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The long term consequences of stroke

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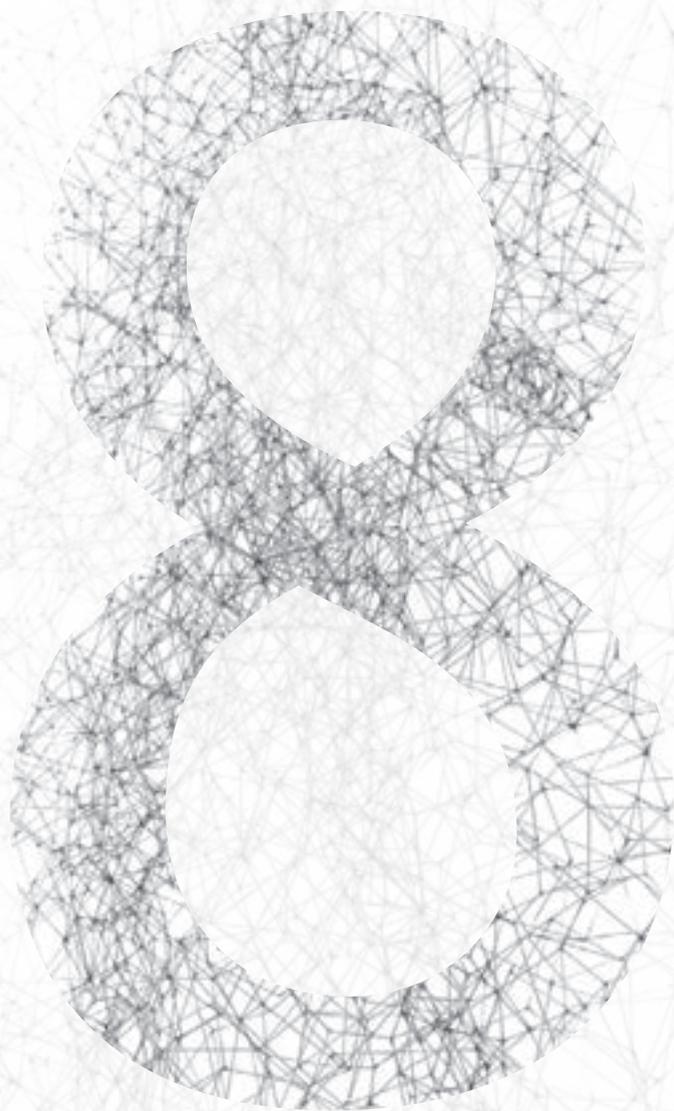


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Chapter 8

Primary care networks for the management of stroke patients

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Abstract

Aim: Most stroke patients are in need of care after initial hospitalization. Primary care stroke networks (PCSN) are set up to ensure the quality and accessibility of a continuum of health services. This study aimed to describe the structure and processes of PCSN in the Netherlands and formulate recommendations for their optimal organization and further development.

Methods: PCSN were defined as collaborations of primary health care providers with formal agreements on cooperation and/or the content of care for stroke patients. By searching the internet, contacting health care institutions, professional organizations and opinion leaders in stroke care, PCSN in the Netherlands were identified. By means of structured telephone interviews and online questionnaires information on the structure and processes of the PCSN was systematically gathered from their coordinators and members. During an invitational conference with relevant stakeholders, results were discussed, and recommendations were formulated.

Results: Fifteen PCSN met the definition, with their size varying from 4-140 members. Most members were physical therapists; 12 networks were multidisciplinary. 14 networks had membership entry criteria and 8 imposed a membership fee. Collaborations were reported with hospital and/or rehabilitation centers (n=14); the regional coordinator of a stroke chain of care (n=10); patients or patient association (n=8); and/or the general practitioner (n=7). Standardized treatment programs and/or measurements were used by 9 PCSN. 139 network members (response 25,5%) from 15 networks completed the online survey. Last year, 60 of 126 (48%) had had postgraduate education on stroke, 87 of 97 (90%) had taken part in network meetings and 71 of 91 (78%) had seen more than 5 stroke patients. Time and money were most frequently mentioned as barriers for continuation. Mutual trust, commitment and direct lines of communication were mentioned as success factors. During an invitational conference, a set of recommendations for the future organization and development of PCSN were formulated; the need for a national, centralized approach being a consistent advice.

