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Rehabilitation pathways, satisfaction with functioning and wellbeing and experienced rehabilitation needs after stroke

A stroke cohort study in Norway and Denmark

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Acknowledgments

Years spent in clinical work with patients with stroke have created a need to learn more from the patient's perspective on the disease, treatment and outcome. The opportunity given to participate in an international stroke research collaboration could not be resisted, despite a challenging work situation.

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Abstract

The overall aims of the study were to investigate satisfaction with functioning and well-being and the level of unmet rehabilitation needs during the first year post stroke in a northern Norwegian and Danish region that organizes their rehabilitation services differently.

Design: This thesis is based on an international multicenter observational cohort study.

Methods: A total of 451 Norwegian and 348 Danish adult patients with first-ever ischemic or hemorrhagic stroke were recruited. The participants had been hospitalized at stroke units at one hospital with three locations in northern Norway or at one hospital in Jylland, Denmark.

Demographics and stroke-related data were collected from national stroke registries. Patient-reported data on satisfaction with functioning, function and psychological distress were collected at 3- and 12-months post stroke. Data on the course of rehabilitation were obtained through telephone interviews.

The Quality of Life after Brain Injury-Overall Scale (QOLIBRI-OS), originally developed for use among patients with traumatic brain injuries, was validated for the first time in patients with stroke. Levels of satisfaction with functioning and well-being using the QOLIBRI-OS instrument were obtained twice. The change between the time points was assessed using the minimal clinically important difference (MCID).

Two questions from the Norwegian Stroke Registry were chosen to investigate met, unmet or no needs for help and training at 3 months after stroke. Multivariate logistic regression was applied to explore factors predicting met, unmet or no rehabilitation needs. Correlations between satisfaction with functioning and unmet rehabilitation needs were investigated.

Results: Norwegian patients were older than Danish participants (72 years versus 69.3 years) (p=.03) and had more severe strokes, with a median stroke severity scale score of 47 versus 50, respectively (p=.001). Rehabilitation pathways for participants from the two country-regions differed markedly, with longer stays in stroke units in northern Norway than Denmark. The use of municipality-based rehabilitation services in Denmark was twice as frequent as in Norway, whereas inpatient rehabilitation services were more frequently applied in northern Norway.

The QOLIBRI-OS instrument demonstrated good psychometric properties and appeared to be a suitable instrument to measure satisfaction with functioning and well-being after ischemic and hemorrhagic stroke, although its content validity would improve even more if items measuring language impairments and sensorimotor function were added.

At 3 months post stroke, Norwegian and Danish participants reported equal levels of satisfaction with functioning and well-being. Unadjusted analyses revealed that the Norwegian participants at 12 months were more satisfied with function and well-being. The proportion of participants who stated their health-related quality of life as good was 83% in Norway and 71% in Denmark. There was no change in the overall level of satisfaction with functioning between 3 and 12 months after stroke at a group level, but at an individual level, almost 50% reported clinically important changes in perceived satisfaction over the period of assessment. Younger patients below 65 years of age were more susceptible than older patients to reporting worsening outcomes on the QOLIBRI-OS from 3 months to 12 months post stroke. No variables predicted improved satisfaction with functioning at 12 months.

The patients in the two country cohorts reported equal results for met, unmet or no needs for help and training at 3 months post stroke. A third of the cohort reported no need for training or help. When this proportion was excluded, 78% of all persons reporting needs for training had these needs met, while the corresponding frequency for those with need for help was 85%.

However, about one-fifth of the population reported unmet needs for help or training. Unmet needs for training were associated with lower functioning (OR=.32, p<.05) and more anxiety (OR=.36, p<.05). The patients reporting unmet needs for help more often lived alone (OR=.40, p<.05) and were more often depressed (OR=.31, p<.05). Unmet rehabilitation needs were significantly negatively correlated with QOLIBRI-OS scores.

Conclusion: Despite different rehabilitation pathways in patients from the northern Norwegian and Danish regions, there was no difference in satisfaction with functioning and well-being measured with the QOLIBRI-OS at 3 months post stroke. At 12 months post stroke, the Norwegians were statistically more satisfied with functioning and well-being. Almost 50% of the participants reported clinically important changes in perceived satisfaction over the period of assessment. Being under 65 years of age was the sole predictor for worsening satisfaction with functioning at 12 months. The QOLIBRI-OS instrument demonstrated good psychometric properties and appeared to be a suitable instrument for measuring satisfaction with functioning and well-being after ischemic and hemorrhagic stroke.

The expressed rehabilitation needs seemed to be fulfilled to a large extent due to well-adapted structures and processes. However, a fifth of the patients with stroke conveyed an unmet need for help and training with a correspondingly low health-related quality of life. Optimizing stroke-related structures and processes and implementing strategies to reduce psychological distress would enable a higher degree of fulfilment of rehabilitation needs and subsequently increase satisfaction.

