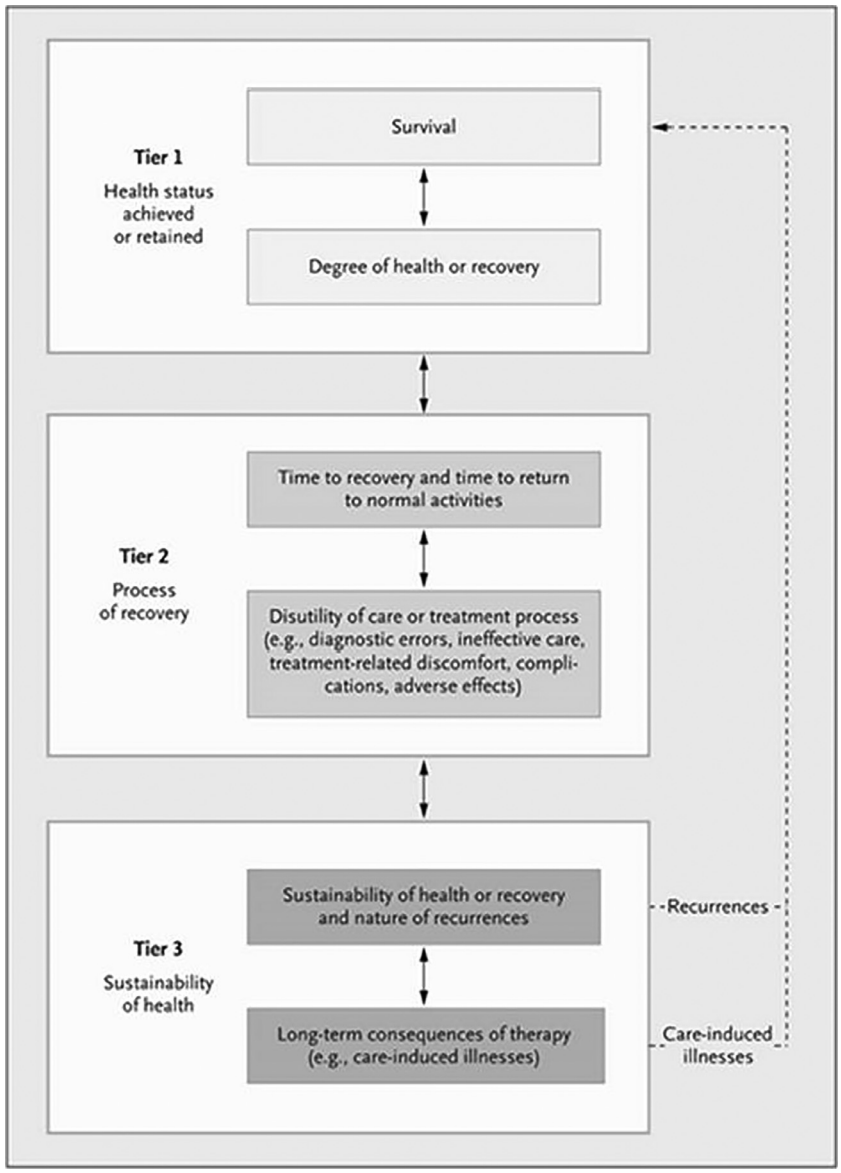


**Figure 1.** *The 'Outcome Measure Hierarchy' as defined by Michael Porter* Source: Porter ME (What Is Value in Health Care? N Engl J Med 2010; 363:2477-2481). Copyright: Massachusetts Medical Society.

complete questionnaires in Dutch; and no written informed consent.

### *Assessments*

The feasibility of conducting routine outcome measurements was determined by calculating participation, retention, and response rate, in line with Ashley et al[26] Stroke characteristics and care-related characteristics were derived from rehabilitation facilities' medical files. Sociodemographic characteristics, vascular and systemic characteristics, and health outcomes were assessed by means of questionnaires. For the Stroke Impact Scale (SIS) and the EuroQol 5 Dimensions (EQ-5D), the first assessment took place at the start of rehabilitation (t0), and follow-up measurements were conducted at discharge (only applicable to inpatients) 3, 6, and 12 months. For all other instruments, the first assessment was at 3 months and follow-up measurements were conducted at 6 and 12 months. The inpatient stroke patients received a total of 5 questionnaires. For participants in outpatient rehabilitation the questionnaire at discharge was not applicable, leaving a total of 4 questionnaires.

The questionnaires were applied on paper or online, depending on the patients' preference. Patients who did not respond to the questionnaire within 10 days were called by telephone, and a week thereafter they were called again. In case they could not be reached by telephone, they received an e-mail message.

## Outcome Measures

### *Feasibility*

*Participation* was defined as the proportion of invited patients providing informed consent and completing at least 1 questionnaire.

*Retention* was defined as the proportion of participants who remained in the study at 12 months. All patients that did not remain in the study were considered dropouts. Reasons for dropout included death, withdrawal due to health problems, withdrawal for other reasons, and loss to follow-up. Loss to follow-up occurred when a patient had failed to complete 2 questionnaires consecutively and could not be reached by phone or email. All patients who did not drop-out continued as a participant in the SCORE study, whether or not they completed the questionnaire at 12 months.

*Response rate* was operationalized as per questionnaire, the proportion of patients who returned the questionnaire. Also, the number (%) of patients who received at least 1 reminder was reported. Lastly, the percentage of participants who returned 4 or 5 questionnaires (inpatients), or 3 or 4 questionnaires (outpatients) was calculated.

