

Shared Decision-Making Supported by Outcome Information During Discharge Planning of Patients Hospitalized With Stroke

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Abstract

Background and Objectives

The SHOUT-STROKE study aimed to evaluate the effects of a shared decision-making (SDM) intervention on decision-making, health, and process outcomes during discharge planning of hospitalized patients with stroke. The intervention included a patient decision aid (PtDA) with integrated outcome information, training for health care professionals, and an implementation strategy.

Methods

A prospective multiple interrupted time-series study was conducted across 7 Dutch hospitals between November 2019 and March 2022. The study comprised 3 phases: a pre-implementation phase evaluating standard care, a transition phase integrating the PtDA and training into existing stroke care pathways, and a post-implementation phase evaluating the new workflow. Effects per hospital were estimated using segmented autoregression and combined in a meta-analysis to assess the overall effect.

Results

Of 635 eligible patients, 462 (73%) completed the primary outcome measure, the SDM-Q-9, a 9-item questionnaire assessing patient-reported levels of SDM (score range 0–100). The overall effect on SDM-Q-9 scores was -4.5 points (95% CI -11.3 to 2.2). No significant overall differences were observed in secondary decision-making outcomes (e.g., decisional conflict) or health outcomes (e.g., quality of life). Knowledge scores improved significantly in 2 hospitals, with an effect of 0.85 points (95% CI 0.08 to 1.6) in Hospital 4 and 0.94 points (95% CI 0.20 to 1.7) in Hospital 6. Of the 234 patients in the post-implementation phase, 137 (59%) received the PtDA, of whom 40% used it. Most patients reported that the PtDA with integrated outcome information was useful for decision-making and indicated that they would recommend the PtDA to other patients.

Discussion

The SDM intervention was appreciated by patients but did not significantly improve SDM levels or other decision-making or health outcomes. The significant improvement in patient knowledge scores in 2 hospitals is notable but insufficient to fully empower patients to actively participate in SDM. Future efforts should focus on optimizing the implementation process to achieve more impactful outcomes.

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Clinical Trials Registration

The SHOUT-STROKE study was registered in the Dutch Clinical Trial Register and automatically listed in the International Clinical Trial Registry Platform: Registration IDs: NL8375 | NL-OMON21735. Link to the registration: trialsearch.who.int/Trial2.aspx?TrialID=NL-OMON21735.

Introduction

Patients with stroke are not routinely involved in decision-making during hospitalization.^{1,2} Shared decision-making (SDM) promotes patient-centered care by fostering a collaborative process between health care professionals and patients. This approach enables well-informed decisions that integrate the best available evidence with the patient's values and preferences.³⁻⁵ Patient decision aids (PtDAs) are evidence-based tools designed to support SDM by providing clear information about health-related options and helping to clarify patients' values and preferences.^{6,7} Despite the demonstrated benefits of PtDAs and policies encouraging their use, their adoption in stroke care remains limited.^{1,8,9}

Previous research on patients with conditions other than stroke has shown that PtDAs effectively enhance patient knowledge, reduce decisional conflict, and improve patient-provider communication.¹⁰ These studies provide limited data on the use of PtDAs to support SDM in acute conditions and inpatient settings. Moreover, the PtDAs in these studies rarely include personalized information about outcomes, such as clinical and patient-reported outcomes. Such information is deemed crucial for delivering tailored insights into the benefits and harms of different treatment options¹¹ and can meaningfully contribute to the SDM process.¹²

For patients with stroke, several PtDAs have been developed, including those for acute reperfusion therapy^{13,14} and secondary stroke prevention.^{15,16} While involving patients in acute treatment decisions has been shown to be challenging because of time constraints,¹⁷ discharge planning may offer a more suitable opportunity for SDM within the stroke care pathway. During discharge planning, a multidisciplinary team of health care professionals assesses patients' post-stroke rehabilitation needs to determine the most appropriate discharge destination, such as home (with or without therapy), an inpatient rehabilitation facility, or a skilled nursing facility. Although clinical guidelines recommend involving patients with stroke in decision-making during discharge planning, informing them about stroke outcomes, and preparing them for post-stroke rehabilitation,^{18,19} no PtDA currently exists for this purpose.

The aim of this study, known as "shared decision-making supported by outcome information for patients with stroke" (SHOUT-STROKE), was to evaluate the effects of a multi-component SDM intervention on decision-making

outcomes, health outcomes, and process outcomes of stroke care. The intervention was developed for hospitalized patients with stroke and included a PtDA with integrated outcome information for discharge planning, a training for health care professionals, and an accompanying implementation strategy.

Methods

The development of the PtDA²⁰ and the study protocol²¹ have been detailed in previously published articles. To optimize usability for patients with stroke and ensure generalizability across clinical settings, the PtDA was designed with consideration for health literacy, clear communication, and accessibility.²⁰ Content was written at a B1 reading level (according to the Common European Framework of Reference for Languages) and received the "easy reading" quality mark from the Dutch foundation "Makkelijk Lezen." The design was user-friendly, and the information was structured in layers, with essential content presented upfront and optional "read more" sections included to prevent information overload. For patients with aphasia, health care professionals received tailored instructions, including strategies such as routinely involving family members. Patient focus group feedback confirmed that the PtDA was widely accessible and useable.²⁰

Setting

The SHOUT-STROKE study was conducted in 7 large stroke centers across various regions of the Netherlands, all of which are members of Santeon, a cooperative association of hospitals committed to improving quality of care through value-based health care principles.²²

Study Design

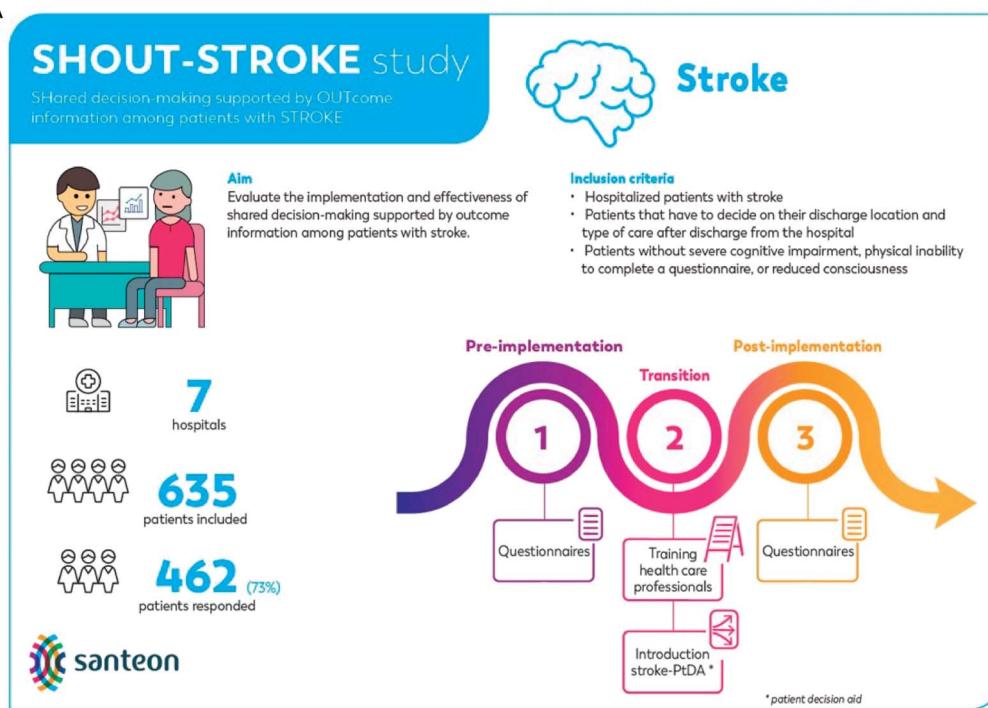
A prospective multiple interrupted time-series (mITS) design was used, comprising 3 phases (Figure 1A):

1. Pre-implementation phase (≥ 6 months): standard care was evaluated;
2. Transition phase (1–2 months): health care professionals were trained in SDM supported by outcome information and instructed on PtDA use in daily practice;
3. Post-implementation phase (≥ 6 months): the new workflow was evaluated.