List of papers

The following three manuscripts are included in this dissertation:

Guri Anita Heiberg, Synne Garder Pedersen, Oddgeir Friborg, Jørgen Feldbæk Nielsen, Henriette Holm Stabel, Nicole von Steinbüchel, Cathrine Arntzen, Audny Anke***. Can the health related quality of life measure QOLIBRI-Overall Scale be of use after stroke? A validation study***. Published in *BMJ Neurology* 2018; 18:98 https://doi.org/10.1186/s12883- 018-1101-9

Guri Anita Heiberg, Oddgeir Friborg, Synne Garder Pedersen, Gyrd Thrane, Henriette Holm Stabel, Jørgen Feldbæk Nielsen, Audny Anke. ***Health-related quality of life at 3 and 12 months post-stroke in a Central Danish and Arctic Norwegian Region: Satisfaction with functioning and predictors for change.*** J Rehabil Med. 2020 Sep 8;52(9):jrm 00096. doi: 10.2340/16501977-2716. PMID: 32735024

Guri Anita Heiberg, Cecilie Røe, Oddgeir Friborg, Synne Garder Pedersen, Henriette Holm Stabel, Jørgen Feldbæk Nielsen, Audny Anke. ***Factors associated with met and unmet rehabilitation needs after stroke:*** A multicentre cohort study in Denmark and Norway. J Rehabil Med. 2021 Apr 13. doi: 10.2340/16501977-2828 PMID: 33846761

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Contributions	Paper 1	Paper 2	Paper 3
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Study design and methods	**GH**, AA, SGP, OF	**GH**, SGP, AA, OF, GT	**GH**, CR, OF, SGP, AA
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In addition to the three published papers listed in the thesis, I have contributed to the following papers during the Ph.D. period:

1. Synne Garder Pedersen, Guri Anita Heiberg, Jørgen Feldbæk Nielsen, Oddgeir Friborg, Henriette Holm Stabel, Audny Anke, Cathrine Arntzen. ***Validity, reliability and Norwegian adaptation of the Stroke-Specific Quality of-Life scale***. Published in *SAGE Open Medicine* 2018; 6: 1-10 https://doi.org/10.1177/2050312117752031

2. Synne Garder Pedersen, Oddgeir Friborg, Guri Anita Heiberg, Cathrine Arntzen, Henriette Holm Stabel, Gyrd Thrane, Jørgen Feldbæk Nielsen, Audny Anke. ***Stroke Specific Quality of Life one-year post-stroke in two Scandinavian country-regions with different organization of rehabilitation services. A prospective study.***
   Disability and Rehabilitation, DOI: 10.1080/09638288.2020.1753830

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Abbreviations

NORDA	Name of the main study
WHO	World Health Organization
ICD	International Statistical Classification of Diseases and Related Health Problems
DALY	Disability adjusted life years
ICF	International Classification of Function
ESD	Early supported discharge
LOS	Length of stay in stroke units
PAC	Postacute care
QOL	Quality of life
HRQOL	Health-related quality of life
PROM	Patient reported outcome measure
QOLIBRI-OS	Quality of Life after Brain Injury-Overall Scale
HADS	Hospital Anxiety and Depression Scale
mRS	Modified Rankin scale
TIA	Transient ischemic attack
SS-QOL	Stroke Specific Quality of Life
EQ-5D-3L	EuroQol Five Dimensions Questionnaire 3-Level
NIHSS	National Institute of Health Stroke Scale
SSS	Scandinavian Stroke Scale
VIF	Variance inflation
MCID	Minimal clinically important difference
SEM	Standard error of measurement
COSMIN	Consensus-based Standards for the Selection of Health Measurement Instruments
ICC	Intraclass correlation coefficient
RMSEA	Root mean square error of approximation
SRMR	Standardized root mean square
CFI	Comparative fit index
NNFI	Non-normed fit index
UNN	The University Hospital of North Norway
ADL	Activity of daily living

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1 Introduction

The studies constituting this thesis are part of a larger observational multicenter cohort study, the 'NORDA study', describing and comparing stroke rehabilitation courses in regions in northern Norway and central Denmark.

The two regions differ in size, hospital structure and rehabilitation organization. The main research rationale for the choice of study setting was an attempt to elucidate whether different structures of organization and processes of rehabilitation have an impact on patient-reported outcomes after stroke.

An important part of the research collaboration was to introduce a new research instrument measuring health-related satisfaction with functioning and well-being post stroke.

By collecting data from two county regions with fairly common acute stroke treatment protocols but differently organized stroke rehabilitation pathways, we aimed to apply the instrument to investigate and compare satisfaction with functioning and well-being.

Rehabilitation needs were also explored, and both satisfaction and met or unmet rehabilitation needs were analyzed with regard to differences and similarities based on country regions, rehabilitation pathways and patient features.

The introductory chapter provides overall background information about the epidemiology and clinical features of stroke in addition to definitions and descriptions of rehabilitation.

A modified Donabedian model for structure, process and patient features in relation to outcomes is presented.

Finally, the aims, based on the scientific work of three published papers and additional data exclusively for the thesis, are presented.

1.1 Stroke

1.1.1 Definition of stroke

Apoplexy, the Hippocratic term for stroke, literally means being stuck by a deadly blow, regarded impossible to cure if severe, and difficult to cure if mild (1).

In 1980, the World Health Organization (WHO) defined stroke as a rapidly developed clinical sign of focal (or global) disturbance in cerebral function lasting more than 24 hours or leading to death (2). This definition is completely based on the clinical presentation of symptoms.