### *Patient Characteristics*

The case-mix variables were categorized in line with the ICHOM Standard Set for Stroke guideline.[22]

*Sociodemographic characteristics* included age, sex, ethnicity (native Dutch, western immigrant, non-western immigrant), prestroke living location (nursing home/home), and living situation (alone/with others). Prestroke ambulation, dressing, and toileting were assessed by items 2-4 on the Groningen Frailty Indicator (GFI; in patients aged >65).[27] Frailty was reported by means of the GFI total score, dichotomized into frail (GFI ≥4) or not frail (GFI <4).

*Stroke characteristics* included type (ischemic/ haemorrhagic, including subarachnoid haemorrhage) and localization (right/left/other) of stroke. Stroke severity was based on the patients' independence in activities of daily living at the start of rehabilitation, assessed by means of the Barthel Index (0 [totally dependent] to 20 [totally independent]).[28] For patients who had been hospitalized in academic hospitals, a National Institutes of Health Stroke Scale score was available. The 5 National Institutes of Health Stroke Scale categories[29] were collapsed into 3: 0 = no symptoms of stroke; 2-3 = minor to moderate stroke; and 4-5 = severe stroke. The presence of aphasia was based on the Token test, using the cut-off of greater than or equal to 7.[30]

*Vascular and systemic characteristics* included the presence of prestroke myocardial infarct, other heart disease, diabetes mellitus, and hypertension, based on the Dutch Life Situation Cohort Permanent Onderzoek naar de Leefsituatie (POLS; Dutch Life Situation Cohort Study) Questionnaire,[31] as well as smoking (yes/no) and alcohol use (≥1 drink/day).

*Care-related characteristics* included length of hospital stay, length of inpatient rehabilitation trajectory, and length of outpatient rehabilitation trajectory, where applicable.

### *Health Outcomes, Categorized According to the Domains of Patient-Reported Health Status of the ICHOM Standard Set for Stroke*

#### General health status and health-related quality of life

EQ-5D was applied to assess general health and HRQOL. The EQ-5D is a generic 5-item instrument on mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, each item having 3 levels (no problems to extreme problems).[32] A Dutch formula attaches a weight to each level, yielding a summary index between −0.23 (worst health) and 1.00 (best health).[33,34] The EQ-5D also comprises a vertical VAS scale ranging from 0 (worst possible health) to 100 (best possible health), to indicate current HRQOL. The EQ-5D index was found reasonably valid and reliable,[35] and well responsive in stroke patients.[36]

#### Cognitive and psychiatric functioning and motor functioning

The SIS version 3.0 was used to measure communication (7 items), memory and thinking (7 items), hand function (5 items), and mobility (9 items).[37] The SIS has 5-point scales ranging from "not difficult at all" to "extremely difficult." The SIS 3.0 showed excellent internal consistency (Cronbach's α 0.86-0.98) and good test-retest reliability (r > .70).[38]

Communication and physical functioning were also measured using the communication (7 items) and physical (16 items) scales of the 39-item Stroke and Aphasia Quality of Life-scale (SAQOL-39NL). Each item was scored on a 5 point scale (1: "could not do it al all;" to 5: "no difficulties at all"). The SAQOL-39 was validated for use in people with and without aphasia.[39,40] The cross-culturally adapted Dutch version[41] showed good internal consistency (Cronbach's α 0.84-0.91) and convergent validity (r = .45) and excellent test-retest reliability Intraclass Correlation Coefficient (ICC .70-.93).[37]

Depressive symptoms and anxiety were measured by the Hospital Anxiety and Depression Scale (HADS). Both the subscales consist of 7 items that are scored on a 4-point Likert scale (0-3), yielding a maximum score of 21. A cut-off score of greater than or equal to 8 can be used to indicate symptoms of depression or anxiety, but the instrument can also be used as a continuous scale.[42] The HADS scales have good internal consistency, good to excellent sensitivity and specificity, and good to very good concurrent validity.[43] Additionally, general psychosocial health

was assessed by means of the psychosocial domain (16-items) of the SAQOL-39NL.

### Social functioning

Social participation was measured with the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P), consisting of 3 scales: Frequency of activities (11 items), Restrictions (11 items), and Satisfaction with participation (10 items), scored on scales from 0 ("no activities at all;" "not possible;" "very unsatisfied," respectively) to 5 ("36 hours/19 times or more;" "without difficulty;" "very satisfied," respectively). The internal consistency (Cronbach's α .70-.91) and test-retest reliability (ICC .65-.85) in a general outpatient rehabilitation population were satisfactory.[44] The USER-P showed significant correlations with existing instruments, and small (Frequency, Satisfaction) to moderate (Restrictions) responsiveness in an outpatient rehabilitation population with brain or neuromuscular disease in Dutch rehabilitation facilities.[45]

### Nonmotor functioning

Fatigue was measured using the Fatigue Severity Scale (FSS),[46] comprising 9 statements on fatigue with 7-point scales ranging from "totally disagree" to "totally agree." The final score represents the mean value of the 9 items. A cut-off score of greater than or equal to 4 is used to distinguish patients with moderate to severe fatigue.[47] The FSS has good internal consistency (Cronbach's α .85-.95), test-retest reliability, and discriminative validity.[48]

## Data Analyses

*Feasibility*

Participation, retention, and response, and the numbers who received the questionnaires per postal-mail or e-mail, were expressed as numbers (%). The reasons for not participating and dropout were described.

*Patient Characteristics*

The patient characteristics were expressed using numbers and percentages, means (standard deviation [SD]), or medians (interquartile range), depending on the type and distribution of the data. For inpatients, age and sex were compared between participants and nonparticipants using the unpaired *t* test and $\chi^2$ test, respectively. Inpatients and outpatients who were still in the study at 12 months were compared to those who were not, by means of the unpaired *t* test, Mann-Whitney *U* test, or $\chi^2$ test, where appropriate.