Conclusion: Large variation was observed in the structure and processes of 15 PCSN in the Netherlands. A national, centralized approach towards their organization and further development was advocated.

Introduction

Every year around 45,000 people in the Netherlands suffer from a first cerebrovascular accident or stroke.¹ The prevalence of stroke patients in the community is 315,000 in the Netherlands (2% of the population).² The death rate with respect to stroke is decreasing considerably, which leads to an increasing prevalence.³ In the United States of America, 56% of stroke patients were discharged to their homes after hospitalization in 2011; 44% were discharged to inpatient rehabilitation or skilled nursing facilities of whom a majority returned to their homes as well after rehabilitation.³ This pattern is comparable to the Netherlands.⁴

Recent literature shows that community dwelling stroke survivors do not always receive an optimal amount and type of care,⁵ which may lead to unmet needs^{6,7} and unnecessary restrictions in activities and participation.⁸ These problems could be overcome by implementing well-organized networks of health professionals in primary care, with the common goal of improving the quality and continuity of care and enhancing communication between primary health care providers.⁹ Working in networks may lead to better implementation of guideline recommendations, fewer healthcare costs, a higher treatment volume and better multidisciplinary collaboration around the patient.¹⁰ On the other hand, a Cochrane review showed there is not sufficient evidence to draw clear conclusions on the effects of interprofessional collaboration interventions.¹¹ In a systematic review, nine randomized controlled trials on interventions by stroke support workers, care coordinators or case managers were identified. The methodological quality of the studies was variable. Patients and caregivers receiving formal primary care-based follow-up did not show gains in physical function, mood, or quality of life when compared with those who did not. Patients and caregivers receiving follow-up were generally more satisfied with aspects of communication, and had a greater knowledge of stroke.¹² A randomized controlled trial in the UK concerning a new post-discharge system of care comprising a structured assessment covering longer-term problems experienced by patients with stroke and their carers, demonstrated no benefit in clinical or cost-effectiveness outcomes associated with the new system of care compared with usual practice.¹³

Knowledge in this respect is still developing. Currently, a review is being carried out to construct hypotheses for the development of a primary care model which aims to provide sustainable long-term support for stroke survivors and informal carers in the community.¹⁴ Another systematic review protocol has been developed regarding the impact of quality

improvement strategies on quality of life as well as physical and psychological well-being of individuals with stroke.¹⁵

In the Netherlands, primary care networks have been established for several other chronic conditions such as rheumatic and musculoskeletal conditions, Parkinson's disease or peripheral arterial disease resulting in increasing expertise, better communication and higher patient satisfaction.¹⁶⁻²⁰ Over the past years, primary care stroke networks (PCSN) have also been formed in several regions in the Netherlands. However, insight into their number and organizational features is lacking.

The aim of this project is to obtain an overview of the PCSN in the Netherlands and describe the structure and processes. Moreover, an inventory of barriers and facilitators for their continuation is made, and recommendations for their optimal organization and further development are formulated.

Methods

This study was carried out between June 2016 and September 2017. It concerned an online survey among network coordinators and members, and an invitational conference with relevant stakeholders. Because patient data were not involved the study fell outside the remit of the Medical Research Involving Human Subjects Act. All data of coordinators and members were processed anonymously.

The triad of structure, process, and outcome was used to evaluate the quality of PCNS.²¹ In this concept "structure" is defined as the settings, qualifications of providers, and administrative systems through which care takes place; "process" as the components of care delivered; and "outcome" as recovery, restoration of function, and survival. These concepts remain the foundation of quality assessment and are used to describe the characteristics of a PCN in a formal way.²²

Identification of existing networks

The following definition of a network was used: "Any collaboration of health care providers (either or not with the same professional background and not only comprising general practitioners and / or home care) in primary health care, with formal agreements about

cooperation and / or the content of care provision to people with stroke.” The network could be focused on other patient groups as well (e.g. brain injury) but their dedication to stroke had to be explicitly formulated.

