Development of a Poststroke Checklist to Standardize Follow-up Care for Stroke Survivors

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Background: Long-term care for stroke survivors is fragmented and lacks an evidence-based, easy-to-use tool to identify persistent long-term problems among stroke survivors and streamline referral for treatment. We sought to develop a poststroke checklist (PSC) to help health care professionals identify poststroke problems amenable to treatment and subsequent referral. *Methods:* An instrument development team, supported by measurement experts, international stroke experts, and poststroke care stakeholders, was created to develop a long-term PSC. A list of long-term poststroke problem areas was generated by an international, multidisciplinary group of stroke experts, the Global Stroke Community Advisory Panel. Using Delphi methods, a consensus was reached on which problem areas on the list were most important and relevant to include in a PSC. The instrument development team concurrently created the actual checklist, which provided example language about how to ask about poststroke problem areas and linked patient responses to a specific referral process. *Results:* Eleven long-term poststroke problem areas were rated highly and consistently among stroke experts participating in the Delphi process ($n = 12$): secondary prevention, activities of daily living, mobility, spasticity, pain, incontinence, communication, mood, cognition, life after stroke, and relationship with caregiver. These problem areas were included in the long-term PSC. *Conclusions:* The PSC was developed to be a brief and easy-to-use tool, intended to facilitate a standardized approach for health care providers to identify long-term problems in stroke survivors and to facilitate appropriate referrals for treatment. **Key Words:** Stroke—long-term care—stroke rehabilitation—continuity of patient care—assessment of health care needs—referral and consultation—quality of life.
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As the second leading cause of death and one of the leading contributors to adult disability worldwide, stroke poses a significant personal, social, and financial global burden.[1,2] Stroke survivors can experience long-term problems at different points in their recovery, and these will affect their quality of life for up to 5 years poststroke[3,4] and possibly longer.[5] Stroke survivors may experience impairments, such as memory loss,[6] pain,[7] spasticity,[8] fatigue,[9] urinary incontinence,[10,11] cognitive impairment,[12] communication disorders[13], and disability and activity limitations, such as social isolation,[14] emotional change,[15] reduced physical functioning (eg, mobility and performing activities of daily living [ADLs]),[16] and impact on the stroke survivor and caregiver relationship.[17-20] These long-term problems affect a considerable percentage of stroke survivors. One review demonstrated that approximately 33% of stroke survivors did not feel prepared to manage their problems upon discharge from acute-stroke treatment and, over the long term, between 18%-46% experienced social problems and between 19%-62% experienced emotional problems.[3] The impact of these long-term problems are significant and contribute to an overall decrease in quality of life among many stroke survivors.[14,21]

Compounding the long-term problems stroke survivors experience is the fragmentation of the health care delivery system following the acute and subacute phases of stroke treatment.[22] This is unfortunate, as about 50% of stroke survivors report unmet needs (eg, incontinence, emotional problems, mobility, pain, and speaking problems). Patients likely seeing health care providers for long-term problems also regularly report unmet needs.[23] Despite the perceived need for rehabilitation after discharge, many stroke survivors will not receive a rehabilitation review or additional therapeutic contact.[3]

The prevalence of long-term poststroke problems, often unidentified or untreated although potentially amenable to effective interventions, and the common fragmentation of health care systems[22] indicate a need for a comprehensive stroke strategy to facilitate long-term management for stroke survivors. In the United Kingdom, the National Stroke Strategy recommends that clinical assessments be carried out 6 and 12 months poststroke and annually thereafter.[24] The Australian stroke guidelines recommend that stroke survivors have regular and ongoing review by a member of a stroke team, including at least 1 specialist medical review, with an initial review within 3 months, and again at 6 and 12 months postdischarge.[25] In the United States, primary care physicians have 140 quality care indicators covering general aspects of poststroke management, although most are not implemented into clinical practice.[26] The World Health Organization has also called for research into the barriers and opportunities for providing poststroke management in low- and middle-income regions in the world.[27] Despite these strategies, guidelines, and recommendations, there is a lack of systems and tools that can enable health care providers to actively identify opportunities for intervention and manage referral to appropriate services. The practice of long-term care for stroke survivors lacks an evidence-based and easy-to-use tool that can both identify long-term problems among stroke survivors and facilitate their referral from primary/community-based care to appropriate specialist management. The development, adoption, and implementation of such a tool can help fulfill the promise of an improved research effort into understanding long-term stroke problems and help meet the long-term health needs of stroke survivors.