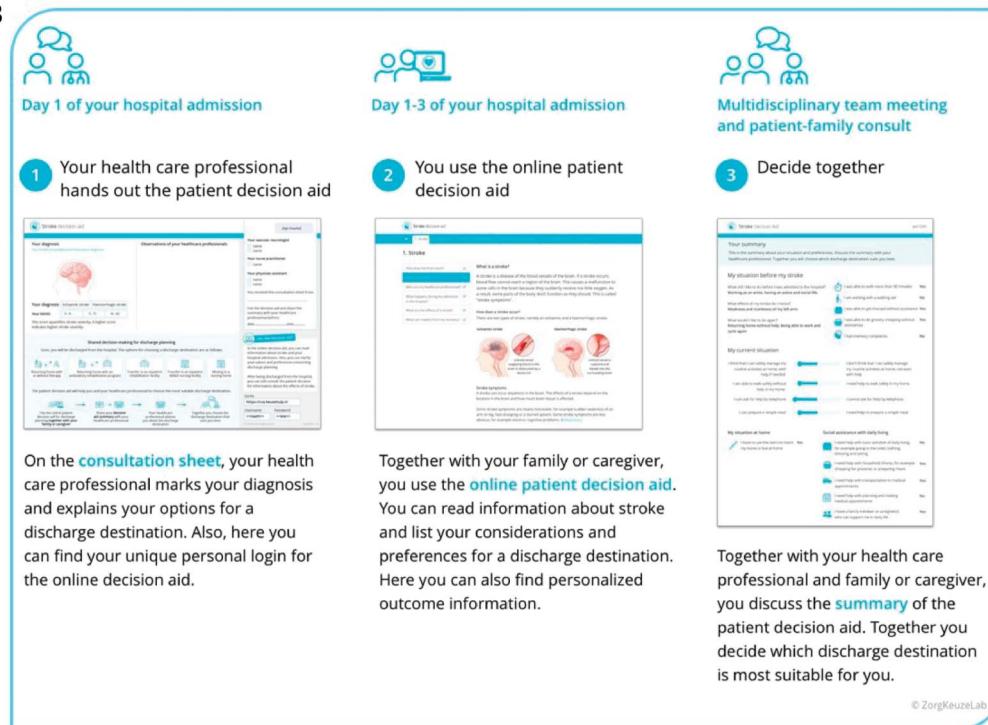
Each hospital transitioned to the post-implementation phase at different times, following the mITS design schedule

Figure 1 Overview of (A) the SHOUT-STROKE Study and (B) the Components and Instructions for Using the Patient Decision Aid

A



B



SHOUT-STROKE = shared decision-making supported by outcome information for patients with stroke.

(details in eAppendix 1). The effects of the intervention were assessed by comparing patient-reported SDM levels and secondary outcome measures between participants in phase 1 and phase 3, both across all hospitals and at the individual

hospital level. The mITS analyses accounted for time trends, between-hospital variation, and autocorrelation of repeated within-hospital measurements. Concurrently, the implementation process was evaluated, focusing on training

attendance, health care professionals' experiences, facilitators and barriers, and recommendations for improvement; these findings have been published separately.²³

Participants and Ethical Approval

Patients with stroke were consecutively included between November 2019 and March 2022 across all participating hospitals during their admission at the stroke unit or the neurology ward if they were older than 18 years, were capable of providing informed consent, and were able to complete a structured survey (either digital or on paper). Patients with ischemic stroke and intracerebral hemorrhage were eligible for inclusion. Patients were excluded from participation if they had insufficient Dutch language proficiency or were unable to complete the survey because of cognitive impairments, global aphasia, or altered consciousness. Patients were asked to participate in the study by their health care professional during the first days of admission and before the options for their discharge destination were discussed. Interested patients received a patient information letter, and all participating patients provided written informed consent. This study was conducted in accordance with local laws and regulations. Ethical and research governance approval was obtained from the Medical Research Ethics Committees United in Nieuwegein, the Netherlands (reference number: W19.154), and the local medical ethics committees of the participating hospitals (reference number: Santeon 2019-075). The SHOUT-STROKE study was registered in the Dutch Clinical Trial Register (NL8375) and automatically listed in the International Clinical Trial Registry Platform (NL-OMON21735). This study was conducted in accordance with the Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0) guidelines.²⁴

Multicomponent SDM Intervention

The multicomponent SDM intervention included the PtDA for discharge planning, training for health care professionals, and an implementation strategy. The PtDA comprises 3 components (Figure 1B and eAppendix 1):

1. A printed consultation sheet to introduce the options for discharge destinations;
2. An online information and deliberation tool with an integrated "patients-like-me" model that presents personalized outcome information based on data from similar patients;
3. A summary sheet to support final decision-making.

The training was offered to the entire stroke care team and included a 1-hour e-learning module on SDM, focusing on the use of personalized outcome information to support SDM. This was followed by a 4-hour group session led by an experienced SDM trainer, featuring SDM theory, skill practice with an actor, and discussions on anticipated challenges. The PtDA implementation strategy, based on previously successful approaches,^{8,21} emphasized fostering awareness, willingness, and behavior change among both health care

professionals and patients to adopt the PtDA. A local ambassador ensured optimal timing and conditions for implementation and provided practical support throughout the post-implementation phase.

Data Collection

Participants received a questionnaire, either digital or on paper, at 2 time points: the first immediately after hospital discharge and the second 3 months later. A visual time line of questionnaire distribution is provided in eAppendix 1. Baseline sociodemographic and clinical characteristics (e.g., stroke type, stroke severity based on the NIH Stroke Scale, and length of stay) were obtained from the patients' electronic health record (EHR) using a standardized electronic case record file. In addition, comorbidity data were obtained from the EHR using the Charlson Comorbidity Index, which is a comorbidity scoring system that includes weighting factors on the basis of disease severity of 16 separate health conditions with a total score ranging from 0 to 37.^{25,26} The modified Rankin Scale (mRS) was used to measure disability due to stroke at 3 months.²⁷ The mRS is a single ordinal 7-point scale ranging from 0 (no symptoms) to 6 (death). It is the most commonly used outcome measure in clinical stroke trials to assess functional outcome (scores of 0–2 indicate good functional outcome; scores of 3–6 indicate poor functional outcome). The mRS scores were retrieved from the EHR, where they were routinely documented for the national quality registry. Patients' health literacy was measured with the 3-item Set of Brief Screening Questions. Total scores range from 3 to 15, with higher scores reflecting more adequate health literacy.²⁸

Outcomes

The primary outcome was the patient-reported level of SDM, measured using the 9-item SDM Questionnaire (SDM-Q-9).^{29,30} Each item represents a step in the SDM process and is rated by patients on a 6-point Likert scale. The total score, ranging from 0 to 45, was converted to a standardized score from 0 to 100, with higher scores indicating greater levels of SDM. Secondary outcomes included other decision-making outcomes, health outcomes, and process outcomes. Table 1 provides an overview of all outcomes, including the instruments, scoring ranges, and score interpretations.

