

# Association between clinician reported outcome and patient reported outcome measures one year after stroke

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**Objectives:** Patient reported outcome measures (PROM) are increasingly important in the evaluation of care. In this study we evaluate patient PROM in stroke patients and the association with clinical reported outcomes. **Materials and methods:** Of 3706 first-ever stroke patients, 1861 were discharged home and invited to fill out PROM at discharge, 90 days and one-year after stroke. PROM include mental and physical health and patients' self-reported functional status, all available via International Consortium for Health Outcomes Measurement. Clinician reported measures as NIHSS, Barthel index were collected during hospital admission and modified Rankin Scale (mRS) 90 days after stroke. PROM compliance was evaluated. Clinician reported measures were related to PROM. **Results:** 844 (45%) of the invited stroke patients filled out PROM. In general, those patients were younger and less severely affected (higher Barthel index and lower mRS). Compliance after enrolment is about 75%. Barthel index and mRS correlated with all PROM at 90 days and one-year. In age and gender adjusted multiple regression analysis, mRS was a consistent predictor for all PROM subsets, and Barthel index holds predictive value for physical health and patients' self-reported functional status. **Conclusions:** Participation rate to fill out PROM is only 45% among stroke patients who were discharged home, and compliance rate is around 75% up one-year follow-up. PROM associated with the clinician reported functional outcome measures Barthel index, and mRS score. Low mRS score is a consistent predictor of better PROM at one year. We propose to use mRS in stroke care evaluation, until PROM participation improves.

**Keywords:** Stroke—Patient reported outcome measures (PROM)—Clinician reported outcome measures—modified Rankin Scale (mRS)—Barthel index—Prediction—Outcome

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## Introduction

In evaluating the burden of stroke and the effect of stroke treatment, several clinicians' outcome measures

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regarding physical functioning are used, such as National Institutes of Health Stroke Scale (NIHSS),<sup>1</sup> Barthel index,<sup>2</sup> and modified Rankin Scale (mRS).<sup>3</sup>

Apart from functional disability, patients experience more subtle complaints. Impairment of memory, mental speed and concentration are quite common in stroke survivors.<sup>4</sup> These cognitive complaints can unfavorably affect treatment success.<sup>4</sup> Furthermore, about one-third of stroke survivors experience depression, anxiety or apathy.<sup>5</sup> Poststroke cognitive impairment and neuropsychiatric sequelae are associated with activity limitations, participation restrictions, and decreased quality of life.<sup>5,6</sup>

Hence, patient reported outcome measures (PROM) which include mental functioning, should preferably be considered equally important and used in patients' outcome evaluation.<sup>7</sup> In case of stroke, several instruments measure the patient's mental and physical health

condition and are widely available, such as Short Stroke Specific Quality of Life Scale (SS-QOL-12),<sup>8</sup> and Stroke Impact Scale,<sup>9</sup> or the Patient Reported Outcomes Measurement Information System (PROMIS-10).<sup>10</sup>

Whereas clinical outcome measures such as mRS and Barthel index are expected to discriminate well between patients with poor outcomes discharged to a nursing home and patients with relatively good outcome discharged home, these measures might be less sensitive to more subtle impairments experienced by patients discharged home. Moreover, one would expect clinical outcome measures to correlate well with PROM in the physical domain but less so in the mental domain.

This study aimed to evaluate the fitness and feasibility to obtain PROM in stroke patients discharged home. We examined differences in demographics and outcomes between stroke patients who did and those who did not fill out the PROM questionnaires. Furthermore, we explored how many patients fill out the PROM at 90 days and one year after stroke, and if they were capable to fill it out by themselves or needed help from relatives. Moreover, this study aimed to identify predictors for the PROM scores at one year after stroke, and thereby determining the correlation between PROM and clinician reported measures. We hypothesize that patients discharged home who do fill out the PROM questionnaires are only mildly affected and therefore have better scores both on the NIHSS and mRS. Finally, we expect the physical health PROM subset to correlate well to the clinical outcome measures.