Subsequent advances in neuropathology and neuroimaging have enhanced our understanding of the nature of stroke, thus leading to debate if a broader definition of stroke is necessitated. Neuroimaging has revealed that the appearance of stroke without clinical symptoms is frequent (3), but there is no agreement regarding the use of extended criteria for stroke (4). Changing the definition of stroke would drastically alter incidence and prevalence rates worldwide. It would also complicate comparisons between countries, as neuroimaging capacities differ profoundly.

In this thesis, the WHO criteria for stroke were used, and the following stroke subtypes were included:

A) Ischemic stroke of thrombotic or embolic origin. ICD (The International Statistical Classification of Diseases and Related Health Problems) version 10, code I.63: occlusion and stenosis of precerebral or cerebral arteries, resulting in cerebral infarction.

B) Intracerebral hemorrhage. ICD-10, code I.61: nontraumatic intracerebral hemorrhage.

Radiologically detected strokes without clinical symptoms were not included.

1.1.2 Burden of stroke

The Global Burden of Disease Study 2019 (5) provides an overview of stroke epidemiology from 1990 to 2016. Although incidence, prevalence and mortality rates tended to decline during the observational period, the overall burden in terms of absolute numbers of persons affected by stroke has increased globally due to population growth and aging (6). The WHO predicts an annual increase in the number of strokes from 1,1 million in 2000 to 1,5 million per year in 2025 in Europe because of the aging population (5). Disability-adjusted life years (DALYs)(7), a measure of overall disease burden expressed as the number of years lost to ill health, disability or early death, was also reported.

In 2013, stroke was the second most frequent cause of death, responsible for 11,8% of all deaths worldwide, and the third most common cause of disability, accounting for 4,5% of DALYs from all causes. There are marked geographical differences in stroke incidence. The burden of stroke is increasing most in developing countries. In Europe, Russia and Eastern European countries have the highest mortality rates and number of DALYs. In Nordic countries, Ellekjær et al (8) in 2007 found similar incidence rates of stroke in Norway, Denmark and Sweden. In Norway, the national Norwegian Heart and Vascular registry reported an 8% decrease in the incidence of first-time stroke from 2012-2016 (9).

The absolute number of strokes registered in the national Norwegian Stroke Registry in the period was stable at approximately 8500 per year in the four-year period. In 2019, based on data in national registries, 9022 strokes among a population of 5,328000 inhabitants were registered in Norway, and an equivalent 12283/5,806000 strokes/population was registered in Denmark.

This corresponds to an unadjusted incidence rate of stroke of 169/100,000 in Norway and 211/100,000 in Denmark. Between 15 and 30% of stroke survivors suffer from permanent disabilities (10).

Based on some studies, it has been suggested that the proportion of patients with functional independence after stroke has declined annually, and this decrease is independent of age, stroke severity and other predictors of functional decline (11).

The Norwegian stroke registry reported in 2018 that 75% of stroke patients were independent post stroke, a decrease of 16%, as 91% of the cited population had no need for assistance pre-stroke. The consequences of stroke are also challenging for caregivers (12). Traditionally, stroke has been regarded as a disease of the elderly population.

The Global Burden of Disease Study from 2013 indicated that this was no longer the case, as 2/3 of all strokes worldwide affect persons below 70 years of age (13). In northern parts of Europe, however, stroke is predominantly a disease appearing in the elderly segment of the population. Recent studies have found that more than 50% of all strokes occur in those over the age of 75 years and as many as 30% of strokes occur in those over 85 years in Nordic countries (14).

Worldwide, stroke is more common among men, but women become more severely ill, mostly due to higher age at the time of stroke (15).

The economic implications of medical and caregiving costs post stroke are huge, though they are also variable among Western countries (16). A Swedish study reported in 2012 that in essence, 50% of costs for stroke care are associated with acute hospital care, and 40% are associated with rehabilitation and long-term care. Informal care and productivity loss explain 10% of the total cost associated with stroke (17,18). Stroke in younger patients results in a significantly higher burden on society than stroke in older patients due to the loss of productivity and the increased use of health care resources (18). In Denmark, after the incidence year, the costs of social care services, including costs of home help and nursing homes for first-ever embolic stroke, exceeded the health care costs (19).

The burden of stroke has major and longstanding impacts on health-related quality of life (HRQOL) for patients (20).

The extent to which suboptimal structures or processes in health services increase the burden of stroke or reduce the fulfillment of rehabilitation needs after stroke need is unclear.

1.2 Rehabilitation

1.2.1 Definitions of rehabilitation

The WHO (World Health Organization) (21) stated that rehabilitation is an essential component of universal health coverage along with the promotion of good health, prevention of disease, treatment and palliative care (22).

The WHO defines rehabilitation as following:

“Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination" (23).

In attempting to form a conceptual description of rehabilitation as a health strategy (24), several groups have argued for the necessity to adopt the principles of the International Classification of Function (ICF) (25) as the basis for the definition of rehabilitation.

The definition of rehabilitation is, however, still not universal.

Many countries also have their own nationally adapted definitions of rehabilitation, including Norway and Denmark.

1.2.2 Norwegian definition of rehabilitation

Habilitation and rehabilitation must be based on the life situation and goals of the individual patient and user. Habilitation and rehabilitation are targeted collaborative processes in various arenas between patients, users, relatives and service providers. The processes are characterized by coordinated, coherent and knowledge-based measures. The purpose is that the individual patient and user, who have or are at risk of being restricted in their physical, mental, cognitive or social functioning, should be given the opportunity to achieve the best possible functional and coping abilities, independence and participation in education and working life, socially and in society (26).