Data Analysis

The sample size was calculated based on the SDM-Q-9, assuming a small-to-moderate effect size (Cohen's $d = 0.3\text{--}0.4$), a significance level of $\alpha = 0.05$, and an intraclass correlation coefficient of 0.05. Power calculations accounted for the stepwise mITS design by incorporating a correlation structure between months, modeled using a linear exponent autoregressive structure; full details are provided in the previously published protocol article.²¹ The baseline demographic and clinical characteristics of participants who completed the primary outcome measure in the pre-implementation and post-implementation phases were compared using the Wilcoxon rank sum test, Pearson χ^2 -squared tests,

Table 1 Overview of All Outcomes

Measure	Description	Scoring	Interpretation
Decision-making outcomes^a			
Patient-reported SDM			
SDM-Q-9^d (primary outcome)^{29,30}	9-item, 6-point scale, measuring different steps in SDM	0–100	Higher scores: higher level of self-reported SDM
CollaboRATE^{d,31}	3-item, 10-point scale, measuring 3 core dimensions of SDM	0–100	Higher scores: higher level of self-reported SDM
Decision-making process			
CPS^{d,32}	2-item, 5-point scale, measuring the patient's role in decision-making	0–4	Higher scores: a more active (preferred or actual) role in decision-making
DCS^{d,33,34}	16-item, 5-point scale, measuring decisional conflict ^e	0–100	Scores ≤25: implementing decisions scores >37.5: delay in decision-making
Knowledge^d (self-composed)	7-item, varying scale, measuring knowledge about stroke	0–7	No. of correct answers are summed; higher scores: greater knowledge
DRS^{d,2,35}	5-item, 5-point scale, measuring decision regret	0–100	Higher scores: greater regret
Health outcomes^b			
Quality of life			
PROMIS-10^{d,36}	10-item, 5-point scale, measuring psychical, mental and social health	T-scores ^g	Higher scores: more of the concepts being measured
EQ-5D-5L^{d,37,38}	5-item, 5-point scale, measuring health-related quality of life on several domains ^f	EuroQol crosswalk index value	Higher index value: better health state
EQ-VAS^{d,37,38}	Visual analogue scale measuring health-related quality of life	0–100	Higher scores: better health state
Participation			
USER-P-R^{39,40}	11-item, 4-point scale, measuring participation restrictions (e.g., work, household, and social interactions)	0–100 ^h	Higher scores: a more favorable level of participation (i.e., fewer restrictions)
Caregiver strain			
CSI⁴¹	13-item, 2-point (y/n) scale, measuring strain of caregivers	0–13	Scores ≥7: high level of caregiver strain
Process outcomes^c			
PtDA usage			
PtDA recipient rate	The percentage of included patients who received the PtDA during their admission		
PtDA user rate	The percentage of PtDA recipients who accessed the PtDA by logging in online		
Patient feedback on PtDA			
PtDA evaluation	7 self-composed items, measuring patients' experiences with the PtDA (eAppendix 1)		

Abbreviations: CPS = Control Preference Scale; CSI = Caregiver Strain Index; DCS = Decisional Conflict Scale; DRS = Decision Regret Scale; EQ-5D-5L = EuroQol 5-Dimensional 5-Level Questionnaire; EQ-VAS = EuroQol Visual Analogue Scale; PROMIS-10 = Patient-Reported Outcomes Measurement Information System 10-Question Global Health Short Form; PtDA = patient decision aid; SDM = shared decision-making; SDM-Q-9 = 9-item SDM Questionnaire; USER-P-R = Utrecht Scale for Evaluation of Rehabilitation-Participation Restrictions.

^a During discharge planning unless otherwise specified.

^b Three months post-stroke.

^c Post-implementation phase.

^d Included in the multiple testing procedure.

^e Based on 3 subscales: uncertainty in choosing options, modifiable factors contributing to uncertainty, and effective decision-making.

^f Health-related quality of life domains include mobility, self-care, daily activities, pain/discomfort, and anxiety/depression.

^g Raw sum scores on physical and mental health items were converted to T scores for analysis; summary scores are based on the US population scoring system. For the remaining 2 items, raw response scores were used for analysis.

^h Based on applicable items.

and Fisher exact tests (according to variable type, sample size, and distribution of data). Multiple testing of primary and secondary outcomes was corrected using a Holm-Bonferroni procedure. Continuous data were expressed as a mean with SD or as the median with interquartile range where appropriate. Categorical data were expressed as frequencies (%) unless stated otherwise. For continuous outcomes, the effect of the interrupted time series in each hospital was estimated using a segmented autoregression analysis (lag = 1) assuming only a change in level. The overall effect across all hospitals was estimated using an inverse-variance meta-analysis. Sensitivity analysis assessed presence of trend (slope) changes (pre-implementation and post-implementation) and alternative lags in the autoregression. Missing data in each interrupted time series could occur either due to no patients included in the corresponding month or by design, as the implementation process was ongoing. The missingness was expected to be intermittent and likely completely at random. Because of this, multiple imputation methods such as last observation carried forward or rolling averages were not considered to improve estimation. Details of the analyses are provided in eAppendix 1. All data were analyzed with IBM SPSS (version 29) and SAS (version 9.4 M8 2023).

Standard Protocol Approvals, Registrations, and Participant Consents

All participating patients provided written informed consent. All personal identifying characteristics have been removed or disguised so that the patients described are not identifiable and cannot be identified through the details in the article. Ethical and research governance approval was obtained from the Dutch Medical Research Ethics Committees United and the local medical ethics committees of the participating hospitals.

Data Availability

The data sets used and/or analyzed during this study are available from the corresponding author on reasonable request.

Results

Of the 635 patients who provided informed consent, 462 (73% response rate) completed the primary outcome measure (SDM-Q-9; Figure 2). No differences were observed in baseline demographic and clinical characteristics between pre-implementation and post-implementation phases (Table 2). All patients were initially diagnosed with intracerebral hemorrhage or ischemic stroke; however, a small number (3% of the total study population) who were initially diagnosed with ischemic stroke were reclassified as having had a TIA 24 hours after the initial diagnosis because of full recovery without reperfusion therapy. These patients were included in the analysis because they had already received the intervention and participated in discharge planning before

diagnostic revision. After 3 months, 426 patients completed the second questionnaire, representing an 8% loss to follow-up. Table 3 provides an overview of participant scores for primary and secondary outcomes in the pre-implementation and post-implementation phases. Segmented autoregression analysis showed no significant overall effects of PtDA implementation over time on decision-making or health outcomes (Table 4).

Decision-Making Outcomes

For the primary outcome, the overall effect of PtDA implementation across all hospitals on SDM-Q-9 scores was -4.5 points (95% CI -11.3 to 2.2) (Table 4). Similarly, no significant effects were observed at the individual hospital level. A forest plot illustrating both overall effect and individual hospital effects on SDM-Q-9 scores is shown in Figure 3A. For the secondary outcome of SDM, the overall effect of PtDA implementation across all hospitals on CollaboRATE scores was -2.1 points (95% CI -8.7 to 4.4) (Table 4). None of the individual hospitals demonstrated a significant effect on CollaboRATE scores after PtDA implementation (eAppendix 2).