*Health Outcomes*

The outcome measures at the first assessment (admission for SIS and EQ-5D; 3 months for all other measures) were expressed as means (SD). Additionally, depressive symptoms, anxiety, and moderate to severe fatigue at the first assessment were expressed as numbers (%). Paired *t* tests were conducted to calculate the mean difference (95%CI) between the first and the follow-up assessments. As an exception, the SIS and EQ-5D outcomes at 6 and 12 months were compared to both admission and 3 months. Where applicable, analyses were conducted for the entire group as well as for subgroups of patients who had impairments, limitations, or restrictions in specific areas (SIS domains communication, mobility, and hand function; HADS domains anxiety and depression; FSS fatigue).

## Results

*Patient Characteristics*

This study included 291 inpatients and 82 outpatients, with their characteristics being presented in Table 1. Both in the inpatient and the outpatient groups, the patients who participated did not differ in age and sex from those who did not (results not shown). Of the inpatients, the mean age was 60.4 years (SD 12.3), 170 (58.4%) were male, and 85 (30.6%) lived alone. The patients who did not complete the final assessment were more likely to live alone ($P = .048$) and have a prior myocardial infarction ($P = .03$) than those who did, but did not differ otherwise.

Of the outpatients, the mean age was 57.3 (SD 11.8), 47 (57.3%) were male, 13 (17.3%) lived alone. The 7 dropouts were more likely to have prior myocardial infarct ($P = .04$), to consume greater than or equal to 1 alcoholic drink per day (.04), and to have a higher score on the GFI ($P = .04$).

*Feasibility*

### Participation

Of the 485 stroke inpatients who were invited for participation, 305 (62.9%) provided informed consent with 44% choosing to receive the questionnaire by e-mail.

Of those, 291 (60.0% of invited) sent back one or more questionnaires and were included in the SCORE study (Fig 2a). Of the 101 inpatients for whom the reasons for nonparticipation were not specified, two-thirds was treated for cognitive problems, as indicated by the physician upon admission, as compared to one third of the participants. Of the 189 invited outpatients, 82 (43.4%) were included in the SCORE study (Fig 2b).

### Retention

Of participating inpatients, 246 (84.5%) were retained until 12 months follow-up, and 45 (15.5%) dropped out. The causes for dropping out included death (n = 3, 6.7%), loss to follow-up (n = 6, 13.3%), withdrawal because of health problems (n = 7, 15.6%), and withdrawal because

**Table 1.** *Characteristics of stroke patients in an observational cohort study on inpatient and outpatient rehabilitation*

| | Inpatients N = 291 | | Outpatients N = 82 | |
|---|---|---|---|---|
| **General characteristics** | **n** | | **n** | |
| Age, mean (SD) | 291 | 60.4 (12.3) | 82 | 57.3 (11.8) |
| Male sex, n (%) | 291 | 170 (58.4) | 82 | 47 (57.3) |
| Ethnicity, n (%) | 274 | | 70 | |
| Native Dutch | | 215 (78.5) | | 63 (90) |
| Western immigrant | | 32 (11.7) | | 6 (8.6) |
| Non-Western immigrant | | 27 (9.9) | | 1 (1.4) |
| Living in nursing home, n (%) | 278 | 1 (0.4) | 75 | 0 (0) |
| Living alone, n (%) | 278 | 85 (30.6) | 75 | 13 (17.3) |
| Unable to ambulate, toilet, dress (GFI items 2-4, all yes, n; %). Age >65 | 115 | 3 (2.6) | 58 | 2 (3.4) |
| Frailty (GFI ≥4)*; n (%) | 115 | 13 (11.5) | 58 | 5 (20.8) |
| **Stroke characteristics** | | | | |
| Stroke type, haemorrhage, n (%) | 291 | 72 (24.7) | 82 | 19 (23.5) |
| Stroke localisation, n (%) | 285 | | 77 | |
| Right | | 124 (43.5) | | 27 (35.1) |
| Left | | 132 (46.3) | | 44 (57.1) |
| Other | | 29 (10.2) | | 6 (7.8) |
| Stroke severity, NIHSS, median (IQR) | 69 | 6.0 (3.0; 12.5) | - | - |
| Stroke severity category, n (%) | 69 | | - | - |
| Minor to moderate symptoms | | 59 (85.5) | | |
| Moderate to severe symptoms | | 10 (14.5) | | |
| Independence in ADL upon admission to RF, Barthel Index, mean (SD) | 227 | 14.0 (5.4) | - | - |
| Aphasia at start of rehabilitation, n (%) | 288 | 61 (21.2) | 82 | 19 (23.2) |
| **Cardiovascular conditions and lifestyle** | | | | |
| Prior myocardial infarct, n (%) | 266 | 27 (10.2) | 76 | 11 (14.7) |
| Severe heart disease, n (%) | 254 | 13 (5.1) | 74 | 9 (12.2) |
| Diabetes mellitus, n (%) | 265 | 42 (15.8) | 76 | 16 (21.1) |
| Hypertension, n (%) | 262 | 109 (41.6) | 76 | 35 (46.1) |
| Comorbidities, median (IQR) | 221 | 1.0 (1.0; 3.0) | 69 | 2.0 (1.0;3.0) |
| Smoking, n (%) | 273 | 91 (33.3) | 73 | 17 (23.3) |
| Alcohol ≥1 drink a day, n (%) | 275 | 93 (33.8) | 73 | 29 (39.7) |
| **Rehabilitation characteristics** | | | | |
| Time between stroke and start of rehabilitation, days (median, IQR) | 291 | 10.0 (7.0; 16.0) | 82 | 53.0 (25.0; 101.0) |
| Length of rehabilitation trajectory, days (median, IQR) | 291 | 44.0 (31.0; 65.0) | 82 | 118.5 (81.0; 187.5) |