1.2.3 Danish definition of rehabilitation

A goal-oriented, cooperative process involving a member of the public, his/her relatives, and professionals over a certain period of time. The aim of this process is to ensure that the person in question, who has, or is at risk of having, seriously diminished physical, mental and social functions, can achieve independence and a meaningful life. Rehabilitation takes into account the persons' situation as a whole and the decisions he or she must make and comprises coordinated, coherent, and knowledge-based measures.

The Danish definition is currently under revision.
The Norwegian definition of rehabilitation became more similar to the Danish version when updated in 2018. Both definitions emphasize the need for rehabilitation to prevent loss of function and to optimize function.

1.2.4 Stroke rehabilitation

Not all patients with stroke need rehabilitation. In 2015, 44% of all Norwegian patients were discharged directly to their own home with or without help (27), while approximately 25% were transferred to inpatient rehabilitation services.

Stroke rehabilitation may be performed in the context of inpatient specialist rehabilitation services or at the municipal level. An in-between level of support is early supported discharge (ESD), which is enacted as cooperation between the specialist level and community-based professionals and is preferably performed in the patient's home.

Early inpatient rehabilitation is well documented in stroke units (28,29). A recent meta-analysis found moderate-quality evidence that stroke patients who receive organized inpatient stroke unit care are more likely to be alive, independent, and living at home one year after stroke (30).

For patients with the most severe strokes, further inpatient rehabilitation is necessitated and subsequently performed in rehabilitation wards.

Inpatient rehabilitation programs have beneficial effects by improving functionality (31) for patients of all ages (32). The organization of service and the multidisciplinary approach in rehabilitation wards have a major impact on improvements in activities of daily living (ADLs) outcomes (33).

Earlier rehabilitation admission, higher-level activities early in the rehabilitation process, tube feeding, and newer medications have been associated with better stroke rehabilitation outcomes (34).

Very early mobilization within 24 hours after stroke is, on the other hand, associated with a reduction in the odds of a favorable outcome at 3 months (35).

The following variables are of importance in predicting poorer functional outcomes after inpatient rehabilitation: functional level at admission, stroke severity, dysphasia, impulsivity, neglect, previous stroke and age (36).

Inpatient rehabilitation after stroke unit discharge is, however, costly and thus limited by resources and capacity (37).

Appropriately resourced ESD services provided for a selected group with mild and moderate stroke symptoms can reduce long-term dependency and admission to institutional care as well as shorten hospital stays (38,39). The effect of ESD seem to be long-lasting (40,41). ESD is reported to be most efficient when defined core components of ESD are reported, providing a more responsive and intensive ESD service (42).

Although recommended in stroke guidelines, the implementation of ESD in real-world settings has been highly variable (42) and includes a wide range of organizational model adaptations (43). A major limitation is that early supported discharge seems to provide no functional gain when applied in rural areas (44).

Community-based stroke rehabilitation may be delivered in a variety of settings either in a center, outpatient or day hospital setting. At the community level, there is modest support that suggests the prevention of functional loss (45). A review found home-based rehabilitation to provide the best functional results at 6 weeks post stroke (46). The effect was enhanced as the intensity of the home-based rehabilitation increased (47); however, there is a lack of robust evidence for many of the prevalent poststroke rehabilitation interventions (48).

Package procedures for rehabilitation after stroke were implemented in Norway in 2019 and provide general guidelines for the choice of stroke pathways and strong recommendations on how to minimize the time delay between treatment levels.

The interface between different types of rehabilitation is not clear-cut and varies across organizations and traditions and geographical locations.

From a clinical point of view, rehabilitation in different phases can be described as follows (49):

- Realization of potential: ensuring that the duration of contact with therapy staff has been sufficiently long to reach a plateau phase in recovery.
- Re-enablement: focusing on promoting independence in activity skills such as walking and dressing.
- Resettlement: helping the person to leave the hospital feeling safe, well supported, and confident.
- Role fulfilment: helping the person re-establish their status and personal autonomy.
- Readjustment: helping the person to adapt to and accept a new lifestyle.

Successful implementation of these phases may enhance satisfaction with functioning and fulfillment of rehabilitation needs.

1.3 Donabedian model of structure, process, and outcome

To present the different aspects of stroke treatment and rehabilitation in this thesis, a model published by Donabedian in 1966, defining the relationship between structure, processes and outcome, (50) was chosen. This model is applied in the thesis only to structure the presentation and discussion of the multiple factors that may influence outcomes and was not a part of the underlying studies. A detailed overview of the structures and processes in the two regions is provided in the discussion chapter.

The three elements, structure, process and outcome, were later incorporated into a health care quality model (51). According to this quality theory, improvements in structure would lead to improvements in processes and hence better outcomes (51).

Using the concepts of structure and process of care, different systems can be compared and evaluated against the best evidence (52).

This model has been adapted for several complex medical, multiphase conditions, such as trauma (53), spinal cord injury (54) and stroke (55) rehabilitation.

The Donabedian model has been extended and modified for different purposes.

In the following presentation, patient features, an additional element based on an American report on quality care (56) that includes demographics and stroke characteristics, was added. As stated, structure has an impact on process and hence on outcome, while patient features interact with both processes and outcomes.