Networks were identified and approached between June 2016 and September 2017, using various methods. First, information was obtained from the Knowledge Network for Stroke (www.CVAkennisnetwerk.nl), of the Working group for Stroke the Netherlands (WCN, part of Netherlands Society of Rehabilitation Medicine), the Dutch Society for Neurology and the snowball method among all involved in the project. In addition, a call inviting PCSN to participate in the project was made using various media relevant for healthcare providers involved in the treatment of people with stroke (e.g. websites of local, regional and national stroke patients’ associations, the Rehabilitation Knowledge Network, Quality Network Rehabilitation Centers, professional associations of physical therapy, occupational therapy and speech therapy. Furthermore, the internet and the social media were searched for messages and as well as reports from relevant care networks (search terms (in Dutch) ‘network’, ‘organization’, ‘healthcare’, ‘definition’, ‘integrated care’ and ‘interprofessional’). Finally, during the research, presentations were held at various symposia, after which networks could register to participate in the study.

Questionnaire network coordinators

By means of an online questionnaire among the coordinators of the identified stroke networks, followed by a telephone interview if data were unclear or incomplete, the characteristics of the networks were recorded. The questions concerned the following: the number of professionals and their background (physical therapists, occupational therapists, psychologists, speech therapists, nurses, social workers, dietitians, general practitioners), quality of care (goals set, goals evaluated and reset, exchange of patient data, shared patient record, combined treatment program, case management, requirements for membership yes/no), requirements (education, minimum number of stroke patients treated, registration in quality register of professional body), objectives of the network (improve quality of care, implement guidelines, offer specific expertise, improve communication, improve coordination, share knowledge and information, improve organizational aspects of care, improve efficiency of care, offer care in local community, care, uniform treatment protocols, prevent undertreatment, visibility) and future perspectives (need for uniformity, need for certification, need for nationwide support of content and organization of networks). Two open questions about success factors and barriers

were added (what is in your opinion the reason for success of this network? what barriers are relevant in your opinion regarding this network?).

Questionnaire network members

The network coordinators were asked to invite the network members to fill in an online survey based on questionnaires used to describe the organization and outcomes of primary care networks for other chronic conditions (Fyranet network¹⁶ and the ParkinsonNet network²³).

The survey for members comprised questions regarding: profession, tasks and responsibilities in the network, costs and revenues being a member, requirements to become and stay a member of the network, number of years working as a professional and specifically regarding stroke patients, postgraduate courses or congresses, use of guidelines for stroke, use of a uniform treatment protocol within the network, outcome measures (patient level and aggregated at group level), the use of outcomes to adapt treatment program, the role of a case manager, way of communication between members concerning patients, familiarity with expertise of colleague members, procedures to refer patients to other members, contacts with professionals outside the network, contacts with general practitioner or hospital organizations, organization of network meetings, attendance of network meetings, participation in intervision, number of stroke patient treated last year, number of patients referred to other members and to professionals outside the network, audits being organized, satisfaction (with the network; the network meetings; the number of referred patients; the publicity of the network for patients, colleagues and referrers; the communication between network members), the need for uniformity in stroke networks, the need for nationwide or centralized support for networks, expectations over 5 years, the need for support to be successful as a network member. The following questions about success factors and barriers were added: What is in your opinion the reason for success of this network? What barriers are relevant in your opinion regarding this network?

Invitational Conference

In order to formulate recommendations based on the results of the inventory, an invitational conference with stakeholders was organized: local scientific advisory board of patients, PCSN health providers, stroke network coordinators, national patients' associations, national professionals' associations (physical therapists, physical medicine and rehabilitation, neurology, general practitioner), national stroke knowledge network (CVA Kennisnetwerk),

health insurance companies, The Netherlands Organisation for Health Research and Development (ZonMW; Zorg Onderzoek Nederland Medische Wetenschappen) and the Quality Fund for Medical Specialists (SKMS; stichting Kwaliteitsgelden Medisch Specialisten). Subsequently, the following topics were discussed in smaller groups: the requirements regarding quality of the networks and individual members, communication and cooperation, finance, and standardization.

Results

PCSN: network coordinators' perception

Fifteen stroke networks met the definition. Their geographical distribution over The Netherlands is shown in Figure 1. All 15 coordinators of these networks were willing to collaborate and completed the online survey. In 5 cases additional contact by telephone was necessary.

The median number of members per network was 27, range 4-140. Table 1 presents the professional background of network members and organizational aspects.