This paper describes the development of the poststroke checklist (PSC), designed to be an easy-to-use tool to assist health care professionals in identifying treatable poststroke problems and facilitate referral for care. The goal in developing the PSC is to improve the standard of long-term management provided to stroke survivors, and to improve their quality of life.

Methods

Consistent with good instrument development practices,[28,29] the PSC was developed with the following principles in mind: (1) to be simple and easy to use by health care professionals in primary care settings at 6 and 12 months poststroke and annually thereafter; (2) to focus on problem areas where evidence-based data support the effectiveness of interventions to improve outcomes; and (3) to focus on areas where an intervention has the largest impact on a stroke survivor's quality of life. Consistent with these principles, the PSC was developed over the course of 4 steps (detailed below) and tailored in preparation for an initial pilot within the United Kingdom health care system.

Step 1: Specifying Long-Term Poststroke Problems

The first step in developing the PSC was to create an all-inclusive list of long-term poststroke problems. The rationale for generating this initial list was to ensure that all facets of stroke recovery were considered for inclusion in the final PSC. This list was generated by an international and multidisciplinary group of experts, the Global Stroke Community Advisory Panel (GSCAP), and then cross-referenced with the International Classification of Functioning, Disability, and Health.[30] GSCAP consists of 21 stroke experts and represents 9 countries: Australia (n = 2), Austria (n = 1), Canada (n = 1), France (n = 1), Germany (n = 2), Singapore (n = 1), Sweden (n = 2), the United Kingdom (n = 3), and the United States (n = 8). The 6 specialty areas represented were stroke neurology (n = 9), neurorehabilitation (n = 4), physical medicine and rehabilitation (n = 5), and 1 each from occupational therapy, physical therapy, and care of the elderly.

Step 2: Constructing a Draft PSC

Once the list of long-term poststroke problems was specified under the direction of GSCAP (step 1), a set of instructions, problem areas, and response areas was constructed. The goal of this activity was to create a preliminary instrument. The content of this instrument was confirmed in step 3, and finalized into the PSC in step 4. The instrument development team included a subset of GSCAP experts from the United Kingdom (n = 3) and Germany (n = 1) chosen to represent the larger GSCAP. Representatives from stakeholder groups involved in poststroke care in the United Kingdom, including primary and secondary care physicians, allied health professionals, community nurses, and representatives of stroke survivors, were also included in the draft instrument development process.

Step 3: Delphi Method to Achieve Expert Consensus on Poststroke Problem Areas

Similar to previous studies that required expert consensus on stroke treatment issues, a modified Delphi method was employed.[31,32] The Delphi method characterizes a set of structured communication techniques to facilitate consensus of opinion among experts on a prespecified content area through a series of questionnaires combined with controlled feedback.[33] During each round of activity, information is collected from experts anonymously by a Delphi moderator and returned to the panelists for comment. This process continues until a convergence of opinion is reached, typically after 2 rounds.[17,34,35] Here, the Delphi method was used to achieve consensus among an international group of stroke experts regarding which long-term poststroke problems (identified in step 1) have the greatest impact on a survivor's quality of life and where evidence-based interventions exist to address these problems. It is important to note that the goal was not to evaluate the draft checklist (as developed in step 2), but rather to achieve consensus as to what the instrument should target for assessment. Between November 2010 and January 2011, there were 2 rounds of controlled communication and feedback between the expert panelists (n = 12) and a moderator. An independent health outcomes research organization (Adelphi Values, Boston, MA) served as the Delphi moderator, whose role was to facilitate communication and collect, aggregate, and summarize the data.

Delphi Panel

The Delphi panel consisted of 12 medical experts from 7 countries: Australia (n = 1), Austria (n = 1), Germany (n = 1), Singapore (n = 1), Sweden (n = 2), the United Kingdom (n = 3), and the United States (n = 3). Areas of specialty for the group included stroke neurology, rehabilitation medicine, stroke rehabilitation, physical medicine and rehabilitation, and geriatric medicine. On average, the panelists had been practicing medicine for approximately 29 years (range = 16-40) and managing poststroke patients for 25 years (range = 16-34). Expert panelists did not communicate with each other; to remove potential bias, they communicated only with the moderator.