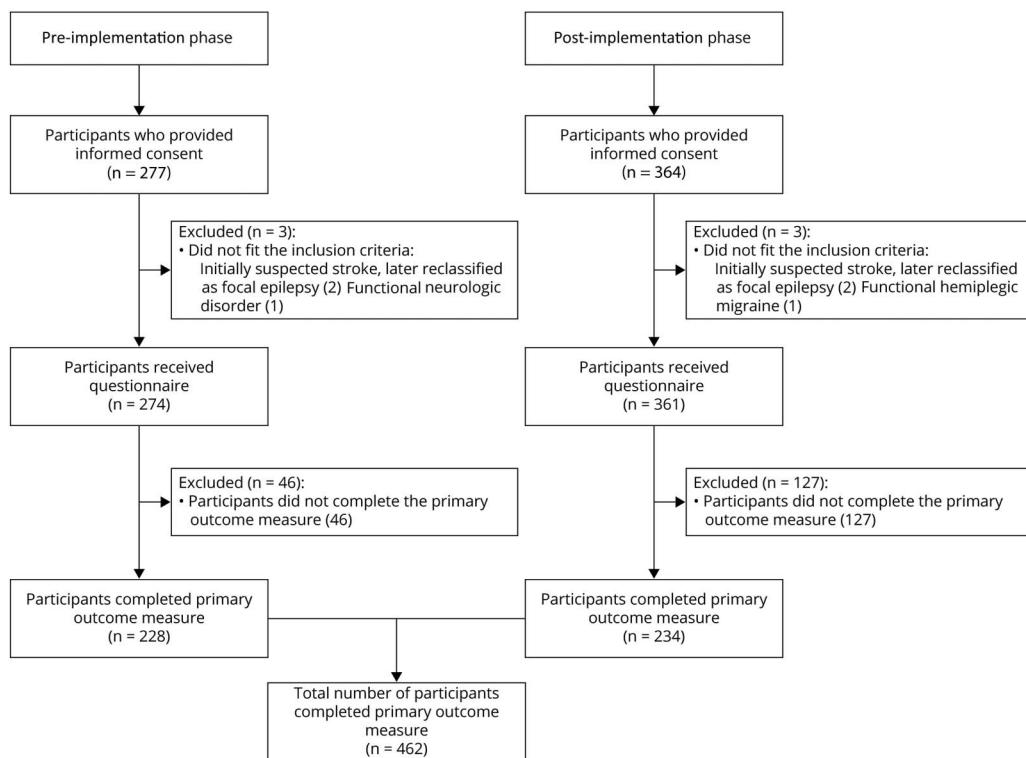
No significant differences were found between the pre-implementation and post-implementation groups across all hospitals in patients' preferred and actual roles in decision-making (Table 4). In 1 hospital (Hospital 7), a significantly higher proportion of patients preferred an active role in decision-making after PtDA implementation, with an effect of 0.65 points (95% CI 0.05 to 1.26) (eAppendix 2). Decisional conflict scores and decision regret scores remained unchanged across all hospitals (Table 4), and none of the individual hospitals demonstrated a significant effect on either outcome after PtDA implementation (eAppendix 2). The overall effect of PtDA implementation on knowledge scores across all hospitals was 0.23 points (95% CI -0.06 to 0.52) (Table 4). In 2 hospitals (Hospitals 4 and 6), patient knowledge improved significantly after PtDA implementation, with effects of 0.85 points (95% CI 0.08 to 1.6) and 0.94 points (95% CI 0.20 to 1.7), respectively (Figure 3B).

For all decision-making outcomes, heterogeneity of the overall effect across hospitals was low (eTable 1).

Health Outcomes

No differences in PROMIS-10 scores were found between the pre-implementation and post-implementation groups across all hospitals. The overall effects were -0.06 points (95% CI -1.2 to 1.1) for the physical health subdomain, 0.01 points (95% CI -1.1 to 1.1) for the mental health subdomain, 0.04 points (95% CI -0.1 to 0.2) for the general health subdomain, and -0.09 points (95% CI -0.3 to 0.1) for the social health subdomain (Table 4). Similarly, no differences were found in EQ-5D-SL and EQ-5D-VAS scores, with overall effects of -0.01 points (95% CI -0.7 to 0.7) and -1.6

Figure 2 Participant Flowchart



points (95% CI –5.7 to 2.5), respectively (Table 4). None of the individual hospitals demonstrated an effect on any of the quality-of-life outcomes after PtDA implementation (eAppendix 2).

The overall effect on participation restriction scores was 3.5 points (95% CI –0.8 to 7.9), and for caregiver strain, the overall effect was 0.1 points (95% CI –1.1 to 1.3) (Table 4). None of the individual hospitals demonstrated an effect on participation restriction or caregiver strain scores (eAppendix 2).

For all health outcomes, heterogeneity of the overall effect across hospitals was low (eTable 1).

Process Outcomes

Of the 234 patients in the post-implementation phase, 137 (59%) received the PtDA. Among these, 55 (40%) used it. Most of the patients (78%) who used the PtDA reported that the online format was appropriate, and 18% preferred a paper-based PtDA, such as a booklet. Half of the patients (51%) considered the amount of information appropriate, and 44% felt that it was much or too much. Most patients found the content of the PtDA comprehensible (91%) and useful (84%) for SDM during discharge planning. The “patients-like-me” information was also considered comprehensible (93%) and useful (82%) for decision-making.

Overall, 82% of the patients indicated that they would recommend the PtDA to other patients (eTable 2).

Missing Data

An overview of data completeness for each hospital is provided in eTable 3, showing the number of months with missing data within the mITS design across the total study period. Missing data resulted from random months without patient inclusion, partly due to COVID-19-related disruptions. These missing months varied across hospitals and study phases, with some hospitals having no missing data and others showing sporadic gaps. Accordingly, a complete case analysis was performed.

Discussion

The SHOUT-STROKE study evaluated the effects of a multicomponent SDM intervention and, to our knowledge, is the first large-scale trial of a PtDA with integrated outcome information for discharge planning of hospitalized patients with stroke. No significant differences in decision-making or health outcomes were observed between patients in the pre-implementation and post-implementation groups across all 7 hospitals. Knowledge scores improved significantly in 2 individual hospitals after PtDA implementation. Patients who used the PtDA reported high satisfaction, with most indicating that they would recommend it to other patients.