Three networks had been instituted in the past 24 months; of the other 12 networks 6 had been instituted before 2010. Three networks did not only focus on stroke but on neurological disorders in a broader sense.

Requirements for membership were imposed on network members in 14 networks. These could concern requirements for admission to the network and/or for continuation of membership. The extent to which admission and continuation requirements were set, operationalized and described varied among networks. In the 11 networks that had set requirements for a minimum number of stroke patients, the minimum number varied from 5 to 14 patients per year.

Concerning the required registrations in professional bodies, coordinators referred to the guidelines and quality registers of the professional groups. Educational requirements for network members were found to differ among professional groups, with reference to the professional group's guideline and to various training courses in the field of stroke.

Some of the network coordinators appointed additional requirements, such as signing a covenant, financial contribution, 'interest, motivation and passion', willingness to collaborate and location of the practice. For continuation of the membership, apart from the aforementioned requirements, the presence at network meetings and / or reference evenings was also required by various networks.

All 15 networks had formulated goals, including quality, coordination, efficiency and publicity (Table 2). Regarding quality of care, aspects that were mentioned concerned the application of national frameworks and guidelines, the provision of high-quality, evidence-based care, to enhance the skills of professionals and the coordination in the chain of care of the organizations involved. For this purpose, they focused on sharing knowledge, education and expertise promotion and some perform structured intervision. From the networks' perspective, the needs of the individual patient should be leading in stroke care.

Six networks had a formalized structure and formed an association or partnership. Two of these networks had a statute and / or regulations. In the other networks, the cooperation structure was less formally established but based on agreements, shaped by informal coordinators or by periodic consultation between the members. Tasks and responsibilities of the network members were described in 8 networks.

The networks were funded in various ways, according to the coordinators' answers. Eight networks were (partly) financed by a contribution from the network members, 5 networks received funds from affiliated centers, hospitals or intramural partners, 1 network received financial support by a health insurer and 1 network indicated that they were not being financed at all.

All coordinators indicated that network meetings were organized. For most of the networks, quality aspects had been elaborated, such as the exchange of patient data, a shared treatment protocol and uniform measurements of the results.

Regarding barriers and facilitators for the continuation of the networks, the coordinators often mentioned a lack of time and money as the most important impeding factors. Furthermore, achieving a minimum number of treatment patients was not always guaranteed. The 'short lines' and interprofessional contacts were mentioned as an important facilitating factor.

People experienced trust, involvement and know each other personally. In addition, the 'bottom-up' formation and organization of the networks was mentioned as a success factor.

Structure and process of PCSN: network members

Table 3 shows the characteristics of the 139 responding network members (response 25,5%). Most of the respondents (83%) worked in the field of stroke patients more than 5 years. Almost half of them had participated in stroke-oriented postgraduate courses or training one or more times during the past year and almost all network members participated in network meetings in the past year.

Communication about patients took place by e-mail (48%), personal contact (45%), telephone (44%), via team meetings (32%) or in writing (24%). To a much lesser extent, communication took place by fax (6%) or a joint electronic patient file (4%).

In general, network members were satisfied with the number and content of network meetings. Almost half of the responding network members were satisfied with the communication within the network, a similar proportion experienced an improvement in quality of care since being part of the stroke network (46%). Two thirds of the network members were unsatisfied with the publicity of the stroke network among colleagues, general practitioners, referring institutions and patients.

The available (inter)national profession-specific guidelines were followed by most practitioners, however, guidelines were not available for every discipline. Just over a third of the responding network members reported to have an interdisciplinary treatment program, about half of them measured progress and outcomes of the treatment of stroke.

Network members mentioned a lack of time and the lack of compensation for network activities as barriers. The volume requirements were in some cases difficult to meet. Few members also mentioned the risk of competition for production as an impeding issue. The above mentioned 'short lines' were considered as a facilitator. Knowing each other's skills and learning from each other was enhanced by working in networks, specifically in networks with less members.

A formal instrument for certification of quality is required according to 41% of the responding

network members. Approximately 60% of network members saw a central or national financial support as a prerequisite to stimulate standardization in the content and organization of the stroke networks. A small proportion of respondents, ranging from 6% to 17%, believed that more uniformity, central support or quality certification was not required.