ADL, activities of daily living; GFI, Groningen Frailty Indicator; IQR, interquartile range; NIHSS, National Institutes of Health Stroke Severity scale; RF, rehabilitation facility.

of other reasons (n = 29, 64.4%), including 'not wanting to be confronted with stroke,' and 'too much of a burden.' Of those who were still in the study 12 months after the start, 208 had completed their 12 month-questionnaire. Of the 82 participating outpatients, 75 (91.5%) were retained and 7 (8.5%) dropped out before 12 months (health: n = 2, loss to follow-up: n = 1, and withdrawal: n = 4). Of those in the study at 12 months, 67 (89.3%) returned their questionnaire.

### Response

Per time point, the numbers who received and returned the questionnaire, and who received greater than or equal to 1 reminders, are presented in Figures 3a and 3b. At most time points the response rate was higher than 80%, except for discharge (68.2%) and 3 months (78.4%) in inpatients. Of the 291 inpatients included, 207 (71.1%) returned greater than or equal to 4 questionnaires, and of the 82 outpatients, 71 (86.6%) returned greater than or equal to 3.

### *Changes in PROMs Over Time*

From admission until 12 months one or more statistically significant improvements of PROMs addressing general health and quality of life (EQ-5D), psychiatric functioning (HADS), motor functioning (SIS mobility),

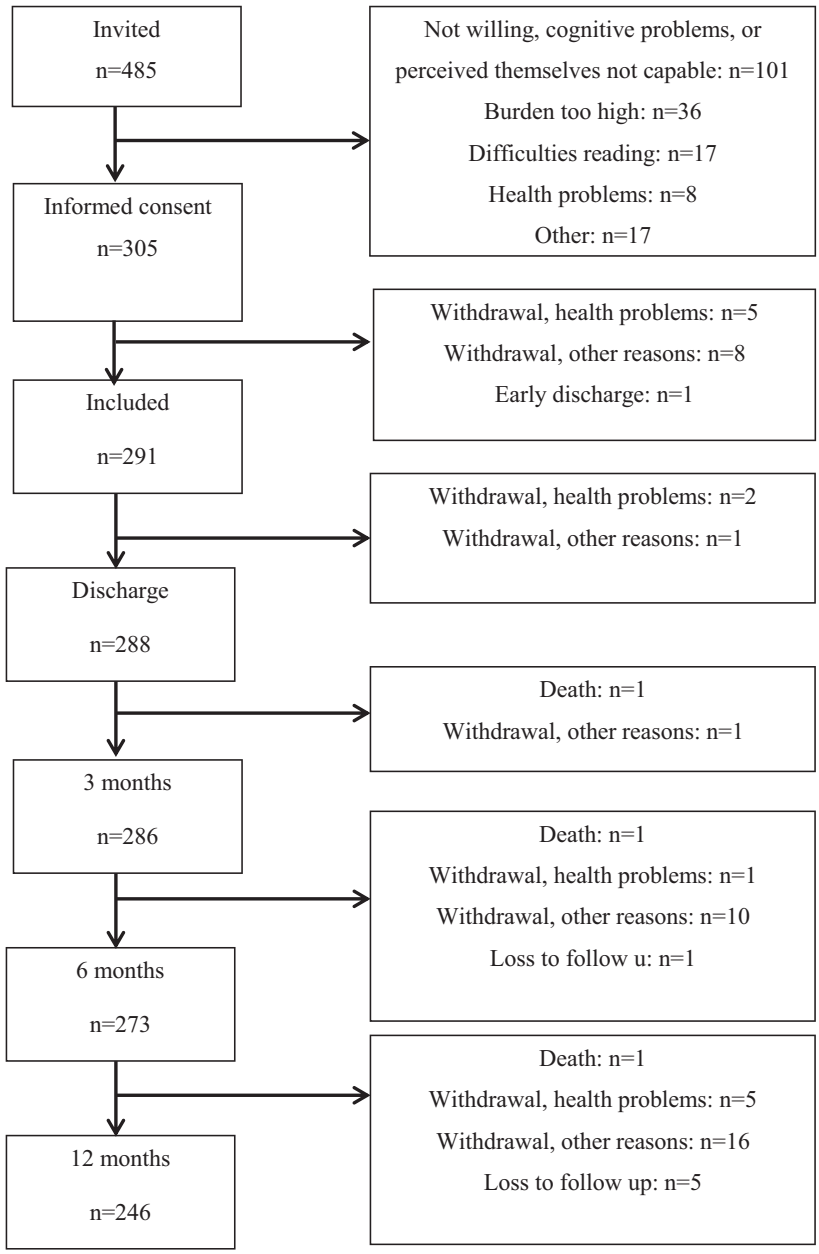


**Figure 2a.** *Flow diagram of stroke patients starting with inpatient rehabilitation, included in the SCORE study until August, 2016.*

and social functioning (USER-P, SIS communication) as compared to admission were seen, both in the inpatient and outpatient groups. The SIS memory scale, the SAQOL-39NL and the FSS did not show any changes (Tables 2a and 2b). The repetition of the analyses within subgroups of patients who had a limitation (SIS domains communication, mobility, and hand function; HADS domains anxiety and depression; FSS fatigue) showed similar results (results not shown).