Table 2 Baseline Demographic and Clinical Characteristics of Participants

Characteristic	Pre-implementation (n = 228)	Post-implementation (n = 234)	p Value ^a
Age, y—mean (SD)	69.8 (11.9)	69.1 (13.1)	0.57
Female sex	91 (39.9)	88 (37.6)	0.61
Marital status: married/with partner	158 (69.3)	164 (70.1)	0.76
Familial status: with children	159 (69.7)	181 (77.4)	0.15
Education level			0.55
Low	77 (33.8)	71 (30.3)	
Middle	101 (44.3)	117 (50.0)	
High	45 (19.7)	46 (19.7)	
Unknown	5 (2.2)	0 (0)	
Health literacy			0.39
Limited (scores 3–9)	42 (18.4)	50 (21.4)	
Marginal (scores 10–12)	62 (27.2)	65 (27.8)	
Adequate (scores 13–15)	124 (54.4)	119 (50.9)	
Daily activities			0.43
Employed or self-employed	55 (24.1)	61 (26.1)	
Unemployed	0 (0)	2 (0.9)	
Retired	122 (53.5)	131 (56.0)	
Incapacitated for work	7 (3.1)	8 (3.4)	
Volunteering	11 (4.8)	4 (1.7)	
Studying	2 (0.9)	1 (0.4)	
Household, leisure, or other	31 (13.6)	27 (11.5)	
Charlson Comorbidity Index			
Mean score (SD)	4.5 (1.8)	4.2 (2.0)	0.15
Mean % 10-y survival (SD)	41.8 (33.0)	46.3 (34.1)	0.16
Diagnosis			0.06
Ischemic stroke	198 (86.8)	216 (92.3)	
Intracerebral hemorrhage	17 (7.5)	14 (6.0)	
TIA	13 (5.7)	4 (1.7)	
NIHSS score			0.98
Median (IQR)	3 (3)	3 (4)	
Range	0–17	0–18	
Treatment at ED^b			0.44
Intravenous thrombolysis	79 (34.6)	74 (31.6)	
Endovascular thrombectomy	9 (3.9)	5 (2.1)	
None	144 (63.2)	156 (66.7)	

Continued

Table 2 Baseline Demographic and Clinical Characteristics of Participants (continued)

Characteristic	Pre-implementation (n = 228)	Post-implementation (n = 234)	p Value ^a
Prehospital living situation			0.64
Alone	62 (27.2)	59 (25.2)	
Alone with services	14 (6.1)	15 (6.4)	
With partner or family	151 (66.2)	159 (68.0)	
In a nursing home	0 (0)	1 (0.4)	
Missing	1 (0.5)	0 (0)	
Discharge destination			0.09
Home without therapy	70 (30.7)	59 (25.2)	
Home with therapy	54 (23.7)	89 (38.0)	
Home with outpatient rehabilitation	18 (7.9)	24 (10.3)	
Inpatient rehabilitation facility	35 (15.4)	28 (12.0)	
Inpatient skilled nursing facility	47 (20.6)	34 (14.5)	
Nursing home for permanent stay	2 (0.85)	0 (0)	
Other	2 (0.85)	0 (0)	
Length of stay, d			0.33
Median (IQR)	4 (6)	3 (5)	
Range	1–91	1–22	
mRS score after 3 mo			0.08
Median (IQR)	1 (1)	1 (2)	
Range	0–6	0–6	

Abbreviations: ED = emergency department; IQR = interquartile range; mRS = modified Rankin Scale; NIHSS = NIH Stroke Scale.

All data are presented as n (%), unless otherwise specified.

^a Tests performed to compare groups: Student *t* test, Wilcoxon rank sum test, Pearson χ^2 test, and Fisher exact test.

^b Treatment modalities were not mutually exclusive.

Our findings align with previous research in patients with stroke, showing that SDM interventions, such as PtDAs or patient-held booklets, improve patient knowledge.^{42–44} In one of the hospitals where knowledge scores improved significantly, a possible explanation may be the presence of a highly experienced stroke nurse practitioner who plays a central role in coordinating inpatient care and ensuring patient education. Although enhancing patients' knowledge about their disease is essential, it alone is insufficient to empower them to actively participate in SDM. Equally important are fostering patient activation and creating a balanced, supportive consultation environment.⁴⁵ Notably, in both pre-implementation and post-implementation groups, only approximately half of the patients had adequate health literacy. This underscores the importance of designing PtDAs that can support patients with varying literacy levels. Because the PtDA in this study was deliberately designed and co-created with patients, with consideration for health literacy, clear communication, and accessibility,²⁰ we do not

believe that limited health literacy or the format of the PtDA contributed to the neutral study findings.

In contrast to our findings, previous studies reported a significant reduction in decisional conflict after PtDA implementation.^{43,44} A possible explanation is that the median Decisional Conflict Scale scores in both pre-implementation and post-implementation groups were not strongly indicative of decision-making behavior. Specifically, the scores were neither low (≤ 25 , associated with decision implementation) nor high (> 37.5 , associated with delays in decision-making). None of the previous studies on SDM interventions in stroke care assessed SDM levels, participation, or quality of life, limiting direct comparisons. Although our results showed no differences in the assessed health outcomes, general stroke research indicates that post-stroke participation levels predict health-related quality of life,⁴⁶ underscoring the importance of measuring these outcomes in patient-centered stroke care.

Table 3 Participant Scores on Decision-Making and Health Outcomes

	Pre-implementation			Post-implementation		
	N (%)	Mean (SD)	Median (IQR)	N (%)	Mean (SD)	Median (IQR)
Decision-making outcomes^a						
Patient-reported SDM						
SDM-Q-9 (primary outcome)	228	63.6 (29.7)		234	63.2 (27.4)	
CollaboRATE	227		77.8 (35.2)	231		77.8 (40.7)
Decision-making process						
CPS—preferred role	229	2.3 (1.1)		242	2.4 (1.1)	
Active (A)	37 (16)			41 (17)		
Active (B)	54 (24)			64 (27)		
Shared (C)	95 (41)			93 (38)		
Passive (D)	29 (13)			29 (12)		
Passive (E)	14 (6)			15 (6)		
CPS—actual role	229	2.0 (1.2)		242	2.1 (1.2)	
Active (A)	31 (14)			37 (15)		
Active (B)	43 (19)			54 (22)		
Shared (C)	79 (34)			79 (33)		
Passive (D)	39 (17)			41 (17)		
Passive (E)	37 (16)			31 (13)		
Decisional conflict	225		31.3 (26.6)	228		29.7 (25)
Knowledge	225	3.6 (1.8)		228	3.8 (1.6)	
Decision regret^b	214	18.1 (18.6)		213	16.3 (17.6)	
Health outcomes^b						
Quality of life						
PROMIS-10	214			212		
Physical health		43.1 (6.3)			42.8 (5.6)	
Mental health		41.8 (5.3)			41.3 (5.0)	
General health		2.7 (1.0)			2.7 (0.9)	
Social health		2.9 (1.0)			2.8 (1.0)	
EQ-5D-5L (index values)	213	0.76 (0.23)		211	0.75 (0.21)	
EQ-5D-VAS	213	68.2 (19.1)		211	69.3 (19.8)	
Participation						
Participation restrictions	207		83.3 (48.2)	206		85.5 (41.2)
Caregiver strain						
CSI total score	58		5.0 (7.0)	56		6.0 (5.0)
CSI score ≥7	24 (41)		9.5 (4.0)	21 (38)		9.0 (3.5)

Abbreviations: CPS = Control Preference Scale; CSI = Caregiver Strain Index; EQ-5D-5L = EuroQol 5-Dimensional 5-Level Questionnaire; EQ-VAS = EuroQol Visual Analogue Scale; IQR = interquartile range; PROMIS-10 = Patient-Reported Outcomes Measurement Information System 10-Question Global Health Short Form; SDM = shared decision-making; SDM-Q-9 = 9-item SDM Questionnaire.

^a During discharge planning unless otherwise specified.

^b Three months after stroke.