Round 1

Delphi participants were mailed a questionnaire asking them to consider the list of long-term poststroke problems developed in step 1 with respect to: (1) those that have the greatest impact on a survivor's quality of life, and (2) those for which evidence-based interventions exist to improve outcomes. The endorsed poststroke problems were then ranked by panelists based on level of importance (ie, 1 = most important, 2 = second most important). Finally, panelists were asked to list stroke-related problems not captured by the current list that they considered relevant for inclusion in a long-term PSC. Panelists mailed completed questionnaires to the moderator.

Round 2

Delphi participants were mailed a second questionnaire. Similar to round 1, they were asked to rank from the previously agreed upon list of long-term poststroke problems that have the greatest impact on a survivor's quality of life and for which evidence-based interventions exist to improve outcomes. Panelists were also provided a summary of the round 1 results and encouraged to change their earlier answers if replies from other members of the panel compelled them to do so. Panelists were also given a new set of long-term poststroke problems to consider (not on the original list, but generated during round 1) and asked if any were important enough to add to a PSC (4-point scale of importance: 1 = not at all, 2 = slightly, 3 = moderately, and 4 = very). Panelists mailed completed questionnaires to the moderator.

Step 4: Finalizing the PSC

In finalizing the PSC, it was determined a priori that problems would only be deleted from the draft checklist if fewer than 25% of the Delphi panelists suggested including the problem. The rationale for this cut point was to ensure adequate coverage of important problems in the PSC. If a long-term poststroke problem was added to the list in round 1, and in round 2 at least 50% of panelists rated the problem as moderately important or very important, this problem was considered for inclusion in the PSC.

Results

Step 1: Specifying Long-Term Poststroke Problems

As a first step in developing the PSC, the multidisciplinary GSCAP generated a list of poststroke problems

Table 1. *Preliminary list of poststroke problems*

Mobility	Mood	Financial needs	Referral possibilities
Activities of daily living	Communication	Risk factor assessment	Cognition
Spasticity	Hearing	Rehabilitation needs	Stroke recurrence
New pain	Getting around	Looking after self	Social participation
Continence	Sleep disturbance	Driving	Education
Seeing	Satisfaction	Tissue viability	Safety and relationships
Hearing	Temperature perception	Nutrition/swallowing	Mental health
Emotional state	Accommodation	Epilepsy	Staying healthy

that could be considered for inclusion in a PSC. This list is provided in Table 1.

Step 2: Constructing a Draft PSC

Select GSCAP members and representatives from key stakeholder groups developed a draft PSC. The draft checklist included a set of instructions and questions about the long-term poststroke problem areas identified by GSCAP in step 1 (Table 1). The draft checklist specified the appropriate referral sequence dependent upon patient response to questions and the problem areas. Several draft versions of the checklist were developed to accommodate formatting suggestions and improve readability and usability, cross-checked in terms of content coverage in step 3, and finalized into the PSC in step 4.

Step 3: Delphi Method to Achieve Expert Consensus on Poststroke Problem Areas

Round 1

Feedback was received from all of the Delphi panelists (n = 12), and results of the panel ratings for poststroke problem areas are summarized in Table 2. Panelists reported the poststroke problems considered relevant for a long-term PSC and ranked each area by how important they considered it to be for stroke survivors. The following problems had the highest average ranking across panelists (lower numbers indicate greater relative importance of the problem area): ADLs (2.0), secondary prevention (3.2), mobility (4.3), mood (6.3), pain (7.2), communication/speech (7.4), social participation (7.6), and cognition (7.9).

Although each panelist had the opportunity to include stroke-related problems not included in the list they were asked to consider, few were suggested. Three panelists (25%) suggested including sexual functioning, and at least 1 panelist included life after stroke; oral/dental hygiene; lifestyle and smoking habits; accessibility for the disabled; interpersonal relationships with spouse, family, and friends; psychosocial support; body image/disfigurement; and caregiver concerns.