## Discussion

This study among stroke patients in rehabilitation found that participation, retention, and response rates for a comprehensive set of PROMS were moderate to good, with clinical improvements seen until 1 year post stroke. The SAQOL-39NL and FSS did not demonstrate changes over time in either inpatients or outpatients.

Regarding the feasibility of comprehensive patient-reported outcome measurements, among eligible patients the main reasons for declining participation were 'high burden' or 'vision problems.' Once included, of the participating inpatients and outpatients, only 15.5 and 8.5% dropped out respectively, mostly because they did not want to be confronted with their stroke, or because the study was too much of a burden. The response rate of most questionnaires was over 80%, which is considered good,[49] but the response to the discharge and 3 months

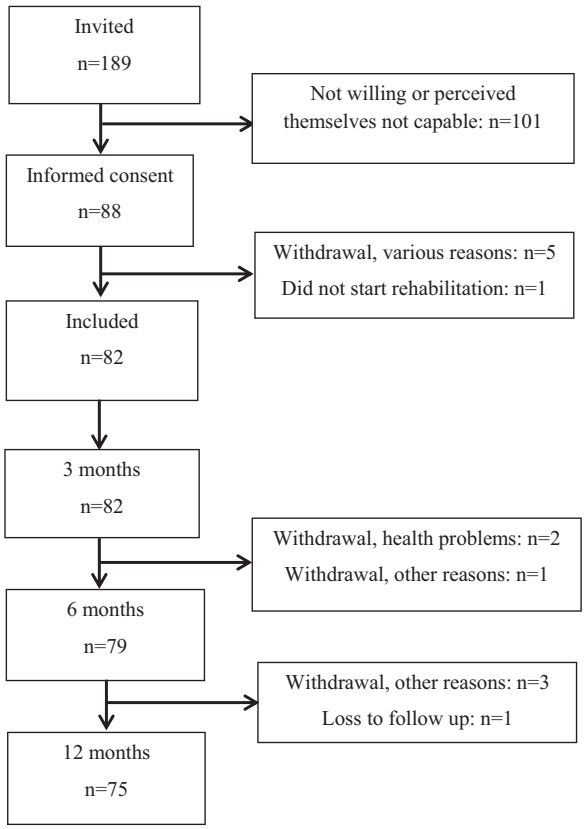


**Figure 2b.** *Flow diagram of stroke patients starting with outpatient rehabilitation, included in the SCORE study until August, 2016.*

questionnaires was somewhat lower. Strategies to enhance participation, retention, and response to the initial questionnaires may include assistance from the researchers in completion of the questionnaires. From the present study we further learned that more than half of the patients preferred postal questionnaires. Thus, full electronic data collection of the set in its present form would probably not be recommendable in this population. In addition, it remains unclear to what extent administering multiple questionnaires in a short period of time in a group of patients of whom many have significant cognitive and/or communication problems may have negatively influenced the response. On the other hand, the head-to-head comparison makes it easy to reveal which instruments are best able to detect changes over time. Regarding the potential reduction of the questionnaire package size, this study demonstrated that the SAQOL-39NL is not preferred, as it shows overlap with some of the SIS subscales and HADS and appeared the least responsive. The SIS memory subscale did not change over time either. This could in part be due to the initial high baseline values, the already documented low responsiveness of the SIS memory scale,[33] or the fact that in general, both subjective and objective cognitive functioning post stroke are more likely to deteriorate than to improve over time.[50,51] Regarding the baseline score, indeed the SIS score for memory at admission was relatively high, as compared to a population of 63 hospitalized stroke patients (mean age 68.7) in the Netherlands.[52] This could imply that patients initially overestimated their cognitive abilities, possibly partly due to anosognosia.[53,54] Nevertheless, the mean SIS memory score at 3 months was equal to that of a population of 124 Dutch stroke patients after completion of inpatient rehabilitation.[55] As an objective instrument such as the Montreal Cognitive Assessment

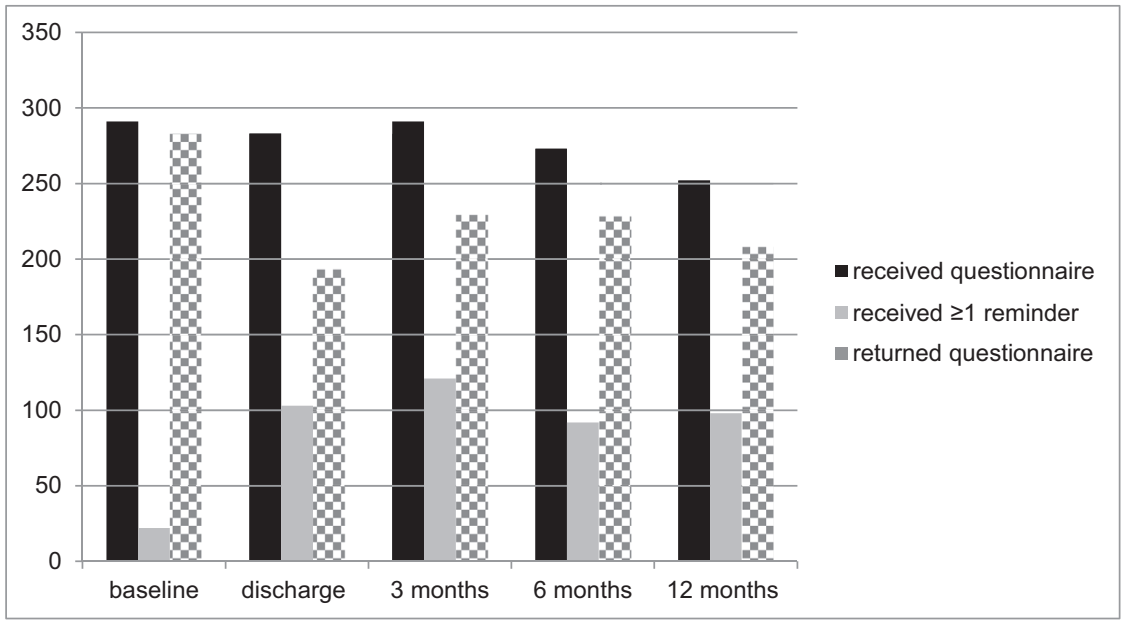


**Figure 3a.** *At each time point, the number of questionnaires sent and returned by stroke inpatients who participated in the SCORE study, and the number of participants who received one or more reminders.*