## Methods

In this retrospective cohort study with prospectively collected data in the context of standard care, we included acute first-ever stroke patients (cerebral infarction or intracerebral hemorrhage) who were hospitalized in comprehensive stroke center Rijnstate hospital from January 2016 through December 2020. As part of the routine care, clinicians prospectively filled in the baseline NIHSS, the Barthel index, and the mRS. Prospectively reported data from the electronic patients files were retrieved, including variables reported in the ICHOM Stroke Standard Set.<sup>11</sup> Per protocol, all stroke patients who were discharged home received an invitation to fill out the *PROMIS Global Health short form (PROMIS-10)* and *Patients' self-reported functional status*, whereas stroke patients discharged to a rehabilitation center or nursing home were not invited, as part of standard care in Rijnstate hospital. Both questionnaires are integrated in the ICHOM Stroke Standard Set.

### *Clinician reported measures*

All the clinician reported measures described below are commonly used in health care settings as part of routine care.

### *National Institutes of Health Stroke Scale (NIHSS)*

The NIHSS is the standard 15-item scale for measuring neurologic impairment after acute cerebral infarction at hospital admission. Each item is scored on a 3- or 5-point scale, with 0 as normal. Scores range between 0 and 42, in which higher scores indicate greater impairment.<sup>1</sup>

### **Barthel index**

The Barthel index is a functional independence measure addressing different aspects of daily life. The measurement is a ten-item scale, scoring to 20 points and interpretation with five-point increments: a higher score indicates a higher level of independence. The Barthel index is assessed through interview and distant observation by a clinician on day 5 or at discharge, whichever comes first.<sup>2</sup>

### **Modified Rankin Scale (mRS)**

The mRS is a one-item measure of global disability, with zero representing no symptoms and six representing death, scored 90 days after stroke.<sup>3</sup>

### *Non-clinician reported measures*

At discharge, stroke nurses invite patients and/or their caretakers to fill out PROM. Questionnaires are shortly explained, and instructions are given to the patients and/or their caretakers. From January 2016 through December 2020 patients could opt for either a paper questionnaire or a digital questionnaire. For the paper questionnaires, the stroke nurses handed these out at discharge and patients were asked to return the questionnaire after completion via mail. At the outpatient clinic visit one month after discharge, the stroke nurse once again asked the patient to fill out the PROM. At 90 days and one year after stroke, patients received the questionnaires via mail and were asked to return these after completion. For a digital version, patients received a link to the PROM questionnaire via e-mail. If patients did not complete the questionnaire, they received electronic reminders on day 5 and day 10 after each original invitation (discharge, 90 days or one year).

### **PROMIS global health short form (PROMIS-10)**

The PROMIS-10<sup>11</sup> is a questionnaire that measures symptoms, functioning, and healthcare related quality of life for several conditions. The ten questions cover overall physical health, mental health, social health, pain, fatigue, and overall perceived quality of life. Answer options consist of a five-point scale, ranging from the ideal to the worst outcome. After re-coding a M-PROMIS (mental health) score and PHY-PROMIS (physical health) score is generated according to manual, each containing the sum of four questions and ranging from 4-20.<sup>11</sup> PROMIS-10

was collected 90 days after stroke and annually thereafter. For the purpose of this study, we only used the data collected at 90 days and one year.

### Patients' self-reported functional status

Patients' self-reported functional status consists of 5 questions, regarding needed support for walking, toileting, dressing/undressing, feeding and problems with communication or understanding.<sup>11,12</sup> When complete, score ranges from 3-9. Lower score reflects better outcome. Patients' self-reported functional status was collected at discharge, 90 days and annually thereafter. For this study, we only used the data collected at discharge, 90 days and one year after stroke.

### Medical ethical committee and informed consent

The study did not require an ethical approval because of the retrospective observational design using anonymized data from electronic patient charts.