Round 2

Feedback was received from 11 of the Delphi panelists, and results are summarized in Table 2. Similar to round 1, the poststroke problem areas given the highest average importance rankings were (in descending order): ADLs (1.6), secondary prevention (3.5), mobility (3.6), mood (5.9), cognition (6.5), communication/speech (6.8), social participation (7.4), and pain (7.5).

Of the poststroke problem areas not included in the prespecified list but suggested by panelists during round 1, sexual functioning and caregiver concerns were each endorsed as relevant (ie, ranked as slightly, moderately, or very important to include) for inclusion in a PSC by 8 panelists (72.7%) in round 2. Additionally, 7 (63.6%), 6 (54.5%), and 6 (54.5%) panelists endorsed interpersonal relationships, physical activity, and oral/dental hygiene, respectively, as relevant poststroke problems. Finally, 4 panelists (36.4%) endorsed including body image/disfigurement, and 3 panelists (27.3%) endorsed accessibility for the disabled as a relevant poststroke problem.

Step 4: Finalizing the PSC

A consensus emerged that the initial list of poststroke problem areas could be reduced to a core set of 11 for the final PSC (Fig 1; currently adapted for use in the United Kingdom). The problem areas of secondary prevention (item 1), ADLs (item 2), and mobility (item 3) were included in the final PSC, as they were endorsed as important by virtually all panelists in round 1 and by all panelists in round 2. Each of these areas was ranked very high in importance (eg, in the top 5 by at least 70% of the panelists). Pain (item 5), communication (item 7), mood (item 8), and social participation (item 10; included as "life after stroke" in the final PSC) were endorsed as relevant poststroke problem areas by virtually all panelists in rounds 1 and 2 and, therefore, selected for inclusion in the final PSC. Spasticity (item 4), continence (item 6; included as incontinence in the final PSC), and cognition (item 9) had a relatively high average importance rating and were endorsed as relevant poststroke problems by all but 1 panelist in rounds 1 and 2, so were included in the final PSC. One additional problem, relationship with caregiver (item 11), was added to the final PSC due to 50% of Delphi panelists considering it important to add. Two problem areas identified as important by panelists, physical activity and sexual function, were not included in the final PSC due to their conceptual overlap with problem areas already assessed by the instrument.

Table 2. *Delphi panel ratings for prespecified poststroke problem areas*

	No. of times endorsed as relevant*		Average ranking†		No. of times ranked in top 5‡		No. of times ranked in bottom 5§		Rank range‖	
Poststroke problems	Round 1¶	Round 2#	Round 1¶	Round 2#	Round 1¶	Round 2#	Round. 1¶	Round 2#	Round 1¶	Round 2#
Activities of daily living	12	11	2.0	1.6	12	11	0	0	1-6	1-4
Secondary prevention	11	11	3.2	3.5	10	9	0	0	1-8	1-8
Mobility	12	11	4.3	3.6	10	9	1	1	1-12	1-8
Mood	12	11	6.3	5.9	7	8	2	2	1-14	1-14
Pain	11	11	7.2	7.5	2	2	0	2	1-12	1-12
Communication/speech	12	11	7.4	6.8	4	4	2	3	3-14	3-11
Social participation/empowerment–ability to do what is important to you	11	11	7.6	7.4	4	3	3	3	3-21	4-13
Cognition	12	10	7.9	6.5	3	4	4	2	2-16	2-13
Spasticity	11	10	9.1	9.2	2	1	2	2	3-16	4-13
Continence	11	10	9.6	10.2	2	1	3	3	2-19	4-19
Swallowing	11	10	10.5	10.7	1	1	4	3	3-17	3-17
Nutrition	8	7	11.0	10.9	0	0	1	1	8-13	8-13
Sleep (disturbance)	7	7	12.1	12.6	0	0	3	2	9-15	9-15
Tissue viability (including skin, sores, pressure ulcers)	7	7	12.6	14.1	1	1	5	4	2-20	2-22
Epilepsy	6	7	12.8	15.6	0	0	3	3	7-17	10-20
Seeing (change poststroke)	4	5	13.3	13.4	0	0	1	1	11-15	11-16
Education/information–did you receive and do you need any more?	9	7	13.3	15.9	0	0	6	5	6-18	11-21
Driving	8	6	13.8	15.7	0	0	4	3	6-19	10-19
Hearing (change in poststroke)	1	3	14.0	18.3	0	0	0	2	14	14-22
Concern about current medications (including side effects)	6	6	14.2	16.8	1	0	3	4	4-21	12-21
Abnormal sensation (eg, abnormal temperature, pins and needles, not knowing where limbs are)	4	5	15.8	16.8	0	0	2	4	10-20	12-12
Waiting for disability/rehabilitation equipment	5	6	16.6	16.2	1	1	4	4	3-22	3-22