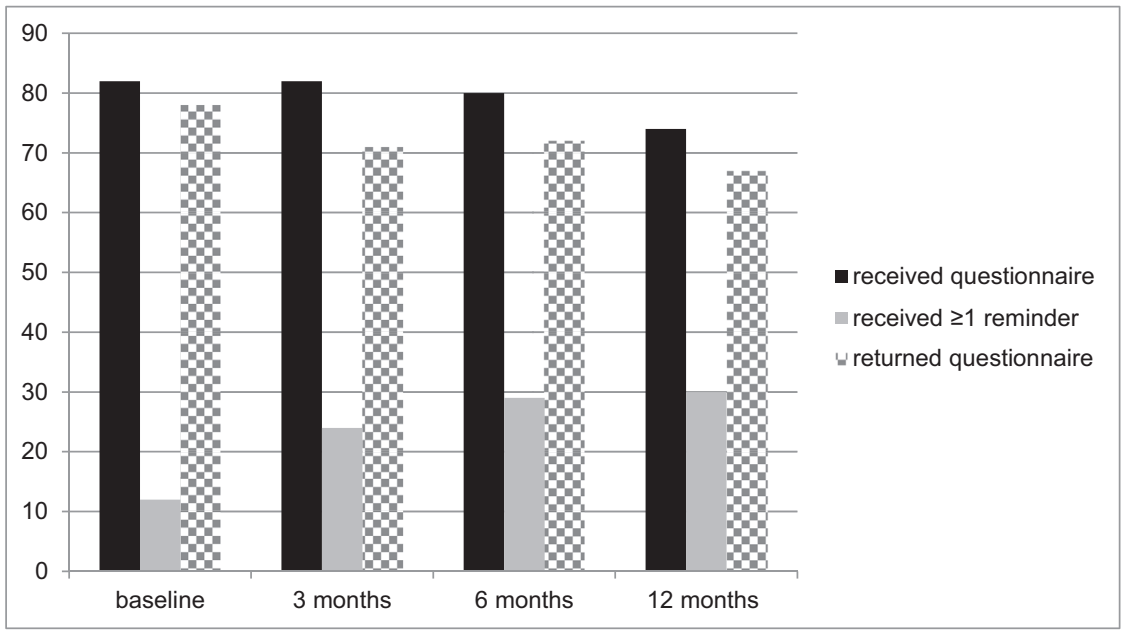


**Figure 3b.** *At each time point, the number of questionnaires sent and returned by stroke outpatients who participated in the SCORE study, and the number of participants who received one or more reminders.*

was applied to identify cognitive problems in only part of the patients, as part of usual care, stratification into a subgroup of cognitively impaired patients was not possible. Like the SAQOL-39NL and the SIS memory scale, the FSS did not change over time in any of the groups. Whether this reflects unresponsiveness of the instrument or a clinical lack of improvement remains unclear.

The SIS subscales for mobility and hand function were able to capture changes in physical functioning were in line with the hypothetical pattern of recovery of Langhorne et al.[56] Mobility and hand function significantly improved within the first 3 months, after which recovery plateaued.[17] As expected, communication improved significantly in patients with aphasia during rehabilitation but not thereafter.[57]

As for general health, for both inpatients and outpatients, the EQ-5D baseline scores were relatively high.[58] Nevertheless, the EQ-5D index and VAS had significantly improved after 6 months, in line with the inpatient rehabilitation population with mild to moderate stroke of Hunger et al.[59]

In addition, small but statistically significant changes were found in mood. The prevalence of depressive symptoms (28.5%) and anxiety (18.6%) 3 months post stroke was comparable to a pooled prevalence of 31% and 23% respectively in systematic reviews.[8,60] In contrast to studies among generic hospital-based stroke populations, depressive symptoms and anxiety decreased between 3 and 12 months.[61,62] The improvements in mental health among patients in the SCORE study could be related to the intensive multidisciplinary rehabilitation trajectory.

Societal participation significantly improved. The 3-month scores on the USER-P scales were comparable to the postrehabilitation scores in a general outpatient population in the Netherlands (N = 389, 46.6% female, mean age 52.1),[39] and strikingly similar to a Dutch outpatient rehabilitation population (53.2% female, mean age 53.0) including patients with brain injury (N = 29) and musculoskeletal disorders (N = 19).[63] In the inpatient population, significant improvements were seen on all USER-P scales. This finding is promising, as participation generally is the ultimate goal for patients with stroke.[64]

Overall, the health outcome changes in outpatients were less pronounced, as they started outpatient rehabilitation on average 10 weeks after stroke[47] and had less physical impairments at the time of inclusion. The latter could partly be due to their previous inpatient rehabilitation trajectory and/or to their less severe stroke. In contrast, outpatients reported worse communicative functioning and memory at the start of rehabilitation than inpatients, although SIS scores were comparable to a population of community-dwelling stroke patients 2 months post stroke.[65] Problems in communication and memory often become apparent after return to the home situation, and are usually a reason for (continuation of) rehabilitation in the outpatient setting.[13]