### Statistical analysis

All patients with an index stroke during the study period were included in the analysis. We checked demographic data for normal distributions and summarized the data using descriptive statistics: number and percentages were used for categorical data, mean and or  $\pm$  standard deviation (SD) for normally distributed continuous data and median  $\pm$  interquartile range (IQR) for continuous, skewed data. Numbers of patients who filled in the PROMIS-10 and whether they filled it in themselves were reported and expressed in percentages. We defined PROM compliance as the availability of complete PROM data at the three timepoints for a patient. Furthermore, differences in characteristics (stroke type, age, gender, treatment, hospitalization days, discharge destination, Barthel index, NIHSS, and mRS) between patients who did and did not fill out the PROM were analyzed using Fisher's exact test for categorical and an independent two-sample t-test or Mann-Whitney U test for continuous data, dependent on the distribution.

We used nonparametric correlation procedure to describe potential correlations between age, gender, NIHSS, Barthel index, mRS at 90 days, patients' self-reported functional status at 90 days, M-PROMIS and PHY-PROMIS at 90 days when  $P < 0.05$ .

To test whether our three outcome variables "M-PROMIS, PHY-PROMIS and patients' self-reported functional status" changed over time we used either Wilcoxon test or Friedman test for repeated measures depending on distribution and number of measurements. If necessary, significance values were corrected for multiple testing.

We used an age and gender adjusted linear regression model to determine baseline predictors for M-PROMIS score, PHY-PROMIS score and patients' self-reported

functional status. Only patients with completed PROMIS-10 questionnaires were included. The univariate linear regression model included variables which had less than 10% missing value(s) and could affect the PROMIS-10 total score. When  $P < 0.2$  and no collinearity was present between the variables, they were included in the backwards age and gender adjusted multiple linear regression model based on complete case analysis. The multiple regression model could include a maximum of 1 variable per 10 subjects. Analyses were run for the time point one year after stroke. Only significant variables ( $< 0.05$ ) were kept in the final age and gender adjusted model. To determine the goodness of fit of the model, the accuracy, we used the adjusted  $R^2$ . Adjusted  $R^2$  identifies the percentage of variance that is explained by the variables in the model.

All analyses were performed using IBM SPSS Statistics (SPSS version 25.0 for windows, IBM Corporation, Armonk, NY, USA). A p-value  $< 0.05$  indicated a statistically significant difference.

## Results

Between 1-1-2016 until 31-12-2020, 3795 consecutive patients admitted with a stroke were identified, of whom 89 patients were excluded with a history of stroke, leaving 3706 patients with first ever stroke. About half of these patients, ( $n = 1861$ ) was discharged home. Per protocol they received an invitation to fill out PROM, which 844 accepted (Fig. 1).

### Patient characteristics

The majority of the 1861 patients with a first ever stroke was diagnosed with an ischemic stroke (1770 patients, 95%) and 91 patients (5%) with an intracerebral hemorrhage. Of the 1770 patients diagnosed with an ischemic stroke, 546 (29%) underwent only intravenous thrombolysis (IVT), 41 (2%) only endovascular thrombectomy (EVT), and 53 (3%) both IVT and EVT.

When comparing patients discharged home with and without PROM data, patients with PROM data were slightly older and more often had an ischemic stroke. They had a better Barthel index. After 3 months, more patients in the PROM group had a relatively good functional outcome (mRS 0-2) than patients without PROM (89% vs. 84%). Furthermore, one-year mortality was significantly lower in the PROM group compared to the group without PROM data (3% vs 9%,  $p < 0.01$ ). Table 1 summarizes the patient characteristics.