*Delphi panelists considered a set of poststroke problem areas and reported which were relevant to include in poststroke checklist (in this case, relevance was described as those problem areas that have greatest impact on survivors quality of life and those for which evidence-based interventions exist to improve outcomes).

†Delphi panelists ranked poststroke problem areas in terms of level of importance to them (in this case, 1 indicates area that is most important to you and other problems were ranked in ascending order). This is average ranking across panelists for each Delphi round.

‡Number of times problem area was ranked among top 5 most important poststroke problem areas to include on poststroke checklist.

§Number of times problem area was ranked among bottom 5 most important poststroke problem areas to include on poststroke checklist.

‖Importance ranking range for each poststroke problem area (eg, activities of daily living was never ranked below sixth and fourth most important poststroke problem area in rounds 1 and 2, respectively).

¶Results from round 1 of Delphi method (n = 12).

#Results from round 2 of Delphi method (n = 11).

Question	Response	Action	
1. Secondary Prevention			
Since your stroke or last assessment, have you seen anyone regarding advice on changes to lifestyle or medications for preventing another stroke?	☐ No →		☐ If No, refer to Primary Care Team for risk factor assessment and treatment if appropriate
	☐ Yes →		Observe Progress
2. Activities of Daily Living (ADL)			
Since your stroke or last assessment, are you finding it more difficult to take care of yourself?	☐ No →		Observe Progress
	☐ Yes →	Do you have difficulty dressing, washing and/or bathing? Do you have difficulty preparing hot drinks and/or meals? Do you have difficulty getting outside?	☐ If Yes to any, refer to the Community Stroke Team or an appropriate therapist (ie, OT or PT) for further assessment
3. Mobility			
Since your stroke or last assessment, are you finding it more difficult to walk or move safely from bed to chair?	☐ No →		Observe Progress
	☐ Yes →	Are you continuing to receive rehabilitation therapy?	☐ If No, refer to the Community Stroke Team for further assessment ☐ If Yes, update patient record and review at next assessment
4. Spasticity			
Since your stroke or last assessment, do you have increasing stiffness in your arms, hands, and/or legs?	☐ No →		Observe Progress
	☐ Yes →	Is this interfering with activities of daily living?	☐ If No, update patient record and review at next assessment ☐ If Yes, refer to a physician with an interest in post-stroke spasticity for further assessment
5. Pain			
Since your stroke or last assessment, do you have any new pain?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer to a physician with an interest in post-stroke pain for further assessment and diagnosis
6. Incontinence			
Since your stroke or last assessment, are you having more of a problem controlling your bladder or bowels?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer to Community Continence Adviser or equivalent for further assessment
7. Communication			
Since your stroke or last assessment, are you finding it more difficult to communicate with others?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer to specialist Speech and Language Therapist for further assessment
8. Mood			
Since your stroke or last assessment, do you feel more anxious or depressed?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer to Primary Care Clinician with an interest in post-stroke mood changes for further assessment
9. Cognition			
Since your stroke or last assessment, are you finding it more difficult to think, concentrate, or remember things?	☐ No →		Observe Progress
	☐ Yes →	Does this interfere with activity or participation?	☐ If No, update patient record and review at next assessment ☐ If Yes, refer to a clinician with an interest in post-stroke cognition changes for further assessment
10. Life After Stroke			
Since your stroke or last assessment, are you finding things important to you more difficult to carry out (eg, leisure activities, hobbies, work, relationships with loved ones)?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer patient to a stroke support organisation (eg, The Stroke Association)
11. Relationship with Family			
Since your stroke or last assessment, has your personal relationship with your family become more difficult or stressed?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, schedule next Primary Care visit with patient and family member. Or if family member is present refer carer to a stroke support organisation (e.g. The Stroke Association)

Figure 1. *Poststroke checklist: improving life after stroke.*

With the poststroke problem areas selected based on expert consensus, the PSC was finalized. Based on instructions, items, and response options crafted earlier in the instrument development process (step 2), the instrument development team produced a final PSC that included prompts for treatment referral in the United Kingdom (Fig 1). Referrals are initiated based on the emergence of new or increasing problems in any of the

11 areas prioritized by the Delphi panelists. For some problem areas, subsidiary questions were added to support efficient referral.