Table 4 Overall Effects Over Time on Decision-Making and Health Outcomes for All Hospitals—Segmented Regression Analysis

	Intervention effect	Standard error	95% CI	p Value
Decision-making outcomes^a				
Patient-reported SDM				
SDM-Q-9 (primary outcome)	-4.5	3.4	-11.3 to 2.2	0.19
CollaboRATE	-2.1	3.4	-8.7 to 4.4	0.52
Decision-making process				
CPS-preferred role	0.19	0.12	-0.06 to 0.43	0.13
CPS-actual role	0.00	0.13	-0.26 to 0.27	0.98
Decisional conflict	0.14	1.67	-3.13 to 3.41	0.93
Knowledge	0.23	0.15	-0.06 to 0.52	0.13
Decisional regret^b	-2.01	1.74	-5.42 to 1.41	0.25
Health outcomes^b				
Quality of life				
PROMIS-10				
Physical health	-0.06	0.59	-1.21 to 1.08	0.91
Mental health	0.01	0.56	-1.09 to 1.11	0.99
General health	0.04	0.09	-0.14 to 0.21	0.66
Social health	-0.09	0.10	-0.28 to 0.10	0.36
EQ-5D-5L	-0.01	0.36	-0.71 to 0.69	0.98
EQ-5D-VAS	-1.61	2.08	-5.69 to 2.48	0.44
Participation				
Participation restrictions	3.54	2.23	-0.82 to 7.91	0.11
Caregiver strain				
CSI total score	0.11	0.62	-1.11 to 1.33	0.86

Abbreviations: CPS = Control Preference Scale; CSI = Caregiver Strain Index; EQ-5D-5L = EuroQol 5-Dimensional 5-Level Questionnaire; EQ-VAS = EuroQol Visual Analogue Scale; PROMIS-10 = Patient-Reported Outcomes Measurement Information System 10-Question Global Health Short Form; SDM = shared decision-making; SDM-Q-9 = 9-item SDM Questionnaire.

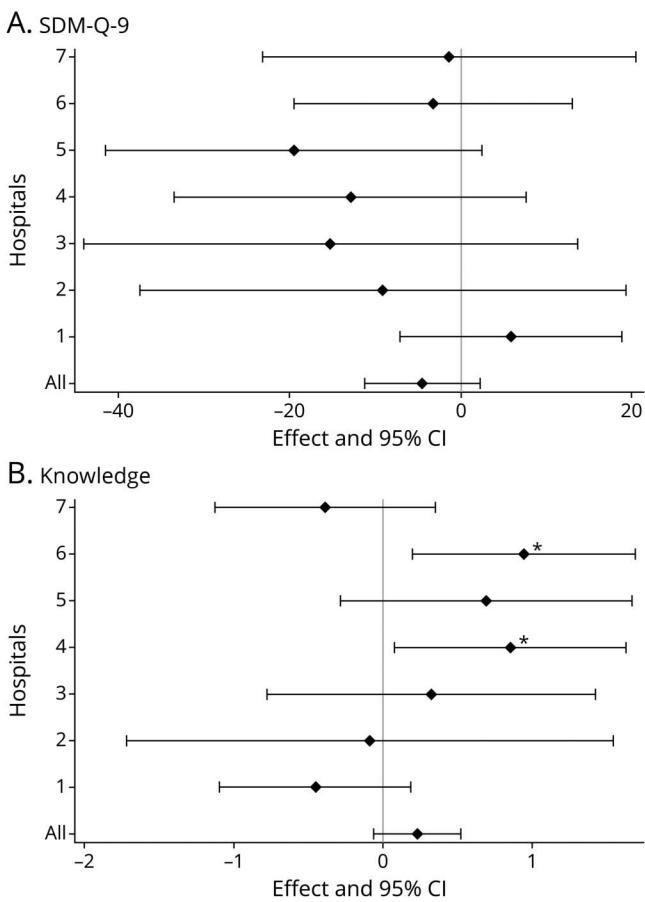
^a During discharge planning unless otherwise specified.

^b Three months after stroke.

The results of our study should be considered within the broader context of PtDA implementation research. Although recommendations for integrating PtDAs into clinical practice have been proposed,⁸ SDM adoption remains limited, often due to time and training constraints among health care professionals.⁴⁷ Evidence suggests that SDM training alone may not sufficiently enhance SDM, as illustrated by a migraine study where SDM-Q-9 and decision conflict scores did not improve after an SDM training for neurologists.⁴⁸ Despite targeting patients (through the PtDA) and health care professionals (through the training), and applying an implementation strategy as recommended by previous research, our SDM intervention did not increase SDM levels. This finding may be attributed to several factors. First, the number of patients who received and used the PtDA was

suboptimal. Although practical training was provided to stroke teams in all hospitals and ongoing support was offered by a local ambassador, further improvements are needed to optimize implementation. In our concurrently conducted process evaluation,²³ we identified facilitators and barriers to PtDA adoption among health care professionals. Key barriers included limited team engagement and insufficient recognition of the PtDA's benefits. To enhance PtDA implementation, a future standardized approach should ensure that the PtDA is offered to all eligible patients, and positive outcomes, such as satisfied and empowered patients, should be emphasized to demonstrate the benefits of the PtDA and SDM. Second, our neutral results might be due to the relatively high baseline SDM-Q-9 and CollaboRATE scores in the pre-implementation group, coupled with the

Figure 3 Forest Plots Illustrating the Individual Hospital Effects (1–7) and Overall Effect (All) of PtDA Implementation on (A) SDM-Q-9 Scores and (B) Knowledge Scores



SDM-Q-9 = 9-item SDM Questionnaire.

known ceiling effects of these measures.⁴⁹ Nevertheless, selecting a measure of SDM as the primary outcome remains appropriate, given that the primary goal of the intervention was to enhance SDM. While previous research has shown that the SDM-Q-9 generally exhibits strong psychometric properties,^{29,30,50} it may lack sensitivity to nuances in the process of SDM. Emerging SDM measures, such as the 16-item iSHARE questionnaire, might better capture the SDM process by assessing both patient and health care professional behaviors, although its validation has been limited to oncologic care.⁵¹ Third, although all patients were consecutively included without selection, selection bias may have influenced questionnaire responses, particularly in the post-implementation phase, as patients with less interest in the PtDA may have been less inclined to complete the questionnaires. Fourth, another potential explanation for our findings is the fragmented nature of decision-making during discharge planning, which extends beyond a single “decision moment.” While our PtDA was provided on the first day of admission, discharge decisions may have been straightforward early on (e.g., for patients recovering rapidly after reperfusion

therapy) or evolved over several days. This variability complicates assessing SDM levels during discharge planning. Similarly, a previous Dutch study involving patients and health care professionals from various disciplines reported low SDM levels because of fragmented decision-making.⁴⁷ Finally, limited time to use the PtDA may also hinder SDM during discharge planning, especially compared with outpatient settings, where patients typically receive a PtDA, reflect on their options at home, and later discuss their preferences to make a shared decision. Nevertheless, patients who used the PtDA provided positive feedback on its format, content, and usability, representing a positive outcome.

Despite the neutral overall study results, we believe that the PtDA provides meaningful value for patients with stroke by supporting SDM and ensuring that decisions align with individual needs and preferences. SDM closely aligns with the principles of value-based health care because it is a core element of patient-centered care, which has been shown to improve patient satisfaction and promote the delivery of appropriate care at the right time and place.⁵² In addition to increasing value for patients, SDM may contribute to more efficient use of health care resources. Given the growing pressure on inpatient hospital care and rehabilitation services, a shift toward more home-based post-stroke rehabilitation is both necessary and desirable. While the PtDA was primarily designed to support patients in preparing for discharge and deciding on the most suitable rehabilitation option, rather than specifically to increase discharge to home, a higher proportion of patients returned home in the post-implementation phase (74% vs 62%). Although this difference was not statistically significant, it suggests potential for cost savings and improved resource utilization. Moreover, among patients discharged home, the proportion receiving any form of rehabilitation increased from 50% to 66% after implementation, indicating that the PtDA may have facilitated more informed discussions about therapy needs—even for patients with minor stroke. These findings highlight the value of structured decision-making support for all patients with stroke, regardless of disability level or discharge destination. To fully assess the impact of SDM interventions, future research should extend beyond process and clinical outcomes to include health care utilization and cost-effectiveness, offering a more comprehensive understanding of their role within value-based stroke care.