### PROM

Table 2 depicts an overview the number of returned invitations, number of completed and partially completed questionnaires, and missing data at 90 days and one year after their initial stroke. The response rate of completed

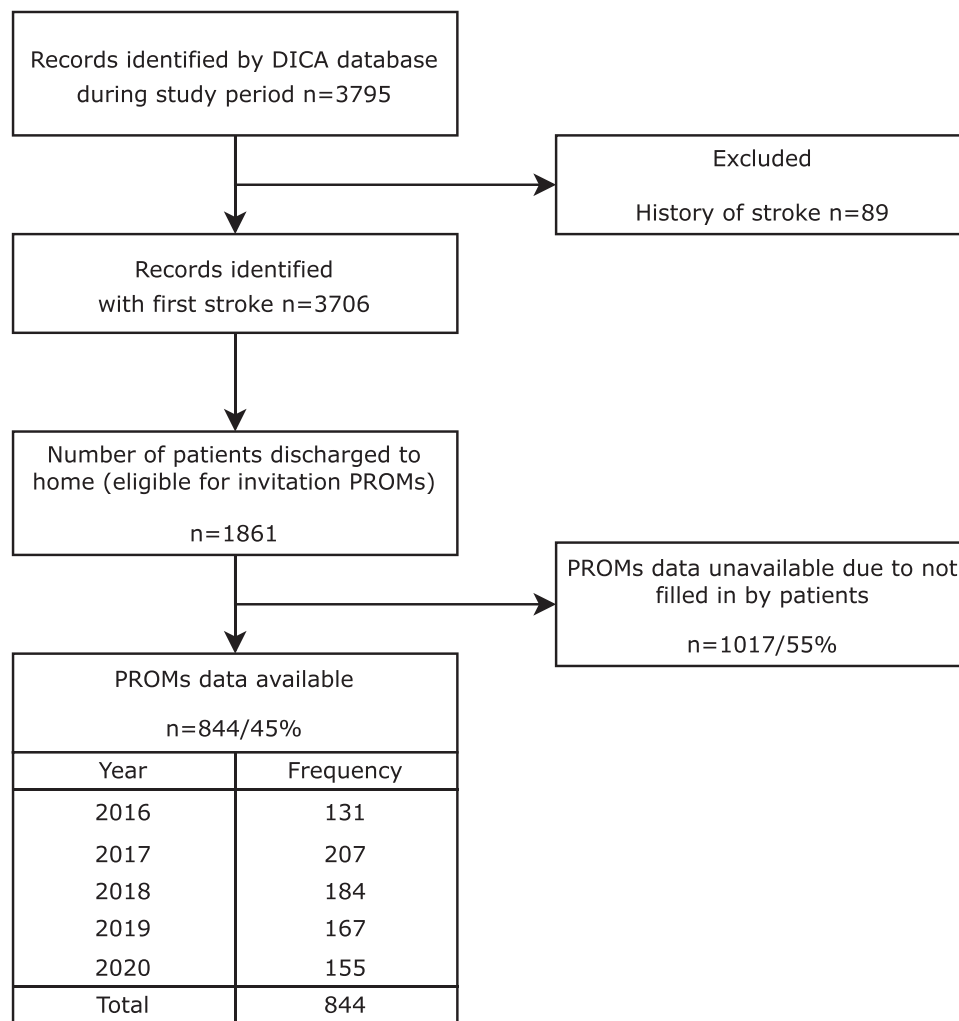


Fig. 1. Flow diagram PROM CVA.

PROM remained stable around 75% up to one-year follow up.

At 90 days, the median M-PROMIS score was 12 (IQR 10-15) and the median PHY-PROMIS score was 14 (IQR 12 - 17). In patients with M-PROMIS scores at 90 days and one year, both scores decreased throughout one-year follow up (median M-PROMIS at 90days: 13 (IQR 10 – 15) and at one-year: 12 (IQR 10 – 15); median PHY-PROMIS at 90 days: 14 (IQR 12-17) and at one-year 13 (IQR 11-16)) (Table 2).