Discussion

The PSC assesses 11 long-term problem areas experienced by stroke survivors, provides example language to ask about the specified poststroke problem area, and links patient response to a specific referral (eg, primary care physician, community continence adviser, and speech language therapist). The 11 long-term poststroke problem areas assessed by the PSC are secondary prevention, ADLs, mobility, spasticity, pain, incontinence, communication, mood, cognition, life after stroke, and relationship with caregiver. The PSC was not designed to cover every possible poststroke problem, but rather target those areas that have the greatest impact on patient quality of life and are treatable through evidence-based interventions. For this reason, an original, more comprehensive list of 22 poststroke problem areas, informed by the literature and generated by an international and multidisciplinary group of stroke experts (GSCAP), was filtered through a Delphi panel of stroke experts ($n = 12$) to achieve consensus on the shorter list of problem areas assessed by the PSC.

To date, the majority of stroke research has targeted acute care, and this has greatly improved short-term stroke outcomes.[36-38] However, a variety of international efforts have identified the need for a better understanding of longer-term stroke problems in both research and practice in order to improve long-term care provided to stroke patients.[10,25-27] To better understand the long-term problems associated with stroke and improve outcomes for stroke survivors, there is a need for a tool that can both standardize the assessment of these problems and facilitate referral for appropriate care. The PSC was developed to fill this gap. Designed with the intention of being brief and an easy-to-use tool, the PSC may help health providers identify long-term problems among stroke survivors and facilitate referrals for treatment.

The PSC provides a clear focus for review of long-term management after stroke that can be readily incorporated into follow-up systems. The suggested referral prompts were developed for use in the United Kingdom and may require modification for different patterns of services available to people following stroke in other countries. Work is under way to evaluate use of the checklist in the United States, Canada, and Singapore with modified referral prompts. In all countries, the 11 problem areas are unaltered. Minor textual modifications have been made to questions 1 and 11 of the PSC to improve patient understanding based on initial findings from the United Kingdom and Singapore pilots. The primary aims of the pilot studies are to evaluate the usefulness of the PSC to health providers, assess the impact of the PSC on clinic visits, and determine whether outcomes for stroke survivors are improved. Although the current focus of the PSC is for use in the primary care setting, it could be used by specialist stroke practitioners or rehabilitation health providers, among others. Widespread use of the PSC would help standardize long-term stroke management, and health providers and researchers in other regions and countries are encouraged to test its usefulness and how its use impacts clinical practice and stroke survivor outcomes.

There are limitations to the present work. First, the PSC was developed based on input from clinicians and other stroke experts, and it may be the case that stroke survivors would have identified different poststroke problem areas for inclusion. However, the literature, which is based on patient experiences, describes many of the same poststroke problem areas targeted by the PSC, and this includes many of those specified in the International Classification of Functioning, Disability, and Health, which informed its development. Second, results and conclusions are dependent on the size and experience of the Delphi panel. Current methods included 12 panelists, and it is possible that if the size of the panel were increased, different results would be obtained. This is unlikely since the consistency in the responses between the 2 rounds suggests broad agreement among the panelists on the core areas of concern, which is consistent with those commonly identified in the literature.[3,4]

Significant long-term problems occur poststroke and impact patients' lives for many years.[5] Because long-term problems associated with stroke decrease quality of life among stroke survivors,[14,21] it becomes critical for health care providers to have tools to both identify those problem areas and specify a referral plan. The PSC, as described in this report, was designed as a brief, easy-to-use, and standardized tool to help health providers identify long-term problems in their poststroke patients and to facilitate appropriate referrals for treatment. Our goal in developing the PSC is to improve the standard of care for stroke survivors and improve their quality of life.

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