Recommendations for future development: Invitational conference

The participants (n = 43) in the invitational conference were representing local scientific advisory board of patients, PCSN health providers, stroke network coordinators, national patients' associations, national professionals' associations (physical therapists, physical medicine and rehabilitation, neurology, general practitioner), national stroke knowledge network (CVA Kennisnetwerk), health insurance companies, The Netherlands Organisation for Health Research and Development (ZonMW) and the Quality Fund for Medical Specialists (SKMS).

The results of the conference, in terms of recommendations, are summarized in Table 4. The participants agreed upon a multidisciplinary network being preferred over a monodisciplinary network. Network meetings were important in meeting other members and for sharing knowledge. Responsibility for the organization and activities of the network must be assigned to a network coordinator. A shared vision on treatment and outcome measures promotes the quality of care.

Minimal requirements for admission and continuation as a PCSN member should comprise postgraduate education, minimal years of experience with and volume of stroke patients, registration in quality registries if applicable, participation in network meetings and intervision.

To improve the quality of care for stroke patients, it was necessary according to the participants in the conference that agreements with referring institutions about content and moment of information transfer were established. Other primary care providers such as GP's (general practitioners) and community nurses and should also be involved in the networks. Effective publicity and accessibility were considered important for the success of the PCSN.

Members contributed financially to the network, but additional funding is needed for both the start and continuation of the network. Participants argued for a central, national support for stroke networks to promote uniformity in the organization of the networks. This central support should facilitate the development of regional networks and their visibility

for referrers as well as for patients, formulation of requirements for education and quality management, and exchange of knowledge within networks. Participants also argued for a national certification.

Discussion

With a considerable proportion of patients having some limitations in functioning after initial hospitalization and/or inpatient or outpatient rehabilitation for stroke, there is a need for integrated care provided in primary care. Networks of primary care professionals may guarantee the quality and accessibility of care but research in this area is scanty. This study identified 15 primary care networks, with a large variety in their structure and processes. Time and money were most frequently mentioned as barriers for continuation, whereas mutual trust, commitment and direct lines of communication were mentioned as success factors. During an invitational conference, a set of recommendations for the future organization and development of PCSN was formulated; the need for a national, centralized approach being a consistent advice.

In most countries some form of network organization regarding stroke patients is pursued. The structure and objectives of these networks may differ. In the Canadian Stroke Network best practices were advocated in the acute, subacute and chronic stroke care and a central registry was developed to collect necessary information on stroke risk factors, symptoms, treatment and hospital management to inform research and to identify gaps in care. [<http://canadianstrokenetwork.ca/en/>] The Kompetenznetz Schlaganfall in Germany is primarily focused on research efforts and implementation of its results. [<http://www.kompetenznetz-schlaganfall.de/89.o.html>]. The NHS in the United Kingdom established in 2013 the Strategic Clinical Networks that serve in key areas of major health and wellbeing challenges such as stroke. Each of the five NHS region teams may develop other Strategic Clinical Networks depending on local need. As an example, the South East Coast Strategic Clinical Networks issued the 'Life After Stroke Commissioning Guidance'. The empowerment of stroke survivors and their carers to manage their care, with the help of appropriately skilled staff, is a key theme of this guidance, offering evidence-based guidelines on care for stroke survivors. [<https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2017/07/life-after-stroke.pdf>]

The evidence for the effectiveness of primary care networks is gradually growing. Enhanced

expertise and coordination of teams in a variety of patient groups showed a limited effect on patient outcomes.⁹ In a recent Cochrane study the impact of practice-based interventions designed to improve interprofessional collaboration amongst health and social care professionals was compared to usual care or to an alternative intervention. Strategies to improve interprofessional collaboration between health and social care professionals may slightly improve patient functional status, professionals' adherence to recommended practices, and the use of healthcare resources.¹¹ Further research is indicated to understand the efficacy of PCNS in stroke populations.

Our results indicate that sufficient financial resources are essential to keep an interprofessional stroke network running. These may consist of a contribution from members, possibly supplemented with funding from other parties (municipality, hospitals, health insurance). The quality of the network can be guaranteed by setting up a quality system for the treatment of stroke patients in which, among other things, performance indicators can be recorded. Process aspects should focus on collaboration, quality of care and visibility of the network. Agreements with referring physicians on sharing information and on shared opinions about treatment protocol is important. Sharing information from patients within the network must be done with due regard to the laws and regulations on privacy. Outcome measures at the level of the individual patient, care provider and the network need to be established. The network should be brought to the attention of local and regional health institutions and practices (hospitals, rehabilitation facilities, nursing homes, general practitioners and community nurses).