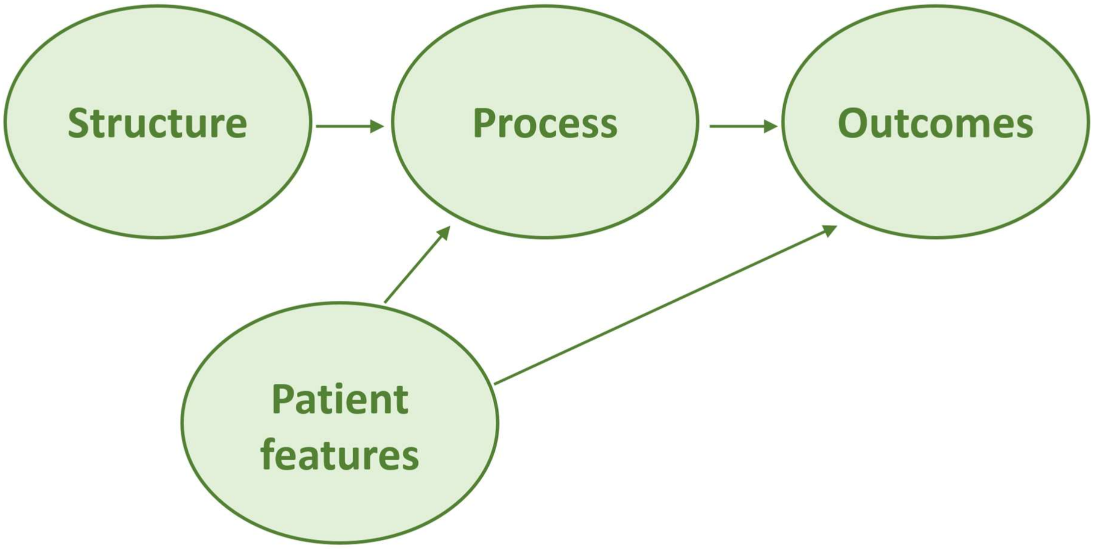


Figure 1: Modified Donabedian model.

1.3.1 Structure

Professional competence, capacity and facilities to offer treatment are essential structural elements in a well-functioning stroke treatment chain.

The structural prerequisites for acute stroke treatment and subsequent rehabilitation also include a juridical framework regulating responsibilities and cooperation between organizational levels and financial systems ensuring admittance into medical services.

A scoping review from 2019 (57) identified seven elements constituting the stroke care structure. The components were accident and emergency departments organizing prestroke transport chains and treatment (58), stroke units with multidisciplinary teams (59,60) and stroke specialists, access to neuroimaging (61), medications (62), and health care policies supporting a customized stroke structure (63).

This comprehensive review analyzed data from low- and medium-income countries (57), but the identified components of stroke care are universally significant. In addition, a well-functioning stroke structure must include the presence of differentiated subacute rehabilitation options at both the hospital and municipality levels (64).

A particular stroke structure defines the limits of feasible treatment or rehabilitation.

Structures that are insufficient or lacking result in unsatisfactory consequences for patients (57).

Structure is a necessary but not sufficient condition for optimal procedures. A study by Hoenig et al. (65) demonstrated that improvements in key structures improved processes and hence outcomes in stroke rehabilitation.

The differences in structure between the Norwegian and Danish regions are mainly constituted by size, hospital structure and uneven distribution of responsibility for rehabilitation between specialized and municipality health services.

1.3.2 Process

The care process refers to practitioner actions that interface with patients and consequently may have an impact on their outcomes. Diagnostics, treatment and specific interventions are essential process elements (66). Additionally, professional team collaboration and cooperation across treatment levels are central components of stroke treatment and rehabilitation processes. Professional guidelines, based on normative or empirical standards (67,68), often underlie quality assurance.

The best investigated intervention for stroke is stroke unit treatment. Stroke units may be acute, offering acute treatment, or comprehensive, including acute treatment and rehabilitation. A dedicated comprehensive stroke unit ward is characterized by a specially trained multi-professional team approach, including a standardized protocol for diagnostic evaluation, observation, acute treatment and a strong focus on rehabilitation (69,70).

The Cochrane database included 28 randomized trials comparing stroke unit treatment to treatment in ordinary wards.

Stroke unit care was associated with reductions in the odds of death recorded at the final (median one year) follow-up (odds ratio (OR): 0.81, 95% confidence interval (CI): 0.69 to 0.94; P = 0.005), the odds of death or institutionalized care (OR=0.78, 95% CI: 0.68 to 0.89; P = 0.0003) and the odds of death or dependency (OR= 0.79, 95% CI: 0.68 to 0.90; P = 0.0007) (71).

The length of stay in stroke units (LOS) may be regarded as both a process measurement and an outcome.

We chose in this context to describe LOS as a component of the rehabilitation process. LOS in a comprehensive stroke unit model covered both the acute treatment and initial rehabilitation periods.

A review from 2013 found that comprehensive stroke units were associated with reductions in length of stay and combined death and dependency. Comprehensive stroke units also improved functional outcomes compared to other stroke unit models (72).

Thrombolysis is another well-documented treatment option for patients with ischemic brain infarction (62,73). Within a maximal time frame of six, but preferably three, hours after stroke onset, thrombolysis improved function at 6 months (74).