Except for the nonmotor function subdomain "Pain and other unpleasant sensations" our set of PROMs comprised the same domains of patient-reported health status included in the ICHOM Standard Set for Stroke. At the time our study was initiated, that set had not yet been published. In future research, the PROMs that are proposed in the Standard Set need to be examined

**Table 2a.** *Health outcomes of stroke patients in **inpatient** rehabilitation*

| | | ICHOM subdomain | n | Admission mean (SD) | *Δ Discharge mean (95%CI)* | *Δ 3 Months mean (95%CI)* | *Δ 6 Months mean (95%CI)* | *Δ 12 months Mean (95%CI)* |
|---|---|---|---|---|---|---|---|---|
| **EQ-5D** | Index (−0.23; 1.00) | General health/ | 239 | .70 (.24) | **.10 (.02;.17)**. *n = 33* | **.04 (.01; .07)** | **.05 (.02; .09)** | **.04 (.01; .07)** |
| | VAS scale (0-100) | Quality of life | 252 | 61.50 (18.88) | −.53 (−8.53;6.85) | **3.15 (.53; 5.76)** | **4.08 (1.45; 6.71)** | **6.54 (3.70; 9.37)** |
| **SIS** | Communication (0-100) | Social functioning | 254 | 84.67 (18.76) | −.44 (−2.60;1.73) | 1.08 (−.77; 2.93) | 1.25 (−.75; 3.25) | .29 (−2.0; 2.55) |
| **SIS** | Memory (0-100) | Cognitive and psychiatric functioning | 261 | 81.2 (19.3) | 1.1 (−1.6;3.8) | .0 (−2.2; 2.3) | .6 (−1.7; 2.8) | −.3 (−1.96;2.53) |
| **SIS** | Mobility (0-100) | Motor functioning Motor functioning | 43 | 68.32 (28.54) | **15.49 (6.37; 24.61)** | **15.33 (5.96;24.70)** | **13.12 (3.44; 22.81)** | - |
| **SIS** | Hand function | | 184 | 48.31 (35.5) | **9.38 (4.31; 14.44)** | **14.92 (9.94; 19.91)** | **14.34 (9.05; 19.63)** | **15.68 (10.50;20.86)** |
| | | | | | | ***3 months Mean (SD*** | ***Δ6 to 3 months Mean (95% CI)*** | ***Δ12 to 3 months Mean (95% CI)*** |
| **SAQOL-39NL** | Physical (1-5) | Motor functioning | 183 | | | 4.10 (.83) | .05 (−.04; .13) | .07 (−.01; .16) |
| | Communication (1-5) | Social functioning | 182 | | | 4.45 (.75) | .03 (−.06; .12) | −.01 (−.09; .08) |
| | Psychosocial (1-5) | Cognitive and psychiatric functioning | 181 | | | 3.57 (.91) | .08 (−.04; .19) | −.05 (−.12; .11) |
| **USER-P** | Frequency (0-100) | Social functioning | 180 | | | 24.97 (11.67) | **2.32 (.66; 2.97)** | **3.22 (1.65; 4.80)** |
| | Restrictions (0-100) | | 185 | | | 71.37 (23.05) | 1.92 (−.94; 4.78) | **5.31 (2.14; 8.49)** |
| | Satisfaction (0-100) | | 183 | | | 65.09 (20.66) | 1.32 (−1.07; 3.71) | **2.93 (.09; 5.78)** |
| **HADS** | Depression (0-21) | Cognitive and psychiatric functioning | 214 | | | 5.45 (4.07) | −.26 (−.68; .16) | −.34 (−.81; .12) |
| | Anxiety (0-21) | | 215 | | | 5.29 (4.07) | **−.4 (−.8; −.0)** | −.19 (−.59; .20) |
| **FSS** | Fatigue (0-10) | Nonmotor functioning | 204 | | | 4.67 (1.45) | −.03 (−.23; .16) | −.01 (−.22; .20) |

EQ 5D, EuroQol 5 Dimensions; FSS, Fatigue Severity Scale; HADS, Hospital Anxiety and Depression Scale; ICHOM, International Consortium for Health Outcomes Measurement; SAQOL-39NL, Stroke and Aphasia Quality of Life Scale; SIS, Stroke Impact Scale; USER-P, Utrecht Scale for Evaluation of Rehabilitation-Participation.

Data are presented as mean with Standard Deviation (SD) or mean change (***Δ***) with 95% Confidence Interval (CI).