A key strength of this study is that it was the first to investigate an SDM intervention in a large, multicenter cohort of patients with stroke across 7 large stroke centers in the Netherlands. It serves as a roadmap for implementing SDM interventions in other hospitals and offers valuable insights to refine future implementation efforts—efforts that have already expanded within the Netherlands, with several non-Santeon hospitals adopting the PtDA. A limitation of this study is that, despite enrolling a large cohort and achieving an overall good overall response rate, the response rate in the post-implementation group was considerably lower than in

TAKE-HOME POINTS

- This multicenter study evaluated shared decision-making (SDM) intervention consisting of a patient decision aids with integrated outcome information, training for health care professionals, and an implementation strategy for discharge planning in hospitalized patients with stroke.
- The SDM intervention was appreciated by patients but did not significantly increase patient-reported SDM levels.
- Knowledge scores improved significantly in 2 hospitals, but no effects were observed on other decision-making outcomes or health outcomes.
- A higher proportion of patients returned home in the post-implementation phase (74% vs 62%), and among these patients, the proportion receiving any form of rehabilitation increased from 50% to 66%, suggesting that the intervention may have facilitated more informed discussions about post-stroke therapy needs.
- Future efforts should focus on empowering patients to participate actively in SDM, contributing to continuous improvements in patient-centered stroke care.

In conclusion, the SDM intervention evaluated in this multicenter study—comprising a PtDA with integrated outcome information, training for health care professionals, and an implementation strategy—was appreciated by patients but did not significantly increase patient-reported SDM levels. Knowledge scores improved significantly in 2 hospitals, but no effects were found on other decision-making and health outcomes. Future implementation studies incorporating emerging SDM outcome measures could identify effective strategies for adopting PtDAs in acute inpatient settings and achieving clinically relevant outcomes. Current and future efforts can empower patients and health care professionals to actively participate in SDM, driving continuous improvements in patient-centered care.

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Author Contributions

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the pre-implementation group, reducing statistical power. This disparity may be attributed to the more extensive post-implementation questionnaire, which included additional questions on PtDA evaluation and may have been more challenging to complete. Post-stroke emotional and cognitive symptoms may have further affected patients' ability to complete the more demanding questionnaire, contributing to the lower response rate in this group. Another limitation is the absence of a formal assessment of patients' decision-making capacity; eligibility was based on clinical judgment. Consequently, we cannot be certain that all participants were fully able to communicate their preferences, which may have influenced the results. Similarly, socioeconomic status was not fully assessed. Although we collected indicators such as education level, occupation, and health literacy, factors such as income and wealth were not included, limiting our ability to examine potential effect modification by socioeconomic status. Furthermore, the COVID-19 pandemic disrupted key aspects of our implementation strategy, such as delivering personal feedback, openly discussing facilitators and barriers, and sharing SDM successes. In addition, frequent turnover of medical staff, particularly among neurology residents and nursing staff, led to ongoing changes within the stroke care team, further complicating the adoption of the new workflow and the development of skills and self-efficacy needed for SDM.