Since thrombolytic treatment is time-critical, the effects depend on a well-organized patient transport process chain (75).

Thrombectomy, which is a neurovascular procedure of increasing importance, in combination with thrombolysis provides a favorable shift in the distribution of functional outcomes on the modified Rankin scale at 90 days (odds ratio, 2.77; P<0.001) (76,77).

This procedure was, however, seldom performed during the study phase and is not further discussed.

Inpatient rehabilitation, early supported discharge and stroke rehabilitation at the municipal level are all processes over the course of stroke. Post-acute care (PAC) stroke processes are challenging to describe and analyze because of the wide variety in courses of stroke. In part, this is caused by a lack of a shared conceptual understanding of what construes quality of care in PAC rehabilitation (66).

The two most striking differences in process between Norway and Denmark are the use of inpatient versus community-based rehabilitation and length of stay in stroke units.

The relationship between process and outcome is not straightforward (78), but a better process of care has been found to be associated with better 6-month functional outcomes. Improving the process of care probably improves stroke outcomes (65). Process of care was positively and significantly associated with greater patient satisfaction with treatment even after controlling for patient functional outcomes (79).

1.3.3 Patient features

Stroke is a heterogeneous disease with a wide range of possible physical (80), cognitive (81), and emotional (82,83) consequences.

The immediate medical effects are determined by stroke subtype, size, localization and extension, which together constitute stroke severity (84). Within the first 3 months post stroke, hemorrhagic strokes are associated with a considerable increase in mortality based on the hemorrhagic nature of the lesion (85). On the other hand, patients with the most severely disabling hemorrhage improve more than those with cerebral infarction of comparable severity (86,87).

Age is the single most important risk factor for stroke. For each successive 10 years after age 55, the stroke rate more than doubles in both men and women (88). The relative level of poststroke functional improvement was found to decrease with increasing age (89), but the speed of recovery does not seem to substantially differ across age (90).

Women tend to be older at first-ever stroke. Stroke incidence becomes higher for women than for men above the age of 85 years, leading to a total higher lifetime risk of stroke (91).

Individual factors such as associated comorbidities (92) or cognitive dysfunction (93) predispose patients to a worse clinical course (12).

Pre-stroke disability increases the risk of adverse outcomes post stroke in the form of a longer LOS and a higher level of care at discharge (94,95). Among male stroke patients below 70 years of age, living alone is associated with increased long-term mortality after ischemic stroke (96). A prospective study found, however, that patients living alone had less severe strokes on admission and better recovery at 3 months compared to the other cohorts living with families or with care support. This finding was interpreted to be due to higher function among those able to live alone before the stroke. Lack of social support and social participation (97,98) are, however, well-documented risk factors for worse quality of life post stroke.

Anxiety (99,100) is common post stroke and a predictor for depression (82). Poststroke depression is the most frequent psychiatric complication of stroke, with an estimated prevalence of 30-35% (101,102). Depression may have devasting effects, as it impedes the rehabilitation and recovery process, jeopardizes quality of life and increases mortality (102).

1.3.4 Outcomes

Survival, recovery and restoration of function are traditionally the main outcomes post stroke (50). In addition, knowledge of how a condition influences individual quality of life (QOL) is essential in assessing the consequences of stroke. A precise definition of the term is necessary, as QOL is a ubiquitous concept with different philosophical, political and health-related definitions (103).

Health-related quality of life (HRQOL), which includes the physical, functional, social and emotional well-being of an individual (103), is defined by both objective functioning and subjective well-being (104).

Strokes are associated with complex physical, cognitive and psychosocial consequences that pose challenges to valid long-term outcome assessments (105,106). Due to a combination of functional, psychological and social constraints, the use of patient-reported outcome measures (PROMs) to assess progress following treatment is advocated (107,108). Generic and disease-specific health-related quality of life (HRQOL) instruments assess the consequences of health conditions on quality of life, comprising psychological, physical, social and daily-life domains (109).

The reliability of HRQOL instruments are comparable to that of clinical assessments, such as measuring blood glucose (110).

In rehabilitation research, function and satisfaction with life are two overall constructs often chosen as QOL outcomes. Function may be reported as a specific function, for instance, hand function (111), but more often as complex functional abilities related to mastering daily activities or social participation (112–114).

In research, the term satisfaction may be applied for different concepts, such as life satisfaction (115), satisfaction with health assessed with condition-specific measurements (116,117) or satisfaction with treatment (118).

Satisfaction with treatment is the patient evaluation of rehabilitation services and is not a part of this thesis.

Life satisfaction is a broad generic concept with some overlapping with disease-specific measurements regarding health aspects. The life satisfaction questionnaires Satisfaction with Life scale (119) and Life Satisfaction (120) have been applied both in patients following stroke (121–123) and traumatic brain injury (124), whereas very few studies have assessed health-related satisfaction with functioning using stroke-specific instruments (125).

Satisfaction is correlated with patient expectations and is highly influenced by psychological distress (126). Studies have found that poststroke depressive symptoms were associated with lower life satisfaction (127). Whether preexisting psychological distress disposes an individual for low satisfaction or whether low satisfaction amplifies a feeling of anxiety or depression post stroke is, however, debatable

In investigating HRQOL post stroke in one Danish and one Norwegian region, we chose to use satisfaction with functioning and general well-being as our main outcome measures.