At discharge, the median patients' self-reported functional status score was 3 (IQR 3-4). In patients with data available at discharge, 90 days and one year, we saw a significant improvement at 90-days. At one year, patients scored better than after discharge, however this increase was not significant. Comparing 90-days to one-year showed non-significant decrease in patients' self-reported functional status score, as shown in Table 2.

Of the completed questionnaires, most patients entered the data themselves; 83% at 90 days and 84% at one-year follow-up (Supplementary table 1).

### Predictors

The three different PROM parameters, both at 90 days and one year after stroke, all associated with the clinician reported parameters mRS and Barthel index. Also, all the PROM scores at the different timepoints associated with each other. For more details, see Supplementary Table 2A and 2B.

Table 3 shows the results of the univariate linear analyses and the final models of the multiple linear regression analyses.

### M-PROMIS score one year

Age and gender adjusted univariate linear regression analysis showed that Barthel index and mRS were significant contributors to the M-PROMIS score. Even though Barthel index was a significant contributor in the univariate linear regression analysis, this result did not hold in the multiple linear regression model ( $B = 0.04$ ,  $[-0.04 - 0.12]$ ,  $p=0.35$ ). Only mRS remained a significant

**Table 1.** Patient characteristics including intervention details, hospitalization data, and death.

	Invited for PROM (n=1861)		P
	No PROM (n=1017)	PROM (n=844)	
Age (years) (mean, SD)	68.6 (0.4)	71.6 (0.4)	<0.01
Male gender (n/%)	565 (56)	485 (58)	0.41
Hospitalization duration (days) (median, IQR)	2 (1-4)	2 (1-4)	<0.01
Diagnosis (n/%)			0.18
Ischemic stroke	961 (95)	809 (96)	
Bleeding	56 (6)	35(4)	
Reperfusion therapy - yes (n/%)	318 (33)	322 (40)	<0.01
none	643 (67)	487 (60)	<0.01
IVT only	272 (28)	274 (34)	
EVT only	30 (3)	11 (1)	
IVT+EVT combined	16 (2)	37 (5)	
Door to needle time (minutes) (n=) (median, IQR)	33.5 (27-39)	30 (24-38)	0.22
Door to groin time (minutes) (n=) (median, IQR)	59 (42-85)	64 (57-76)	0.66
NIHSS score (n=) (median, IQR)	3 (2-6)	3 (2-6)	0.76
Barthel Index (n=) (median, IQR)	17 (13-20)	18 (14-20)	<0.01
Modified ranking scale (n=) (n/%)			0.03
No symptoms	174 (33)	218 (31)	
No significant disability	180 (35)	271 (38)	
Slight disability	85 (16)	139 (20)	
Moderate disability	41 (8)	54 (8)	
Moderately severe disability	14 (3)	13 (2)	
Severe disability	1 (<1)	1 (<1)	
Death	26 (5)	13 (2)	
Death within 1 year (n/%)	91 (9)	28 (3)	<0.01

IVT = intravenous thrombolysis; EVT = endovascular treatment; NIHSS = National Institutes of Health Stroke Scale, on day 0; mRS = modified Rankin Scale, at 3 months, Barthel Index on day five, or discharge

SD = standard deviation; IQR = interquartile range

P denotes the difference between the invited patients with and without PROMS data.

contributor in the age and gender adjusted multiple variable regression model. Accuracy of this final model was 18% ( $R^2$  adjusted).

#### PHY-PROMIS score one year

Age and gender adjusted univariate linear regression analyses showed that NIHSS, hospitalization duration, Barthel index and mRS were significant contributors to the PHY-PROMIS score. However, hospitalization duration highly correlated with the Barthel index and was therefore not included in the multiple regression model. In the final age and gender adjusted multiple variable model only Barthel index and mRS remained significant. Accuracy of this final model was 23% ( $R^2$  adjusted).