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References

1. Armstrong MJ. Shared decision-making in stroke: an evolving approach to improved patient care. *Stroke Vasc Neurol.* 2017;2:84-87. doi:10.1136/svn-2017-000081
2. Mead G. Shared decision making in older people after severe stroke. *Age Ageing.* 2024;53(2):afae017. doi:10.1093/ageing/afae017
3. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med.* 1997;44(5):681-692. doi:10.1016/s0277-9536(96)00221-3
4. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med.* 2012;27(10):1361-1367. doi:10.1007/s11606-012-2077-6
5. Stiggelbout AM, Van der Weijden T, De Wit MP, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ.* 2012;344:e256. doi:10.1136/bmj.e256
6. Legare F, Adekpedjou R, Stacey D, et al. Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database Syst Rev.* 2018;7:CD006732. doi:10.1002/14651858.CD006732.pub4
7. Abhyankar P, Volk RJ, Blumenthal-Barby J, et al. Balancing the presentation of information and options in patient decision aids: an updated review. *BMC Med Inform Decis Mak.* 2013;13(suppl 2):S6. doi:10.1186/1472-6947-13-S2-S6
8. Joseph-Williams N, Abhyankar P, Boland L, et al. What works in implementing patient decision aids in routine clinical settings? A rapid realist review and update from the international patient decision aid standards collaboration. *Med Decis Making.* 2021;41(7):907-937. doi:10.1177/0272989X20978208
9. Elwyn G, Scholl I, Tietbohl C, et al. Many miles to go: a systematic review of the implementation of patient decision support interventions into routine clinical practice. *BMC Med Inform Decis Mak.* 2013;13(suppl 2):S14. doi:10.1186/1472-6947-13-S2-S14
10. Stacey D, Legare F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2017;4:CD001431. doi:10.1002/14651858.CD001431.pub5
11. Porter ME. What is value in health care? *N Engl J Med.* 2010;363(26):2477-2481. doi:10.1056/NEJMmp1011024
12. Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: concepts, evidence, and practice. *Patient Educ Couns.* 2015;98(10):1172-1179. doi:10.1016/j.pec.2015.06.022
13. Flynn D, Ford GA, Stobart L, Rodgers H, Murtagh MJ, Thomson RG. A review of decision support, risk communication and patient information tools for thrombolytic treatment in acute stroke: lessons for tool developers. *BMC Health Serv Res.* 2013;13:225. doi:10.1186/1472-6963-13-225
14. Decker C, Chhatriwalla E, Gialde E, et al. Patient-centered decision support in acute ischemic stroke: Qualitative study of Patients' and Providers' perspectives. *Circ Cardiovasc Qual Outcomes.* 2015;8(6 suppl 3):S109-S116. doi:10.1161/CIRCOUNTCOMES.115.002003
15. Porat T, Marshall IJ, Sadler E, et al. Collaborative design of a decision aid for stroke survivors with multimorbidity: a qualitative study in the UK engaging key stakeholders. *BMJ Open.* 2019;9(8):e030385. doi:10.1136/bmjopen-2019-030385
16. Jaspers NEM, Ridker PM, Dorresteijn JAN, Visseren FLJ. The prediction of therapy benefit for individual cardiovascular disease prevention: rationale, implications, and implementation. *Curr Opin Lipidol.* 2018;29(6):436-444. doi:10.1097/MOL.0000000000000554
17. Prick JCM, Zonjee VJ, van Schaik SM, et al. Experiences with information provision and preferences for decision making of patients with acute stroke. *Patient Educ Couns.* 2022;105(5):1123-1129. doi:10.1016/j.pec.2021.08.015
18. Powers WJ, Rabinstein AA, Ackerson T, et al. Guidelines for the early management of patients with acute ischemic stroke: 2019 update to the 2018 guidelines for the early management of acute ischemic stroke: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke.* 2019;50(12):e344-e418. doi:10.1161/STR.000000000000211
19. Gittler M, Davis AM. Guidelines for adult stroke rehabilitation and recovery. *JAMA.* 2018;319(8):820-821. doi:10.1001/jama.2017.22036
20. Prick JCM, van Schaik SM, Deijle IA, et al. Development of a patient decision aid for discharge planning of hospitalized patients with stroke. *BMC Neurol.* 2022;22(1):245. doi:10.1186/s12883-022-02679-1
21. Hackert MQN, Ankensmid JW, Engels N, et al. Effectiveness and implementation of SHared decision-making supported by OUTcome information among patients with breast cancer, stroke and advanced kidney disease: SHOUT study protocol of multiple interrupted time series. *BMJ Open.* 2022;12(8):e055324. doi:10.1136/bmjopen-2021-055324
22. Engels N, Bos WJW, de Bruijn A, et al. Santeon's lessons from a decade of implementing value-based health care. *NEJM Catalyst.* 2023;5(1). doi:10.1056/cat.23.0232
23. Prick JCM, Engelhardt EG, Lansink Rotgerink FK, et al. Implementation of a patient decision aid for discharge planning of hospitalized patients with stroke: a process evaluation using a mixed-methods approach. *Patient Educ Couns.* 2025;136:108716. doi:10.1016/j.pec.2025.108716
24. Ogrinc G, Davies L, Goodman D, Batalden P, Davidoff F, Stevens D. SQUIRE 2.0 (standards for QUality improvement reporting excellence): revised publication guidelines from a detailed consensus process. *BMJ Qual Saf.* 2016;25(12):986-992. doi:10.1136/bmjqqs-2015-004411
25. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis.* 1987;40(5):373-383. doi:10.1016/0021-9681(87)90171-8
26. Goldstein LB, Samsa GP, Matchar DB, Horner RD. Charlson index comorbidity adjustment for ischemic stroke outcome studies. *Stroke.* 2004;35(8):1941-1945. doi:10.1161/01.STR.0000135225.80898.1c
27. Quinn TJ, Dawson J, Walters MR, Lees KR. Functional outcome measures in contemporary stroke trials. *Int J Stroke.* 2009;4(3):200-205. doi:10.1111/j.1747-4949.2009.00271.x
28. Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med.* 2008;23(5):S61-S66. doi:10.1007/s11606-008-0520-5
29. Kriston L, Scholl I, Holzel L, Simon D, Loh A, Harter M. The 9-item shared decision making questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Educ Couns.* 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034
30. Rodenburg-Vandenbussche S, Pieterse AH, Kroonenberg PM, et al. Dutch translation and psychometric testing of the 9-item shared decision making questionnaire (SDM-Q-9) and shared decision making questionnaire-physician version (SDM-Q-Doc) in primary and secondary care. *PLoS One.* 2015;10(7):e0132158. doi:10.1371/journal.pone.0132158
31. Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: a fast and frugal patient-reported measure of shared decision making in clinical encounters. *Patient Educ Couns.* 2013;93(1):102-107. doi:10.1016/j.pec.2013.05.009
32. Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res.* 1997;29(3):21-43.
33. O'Connor AM. Validation of a decisional conflict scale. *Med Decis Making.* 1995;15(1):25-30. doi:10.1177/0272989X9501500105
34. Garvelink MM, Boland L, Klein K, et al. Decisional conflict scale use over 20 years: the anniversary review. *Med Decis Making.* 2019;39(4):301-314. doi:10.1177/0272989X19851345
35. Brebaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Med Decis Making.* 2003;23(4):281-292. doi:10.1177/0272989X03256005
36. Hays RD, Björner EB, Revicki DA, Spritzer KL, Celli D. Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Qual Life Res.* 2009;18(7):873-880. doi:10.1007/s11136-009-9496-9
37. Herdman M, Gudex C, Lloyd A, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res.* 2011;20(10):1727-1736. doi:10.1007/s11136-011-9903-x
38. M Versteegh M, M Vermeulen K, M A A Evers S, de Wit GA, Prenger R, A Stolk E. Dutch tariff for the five-level version of EQ-SD. *Value Health.* 2016;19(4):343-352. doi:10.1016/j.jval.2016.01.003
39. Post MW, van der Zee CH, Hennink J, Schafrat CG, Visser-Meily JM, van Berlekom SB. Validity of the utrecht scale for evaluation of rehabilitation-participation. *Disabil Rehabil.* 2012;34(6):478-485. doi:10.3109/09638288.2011.608148
40. van der Zee CH, Visser-Meily JM, Lindeman E, Jaap Kappelle L, Post MW. Participation in the chronic phase of stroke. *Top Stroke Rehabil.* 2013;20(1):52-61. doi:10.1310/tsr2001-52
41. Robinson BC. Validation of a caregiver strain index. *J Gerontol.* 1983;38(3):344-348. doi:10.1093/geronj/38.3.344
42. Ayana M, Pound P, Lampe F, Ebrahim S. Improving stroke patients' care: a patient held record is not enough. *BMC Health Serv Res.* 2001;1:1. doi:10.1186/1472-6963-1-1
43. van Til JA, Drossaert CH, Renzenbrink GJ, et al. Feasibility of web-based decision aids in neurological patients. *J Telemed Telecare.* 2010;16(1):48-52. doi:10.1258/jtt.2009.001012
44. Muehlschlegel S, Goostrey K, Flahive J, Zhang Q, Pach JJ, Hwang DY. Pilot randomized clinical trial of a goals-of-care decision aid for surrogates of patients with

- severe acute brain injury. *Neurology*. 2022;99(14):e1446-e1455. doi:10.1212/WNL.00000000000200937
45. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns*. 2014;94(3):291-309. doi:10.1016/j.pec.2013.10.031
46. Slenders JPL, de Graaf JA, Post MWM, et al. Participation in daily life activities at two months after stroke predicts long-term health-related quality of life. *Top Stroke Rehabil*. 2024;31(1):11-20. doi:10.1080/10749357.2023.2202017
47. Driever EM, Stiggelbout AM, Brand PLP. Shared decision-making in different types of decisions in medical specialist consultations. *J Gen Intern Med*. 2022;37(12):2966-2972. doi:10.1007/s11606-021-07221-6
48. Porta-Etessam J, Santos-Lasaosa S, Rodriguez-Vico J, et al. Evaluating the impact of a training program in shared decision-making for neurologists treating people with migraine. *Neurol Ther*. 2023;12(4):1319-1334. doi:10.1007/s40120-023-00495-4
49. Ubbink DT, van Asbeck EV, Aarts JWM, et al. Comparison of the CollaboRATE and SDM-Q-9 questionnaires to appreciate the patient-reported level of shared decision-making. *Patient Educ Couns*. 2022;105(7):2475-2479. doi:10.1016/j.pec.2022.03.007
50. Gartner FR, Bomhof-Roordink H, Smith IP, Scholl I, Stiggelbout AM, Pieterse AH. The quality of instruments to assess the process of shared decision making: a systematic review. *PLoS One*. 2018;13(2):e0191747. doi:10.1371/journal.pone.0191747
51. Bomhof-Roordink H, Stiggelbout AM, Gartner FR, et al. Patient and physician shared decision-making behaviors in oncology: evidence on adequate measurement properties of the iSHARE questionnaires. *Patient Educ Couns*. 2022;105(5):1089-1100. doi:10.1016/j.pec.2021.08.034
52. Catalyst N. What is patient-centered care? *NEJM Catalyst*. 2017;3.

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