The Quality of Life After Brain Injury-Overall Scale (QOLIBRI-OS) was originally validated in patients with traumatic brain injuries (128). With its short form and six items covering aspects relevant to brain conditions, we found it promising as an outcome measure for stroke. The instrument was validated in paper 1 and used as the main outcome measure in paper 2.

Because of the mutual relationship between satisfaction and psychological distress, anxiety and depression were investigated at the same timepoints as the QOLIBRI-OS by using the well-established patient-reported Hospital Anxiety and Depression Scale (HADS)(129), which is described in the Methods chapter.

Using both scales at 3- and 12 months post stroke made it possible to investigate dynamic changes in satisfaction and the level of psychological distress at the individual and group levels.

Our third main outcome measure included single questions about help and training that were chosen to investigate patient perception of the extent to which the offered rehabilitation was sufficient to cover patient-defined rehabilitation needs.

No discipline, including philosophy, economics or medicine, has an unambiguous definition of needs (130,131)

Some authors argue that 'health needs' ought to include personal and social care, health care, accommodation, finance, education, employment and leisure, transport and access (132).

Bradshaw defined needs as *normative* (distinguished by professionals, such as vaccinations), *felt* (wants, wishes and desires), *expressed* (vocalized needs or how people use services) and *comparative needs* (needs arising in one location that may be similar for people with similar sociodemographic characteristics living in another location)(133).

A more pragmatic approach is to adopt the most commonly used definition of health care needs and define rehabilitation needs as the needs that can be fulfilled by rehabilitation interventions and services (134). From the patient perspective, a need represents the perception of a situation in which help or support is desired. If adequate help is not offered, the provision of services does not fit the needs, gaps occur and needs become unmet (135). There may be a potential mismatch between the patients “capacity to benefit” as an outcome measure and needs as the resource input (136), which might lead to both over- and underconsumption of resources in the attempt to meet needs.

1.4 Relevant and unanswered research questions

While there are a vast number of stroke studies dealing with function (137–142) or psychological distress (100,101,143–146), knowledge about stroke-related satisfaction with functioning post stroke onset is limited (121,125,147).

At the time of our study planning, no short-form condition-specific questionnaire assessing satisfaction after stroke was available.

We therefore aimed to validate a brain condition-specific questionnaire that included cognitive dysfunction for the purpose of assessing satisfaction with health functions in regions in Norway and Denmark.

Studies comparing HRQOL scores across different countries (148,149) have reported unexplained differences in perceived poststroke quality of life.

To our knowledge, no study has explored condition-specific HRQOL over time post stroke in the context of different rehabilitation organizations in different countries. Is perceived satisfaction with functioning, adjusted for patient features, influenced by the structure and processes offered to stroke patients? Likewise, are the coverage of needs for help and training dependent on particular structures and processes in different regions?

Divergent results have been reported about how patient-reported health-related quality of life varies during the first year post stroke. Whereas some have reported unchanged HRQOL (97), others have found improved (150) or decreased (151) HRQOL. Guidetti (152) and Bouffioulx, using stroke-specific instruments (125), both reported a combination of improvement and decline across different domains during the first year post stroke.

No consistent predictors for changes in HRQOL post stroke have been described (121,152).

We therefore wanted to investigate factors that might explain changes in satisfaction with functioning post stroke.

1.5 The aims of the thesis

This thesis includes four aims as listed below.

1) To investigate whether the patient-reported HRQOL instrument, the QOLIBRI-OS, which has been validated in those with traumatic brain injury, is a reliable and valid questionnaire in stroke populations.
2) To investigate the level of satisfaction with functioning and well-being using the QOLIBRI-OS and to investigate factors enhancing the fulfilment of rehabilitation needs 3 months post stroke in Norwegian and Danish cohorts.
3) To investigate the correlation between satisfaction with functioning and met, unmet or no needs for help and training.
4) To investigate factors that might explain changes in satisfaction with functioning and well-being during the first year post stroke.

2 Methods

2.1 Design

Multicenter observational cohort study. Patients hospitalized at stroke units at one hospital with three locations in Norway and one hospital in Denmark were recruited. Data were collected at 3 and 12 months post stroke.

2.2 Setting

In Norway, the catchment area of the University Hospital of North Norway, which includes 30 municipalities with populations varying from 870 to 72671 inhabitants, was chosen as the study area (*https://www.ssb.no/kommunefakta, 2015).* The total population in the region was approximately 190.000 in 2015.

In Denmark, patients living in the central region of Denmark in the catchment area of the Aarhus University Hospital in either the Favrskov municipality (47.655 citizens) or the Randers municipality (90.800 citizens) were included (Figure 2) (Danmarks Statistik, søgning 01.01.2016). The two regions differ vastly in area, as the University Hospital of North Norway covers 33.400 km^2, whereas the Danish region covers 1300 km^2.