#### Patients' self-reported functional status one year

Age and gender adjusted univariate linear regression analyses showed that stroke type (hemorrhage), Barthel index and mRS were significant contributors to the patients' self-reported functional status. The variable

stroke type was not entered in the final multiple variable regression model, because of a strong sign for problems with multicollinearity possibly due to the small numbers of patients with the diagnosis bleeding. In the final age and gender adjusted multiple variable regression model Barthel index and mRS remained significant. Accuracy of this final model was 16% ( $R^2$  adjusted).

#### Discussion

This cohort study showed that stroke patients who filled out at least one PROM were less impaired than patients who did not complete a questionnaire. This finding was confirmed by the significant correlations between the PROM (90 days and one year) and scores on the Barthel index, mRS, and to lesser extent the NIHSS. This is supported by the study of Van Mierlo et al. who also found it plausible that only patients with mild symptoms or improved health conditions fill out the PROM.<sup>13</sup>

Approximately 80% of the stroke patients who completed the PROM questionnaires filled it out themselves at all follow-up timepoints. In general, these patients had



**Table 2.** Overview of the invitations of questionnaires PROM (Promis-10: M-PROMIS and PHY-PROMIS) and patients' self-reported status scores over one-year follow-up.

	discharge	90-days	1-year
Invitations of questionnaires			
Returned invitations (N)	844	754	676
Completed (N/% of returned invitations)	843 (99.9)	572 (76)	510 (75)
Inactive (N)	1	171	154
Partially completed (N)	0	5	2
Not started yet (N)	0	2	5
PROM outcomes			
<i>M-PROMIS</i>			
# Respondents (N)	n.a.	513	477
M-PROMIS (median, IQR)	n.a.	12 (10-15)	12 (10-15)
# Respondents (N) for 90-days & 1-year		327	327
M-PROMIS (median, IQR)		13 (10-15)	12 (10-15)
Nonparametric tests between subsequent measures	p compared to previous		<0.01
<i>PHY-PROMIS</i>			
# Respondents (N)		513	477
PHY-PROMIS (median, IQR)		14 (12-17)	14 (11-16)
# Respondents (N) for 90-days & 1-year		327	327
PHY-PROMIS (median, IQR)		14 (12-17)	13 (11-16)
Nonparametric tests between subsequent measures	p compared to previous		0.01
<i>Patients' self-reported functional status</i>			
# Respondents (N)	809	563	493
patients' self-reported functional status score (median, IQR)	3 (3-4)	3 (3-3)	3 (3-3)
# Respondents (N) for discharge, 90-days & 1-year	360	360	360
patients' self-reported functional status score (median, IQR)	3 (3-4)	3 (3-3)	3 (3-3)
Nonparametric tests between subsequent measures*	p compared to previous	<0.01	0.18
	p compared to discharge		0.68

\*Significance values have been adjusted by the Bonferroni correction for multiple tests. IQR = interquartile range; n.a. = not applicable; PROMIS = PROMIS Global Health short form; M-PROMIS = mental health; PHY-PROMIS = physical health; Completed = all questions are answered; inactive = deceased/active withdrawal by patient/wrong or absent email address; partially completed = one or more responses are missing; not yet started = no question answered

a low mRS score, which indicates no or slight global disability. This may raise the question whether the provided answers by relatives or proxies are reliable. However, Lapin et al showed that answers to PROM (> three months after stroke event) given by relatives or proxies of severely affected patients who are not capable to fill out the PROM, do provide similar information to self-reported PROM.<sup>14</sup> We should note that in older patients the mRS could be affected by other non-neurologic conditions.