**Table 2b.** *Health outcomes of stroke patients in **out**patient rehabilitation*

| | Scale | ICHOM domain | n | Admission mean (SD) | *Δ 3 Months mean (95%CI)* | *Δ 6 Months mean (95%CI)* | *Δ 12 Months mean (95%CI)* |
|---|---|---|---|---|---|---|---|
| **EQ-5D** | Index (−.23; 1.00) | General health/ | 71 | .73 (.19) | .05 (−.01; .10) | **.05 (.004; .10)** | **.05 (.003; .10)** |
| | VAS scale (0-100) | Quality of life | 71 | 63.17 (18.28) | **5.57 (1.18; 10.16)** | **4.44 (.31; 8.57)** | 2.46 (−2.81; 7.72) |
| **SIS** | Communication (0-100) | Social functioning | 75 | 81.20 (17.07) | 3.00 (-.42; 6.43) | **4.50 (.15; 8.85)** | 1.73 (−2.09; 5.54) |
| **SIS** | Memory (0-100) | Cognitive and psychiatric functioning | 75 | 75.17 (15.99) | 2.73 (−1.10; 6.55) | 3.73 (−.55; 8.01) | 3.74 (−.61; 8.09) |
| **SIS** | Mobility (0-100) | Motor functioning | 21 | 84.28 (20.01) | 1.99 (−3.94; 7.92) | **5.23 (1.03; 9.42)** | - |
| **SIS** | Hand function, all impaired | | 34 | 70.88 (24.63) | 8.91 (−1.05; 17.90) | 4.71 (−8.23; 17.64) | 5.71 (−4.13; 15.56) |
| | | | | | ***3 months Mean (SD)*** | ***Δ6 to 3 months Mean (95%CI)*** | ***Δ12 to 3 months Mean (95%CI)*** |
| **SAQOL-39NL** | Physical (1-5) | Motor functioning | 69 | | 4.41 (.65) | .01 (−.09; .11) | −.06 (−.18; .06) |
| | Communication (1-5) | Social functioning | 69 | | 4.43 (.70) | .10 (−.07; .27) | .05 (−.13; .24) |
| | Psychosocial (1-5) | Cognitive and psychiatric functioning | 69 | | 3.46 (1.02) | .04 (−.11; .19) | −.08 (−.37; .20) |
| **USER-P** | Frequency (0-100) | Social functioning | 69 | | 29.78 (8.82) | 3.10 (−.06; 6.25) | **3.10 (.02; 6.17)** |
| | Restrictions (0-100) | | 67 | | 78.66 (18.97) | 1.63 (−1.53; 4.78) | 3.82 (−.40; 8.03) |
| | Satisfaction (0-100) | | 65 | | 67.90 (19.21) | −.75 (−4.34; 2.85) | 1.13 (−2.44; 4.69) |
| **HADS** | Depression (0-21) | Cognitive and | 69 | | 4.64 (3.48) | −.003 (−.49; .49) | .13 (−.54; .79) |
| **HADS** | Anxiety (0-21) | psychiatric functioning | 69 | | 5.62 (3.79) | −.10 (−.74; .55) | −.19 (−.83; .45) |
| **FSS** | Fatigue (0-10) | Non-motor functioning | 69 | | 4.73 (1.47) | −.05 (−0.28; .17) | .11 (−.13; .35) |

EQ 5D, EuroQol 5 Dimensions; FSS, Fatigue Severity Scale; HADS, Hospital Anxiety and Depression Scale; ICHOM, International Consortium for Health Outcomes Measurement; SAQOL-39NL, Stroke and Aphasia Quality of Life Scale; SIS, Stroke Impact Scale; USER-P, Utrecht Scale for Evaluation of Rehabilitation-Participation.

Data are presented as mean with Standard Deviation (SD) or mean change (***Δ***) with the 95% Confidence Interval (95% CI).

regarding their feasibility and validity in rehabilitation. Considering the discrepancy in the changes between memory and mood observed in the present study we would recommend the ICHOM to revise the item in the PROMIS-10 in which both health domains are combined (PROMIS 10 Q4_04: "In general, how would you rate your mood, including your mood and ability to think?").

*Limitations*

This study has a number of limitations. First, it concerns patient referred for medical specialist rehabilitation. This selection is illustrated by the mean age of 60 and 57 years, whereas the usual stroke population is aged 70-80 years. In addition, patients with severe aphasia and severe cognitive problems were not eligible as they would be unable to reliably complete the questionnaires. In total, 40% and 57% of invited inpatients and outpatients, respectively did not participate in the study. Although the average age and sex between participants and nonparticipants were comparable, this may have been a selective population in terms of clinical or treatment-related characteristics. Conceivably, the patients with most health problems experienced the study as too much of a burden, whereas the patients in relatively good health might not want to be confronted with stroke anymore. Nevertheless, based on the distribution of the characteristics of the patients at admission, we expect to have covered a heterogeneous group of stroke patients in rehabilitation.

If future routine outcome measurements would become part of usual care and presented as such to the patient, and the questionnaire package would be slightly reduced, we expect the participation rate to be higher. Although patient-reported outcome measurements are extremely valuable, a drawback is that a patients' perceived health status often differs from objectively assessed health, most pronouncedly in patients with cognitive complaints,[3] and communication.[66] In research and clinical practice it may be useful to combine PROMs with objective measurement instruments such as the MoCA[67] and Comprehensive Aphasia Test.[68] However, the application of objective instruments is time-consuming and may be an additional burden for the patient, with the risk of (selective) dropout. Another pitfall is the conduct of multiple testing, which we did not adjust for. Nonetheless, as the majority of significant differences in the inpatient population had a *P* value lower than .01, they can be considered as real differences.

Altogether, the SCORE study yielded a wealth of information on the measurements within domains of health status that are of value for the patient, which is in line with the concept of VBHC. Follow-up measurements continued beyond 3 months, which enabled us to detect changes over a longer period of time. By measuring multiple outcomes and applying repeated assessments, a clear picture is drawn into the health aspects that change, and the timing of their change. In future research and in daily practice outcome measurements should be applied to all stroke patients, starting shortly after hospitalization. When doing so, the changes in health during the patients' journey throughout the integrated care pathway can be evaluated.

## Conclusions

The feasibility of administering a comprehensive set of PROMs was demonstrated in rehabilitation for stroke patients. The PROMs employed were multidimensional and had acceptable to good psychometric properties. The assessments beyond 3 months appeared valuable as some changes in health only became apparent after 3 or 6 months. By slightly reducing the questionnaire size and offering assistance in questionnaire completion, the participation and response rates may be further enhanced.

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