This study has some limitation relevant to be mentioned. Probably not all primary care stroke networks were found that met the criteria, although extensive efforts have been made to identify stroke networks in the Netherlands. A relatively large number of network members did not respond to the invitation of the questionnaire. Strengths of this study are the fact that all coordinators of the included networks did participate, and that a set of recommendations for further development of PCSN was discussed and formulated at an invitational conference.

In conclusion, there is no uniformity regarding the structure and process among 15 regional PCSN in the Netherlands. Recommendations are proposed for the organization of PCSN, based on structured response from network coordinators, network members and stakeholders. Centralized coordination and support is advocated. Further research is

necessary to establish the beneficial effects of coordinated interprofessional care for stroke patients in primary care networks.

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Figure 1. Geographical distribution of fifteen stroke networks that were identified in The Netherlands.



Legenda

CVA network = stroke network; eerstelijns = primary care; zorgketen = chain of care.

Table 1. Health professionals, quality of care aspects, and requirements for membership in primary care networks, and the number of networks in which these (professionals, aspects and requirements) are represented.

Representation of professions:	Number of Networks
Physical therapists	15
Monodisciplinary (only physical therapists)	3
Occupational therapists	12
Psychologists	11
Speech therapists	8
Nurse	7
Social workers	5
Dietitians	5
GP	5
Quality aspects:	
Goals set	13
Goals evaluated and reset	13
Exchange of patient data	12
Shared patient record	1
Combined treatment program	9
Case management	6
Requirements for membership yes/no	14/1
If available, requirements concerned:	
Education	12/14
Minimum number of stroke patients treated	11/14
Registration in quality register of professional body	6/14

PCSN: primary care stroke network; GP: general practitioner.

Table 2. Objectives of PCSN (Primary Care Stroke Networks) as reported by the network coordinators (n = 15).

Improve quality of care	7
Implement guidelines	5
Offer specific expertise	6
Improve communication	5
Improve coordination	5
Share knowledge and information	4
Improve organizational aspects of care	4
Improve efficiency of care	3
Offer care in local community	3
Care	2
Uniform treatment protocols	2
Prevent undertreatment	2
Visibility/publicity	1

Table 3. Results from a survey among members of 15 PCSN (N = 139; answer categories Yes or No)

Experience and education	N	%
Took part in ≥ 1 network meeting last year	87/97	90%
Treats stroke patients > 5 years	102/123	83%
> 5 stroke patients last year	71/91	78%
Followed symposium or congress on stroke < 5 yrs	89/125	71%
Follows education on stroke > 1 per year	60/126	48%
Intervision in network	37/101	37%
Quality of care		
Following guidelines for stroke	100/125	80%
Evaluations of goals during treatment	55/106	52%
Structured outcome measurements	52/108	48%
Using uniform treatment protocol	42/122	34%
Adjustment of goals during treatment	23/81	28%
Being case manager for stroke patient	22/108	20%

Table 4. Recommendations for the organization and future development of PCSN as formulated at an invitational conference.

Structure	
	Formulate a shared vision on the treatment of stroke patients, based on existing guidelines, and a collaborative approach regarding measurable, concrete goals.
	Develop a multidisciplinary network: physical therapy, occupational therapy, speech therapy, supplemented when available with disciplines such as psychology, dietetics and nursing
	Involve Other stakeholders in the network: GP, hospital organizations, rehabilitation facilities and (regional) patient associations
	Tasks and responsibilities of network members must be formulated
	Consider a broader target group with similar neurological problems, for example 'patients with non-progressive central neurological disorders' or 'patients with acquired brain disorders'
	Organize network meetings at least once a year to ensure the coherence within a network and the quality of the care provided.
	Ensure funding for network coordination
	Set up a quality system for the treatment of stroke patients in which performance indicators can be recorded
	Consider a legal status for the network
Process	
	Establish agreements with referring institutions about content and timing of information transfer
	Make arrangements on internal and external lines of communication of the PCSN
	Formulate requirements for entry and continuation of membership
	Ensure publicity and visibility of the PCSN