Per protocol every patient who had been admitted for stroke (cerebral infarction or intracerebral hemorrhage) and was discharged home received a PROM invitation. However, only 45% (844 returned invitations of 1861 eligible respondents) returned the completed questionnaires 90 days after stroke. Groeneveld et al investigated the feasibility of several (different) PROM in the first year after stroke offered to inpatients and outpatients of a big rehabilitation center in the Netherlands. The average age for both groups in this study is much lower than the average age of our population (inpatients: 60.4 years; outpatients: 57.3 years, versus our PROM group: 71.6 years). They found slightly higher participation rates for inpatients

(60%) and slightly lower participation rates for outpatients (43%).<sup>15</sup> After initial enrollment, we found participation rates of 75% up to one year follow-up, this is in line with Groeneveld et al findings for the inpatient group and slightly lower than for their outpatient group.<sup>15</sup>

We found that patients' mental and physical health score decreased between 90 days and one-year throughout follow-up. A similar trend was seen in patients' self-perceived functional status, even though patients initially report an improvement between discharge and 90 days follow up.

We hypothesize that after the event, patients are first relieved that they survived the stroke and then improve physically and mentally during the first 3 months during rehabilitation process before they reach a stable situation where they realize that there will be no further improvement.

Consistent predictor of better outcomes for all PROM at one year was mRS at 90 days. Barthel index score on day 5 was also a predictor for PHY-PROMIS and patients' self-perceived functional status. Since both Barthel index and mRS are scales to measure physical aspects (functional independence and global disability), an association

**Table 3.** Predicting PROM outcomes at 1 year. Age and gender adjusted univariate linear and multiple linear regression results.

	Variable (reference)	Univariate linear regression		Multiple regression – Final model		R <sup>2</sup> adj
		B [95% CI]	P-value	B [95% CI]	P-value	
M-PROMIS 1 year	Age	0.00 [-0.03 – 0.03]	0.98	-0.01 [-0.03 – 0.01]	0.37	0.18
	Gender (male)	-0.60 [-1.21 – 0.01]	0.06	-0.23 [-0.79 – 0.64]	0.43	
	Diagnosis (hemorrhage)	0.59 [-0.89 – 2.07]	0.43			
	NIHSS	-0.01 [-0.08 – 0.07]	0.89			
	Treatment (no)	0.32 [-0.28 – 0.92]	0.30			
	Hospitalization duration*	-0.07 [-0.15 – 0.01]	0.08			
	Barthel index	0.14 [0.05 – 0.22]	<0.01			
PHY-PROMIS 1 year	mRS	-1.40 [-1.67 – -1.12]	<0.01	-1.38 [-1.66 – -1.11]	<0.01	0.23
	Age	-0.02 [-0.04 – 0.01]	0.12	-0.03 [-0.05 – -0.00]	0.04	
	Gender (male)	-1.26 [-1.84 – -0.68]	<0.01	-0.78 [-1.35 – -0.21]	<0.01	
	Diagnosis (hemorrhage)	0.19 [-1.25 – 1.63]	0.80			
	NIHSS	-0.08 [-0.15 – -0.00]	0.04			
	Treatment (no)	0.22 [-0.37 – 0.81]	0.47			
	Hospitalization duration*	-0.12 [-0.20 – -0.050]	<0.01			
Patients' self-reported functional status 1 year	Barthel index	0.22 [0.14 – 0.30]	<0.01	0.13 [0.05 – 0.21]	<0.01	0.16
	mRS	-1.36 [-1.63 – -1.09]	<0.01	-1.23 [-1.52 – -0.93]	<0.01	
	Age	0.00 [-0.00 – 0.01]	0.24	0.00 [-0.00 – 0.01]	0.20	
	Gender (male)	0.10 [-0.04 – 0.24]	0.16	0.02 [-0.12 – 0.15]	0.79	
	Diagnosis (hemorrhage)	-0.35 [-.68 – -0.03]	0.03			
	NIHSS	0.01 [-0.01 – 0.02]	0.51			
	Treatment (no)	-0.06 [-0.19 – 0.08]	0.40			
	Hospitalization duration	0.01 [-0.01 – 0.03]	0.30			
	Barthel index	-0.05 [-0.07 – -0.03]	<0.01	-0.04 [-0.05 – -0.02]	<0.01	
	mRS	0.26 [0.20 – 0.32]	<0.01	0.22 [0.16 – 0.29]	<0.01	

B: parameter coefficient; R<sup>2</sup> adj.: R<sup>2</sup> adjusted; NIHSS: National Institutes of Health Stroke Scale; mRS: modified Rankin Scale; M-PROMIS: mental global health; PHY-PROMIS: global physical health.

\*Hospitalization duration correlated with Barthel index; therefore, not chosen as a variable in the multiple regression model.

with the PROM PHY-PROMIS and patients' self-perceived functional status is to be expected. Age and gender (being male) were significant contributors for better PHY-PROMIS outcome at one year only. This is only partially in line with a recent study, in which they found gender and mRS as independent predictors of all PROM outcomes at 90 days.<sup>16</sup>

### Limitations

The main limitation is the retrospective design of this study; only the prospectively measured variables could be used for data analysis. Perhaps other relevant variables, like living status or comorbid conditions, could hold predictive value for the different PROM after discharge, but were not collected in our data set. Moreover, the prospectively recorded NIHSS, Barthel index and mRS score had missing values and were not reported in 13%, 28% and 16% of the patients, respectively.

A second limitation is the selection bias introduced by the hospital, but also by the patients. Per protocol, only patients who were discharged home received an invitation to fill out PROM. Per definition, this means that only the "better" patients after stroke are represented in this study. Also, the group who did respond to the PROM invitation, was less impaired than patients who did not respond to the PROM invitation. Therefore, our results cannot be generalized to patients discharged to rehabilitation centers or nursing homes.

Another limitation is the decrease in PROM compliance during follow-up. Unfortunately, for most people who did not comply during follow-up we do not know the reason for dropping out. Only for a very small subgroup a reason was provided. From the 844 patients 38 (5%) have died and 13 (2%) actively withdrew.

Ideally, we prefer to use PROM to measure long term outcome, but several matters need to be improved before we can use this in standard care. First, patient participation and compliance need to be improved. We strongly believe this could be achieved by explaining the usefulness of the parameters to monitor rehabilitation and therefore the need to complete the questionnaires at the different timepoints. Since January 2022, we only use the digital version in our hospital, so reminders are sent at five and ten days after the invitation of the different timepoints. This should improve patient compliance. However, we cannot rule out that comorbidities play a role in compliance. Both need to be investigated before we can draw definite conclusions regarding compliance. Second, the PROM needs to be extended to patients discharged to a nursing home or an inpatient rehabilitation center. Health care professionals at these care facilities or patients' relatives and caregivers need to be our allies in data collection. New protocols on how to collect this digital data need to be developed. Since all PROM scores at one-year follow-up correlated with the mRS at three

months and the mRS was found to be the common variable in the different final regression models, we propose to use the mRS as an indicator for long term outcome for now. Since this is part of routine care, this information is already available to the clinician, and it doesn't require more effort from the patient and drop-outs are avoided. Also, this will prevent selection bias since every patient will be approached.

### Conclusion

This cohort study showed that the participation rate to fill out PROM is only 45% among stroke patients who were discharged home, however, after that response rate is around 75% up one-year follow-up. Nearly all respondents had less impairment, measured by the Barthel index and mRS score than the nonrespondents. All PROM outcomes were correlated with the clinician reported functional outcome measures Barthel index, and mRS score. Low mRS score is a consistent predictors of better PROM outcomes at one year.

### Relevance

We argue that clinician reported outcome parameters correlate well with PROM and are suitable measures for patients' outcomes for the evaluation of the clinical intervention. For now, this could be the solution for the difficulty in collecting PROM of more severely affected patients who cannot fill out the PROM themselves and the PROM compliance issues. However, more effort is needed to obtain PROM so it can become the outcome measure in stroke patients.

### Declaration of Competing Interest

None.

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### Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:[10.1016/j.jstrokecerebrovasdis.2023.107156](https://doi.org/10.1016/j.jstrokecerebrovasdis.2023.107156).

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