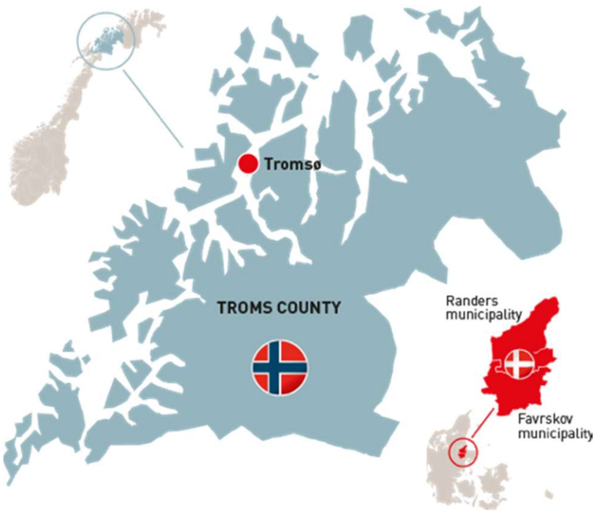


Figure 2: Study area map of Troms, Norway, and Aarhus, Denmark.

2.3 Inclusion and exclusion criteria

Patients with first-ever stroke treated in a stroke unit were consecutively included.

The criteria for stroke diagnosis were based on the ICD-10 (153) codes I.63 (cerebral infarction) or I.61 (nontraumatic intracerebral hemorrhage).

Inclusion was limited to patients above 17 years of age. Only patients living in a predefined geographical area were included. All included patients fulfilled the inclusion criteria of the national stroke registries.

Patients with stroke due to malignancy or subarachnoid hemorrhage were excluded.

Cognitive impairment, aphasia or comorbidity was not defined as an exclusion criterion per se. Patients with difficulties completing questionnaires were invited to participate by using a shorter proxy form that could be completed with the help of relatives.

The inclusion period lasted from 15.03.14 until 31.12.15.

2.4 Data sources

This thesis is based on data from three main sources: a questionnaire package, structured recordings from a telephone interview and data from the national stroke registries in Norway and Denmark.

The questionnaire collected baseline data and data at 12 and 52 weeks post stroke. Additional data for assessing test-retest reliability of the QOLIBRI-OS were collected at week 54.

An overview of the included variables and data sources is given in Table 1.

Table 1: Variables, data sources and timepoints for data assessment used in papers 1, 2 and 3.

Type of data	Data source	Poststroke timepoints for data collection				Paper 1	Paper 2	Paper 3
Timepoint		Baseline	12 weeks	52 weeks	54 weeks			
Demographics								
Age	Registry	x				x	x	x
Sex	Registry	x				x	x	x
Need for help	Questionnaire	x	x	x		x	x	x
Living conditions	Questionnaire	x	x	x		x	x	x
Working status	Questionnaire	x	x	x		x	x	x
Education	Questionnaire	x				x	x	
Marital status	Questionnaire	x	x	x		x	x	x
Stroke characteristics								
Stroke subtype	Registry	x				x	x	x
Stroke severity	Registry Medical records	x					x	x
Thrombolysis	Registry	x					x	x
Length of stay in stroke unit	Registry	x					x	x
Single items								
Received enough training? Yes/No/No need	Registry		x					x
Received enough help? Yes/No/No need	Registry		x					x
Scales								
QOLIBRI-OS								
Satisfaction with physical function	Questionnaire		x	x	x	x	x	

Satisfaction with emotional status	Questionnaire		x	x	x	x	x	
Satisfaction with cognitive ability	Questionnaire		x	x	x	x	x	
Satisfaction with activities of daily living	Questionnaire		x	x	x	x	x	
Personal factors	Questionnaire		x	x	x	x	x	
Present and future prospects	Questionnaire		x	x	x	x	x	
HADS								
HADS total score	Questionnaire		x	x		x	x	
HADS Depression	Questionnaire		x	x		x	x	x
HADS Anxiety	Questionnaire		x	x		x	x	x
EQ5D								
EQ5D mobility	Questionnaire		x	x		x		
EQ5D usual care	Questionnaire		x	x		x		
EQ- VAS	Questionnaire		x	x		x		
SS-QOL								
SS-QOL sum score	Questionnaire		x	x		x		
SS-QOL sum thinking	Questionnaire		x	x		x		
SS-QOL sum mood	Questionnaire	x	x	x		x		
SS-QOL sum social role	Questionnaire		x	x		x		
Modified Rankin scale	Registry, 12 weeks Questionnaire, 52 weeks		x	x		x		x
Type of rehabilitation services	Telephone interview, Registry, Medical records		x				x	x

2.4.1 Questionnaire package

The project management, consisting of researchers from UNN and Hammel Neurocenter, Aarhus University in Denmark, designed a questionnaire package titled "Rehabilitation pathways, functioning and quality of life following stroke" (Appendix 1 and 2).

This package included demographic data collection forms and a number of validated questionnaires, which are presented on page 24. The selection of questionnaires was the result of a careful review by the project management regarding the need for measures covering clinical and functional aspects as well as patient experiences of consequences and satisfaction with functioning after stroke (84).

The instruments covered multi-item disease-specific and generic health-related measures as well as some single questions (84). Levels of anxiety and depression were also recorded.

The 3-month mailed questionnaire gathered pre- and post-stroke data on marital status, education, working or social security status, living conditions and need for care that supplemented registry data (Appendix 3 and 4).

The 12-month questionnaire set was identical to the 3-month questionnaire set except that it included the modified Rankin scale (mRS) and did not record education information (Appendix 5 and 6). At 3 months, the mRS scores were collected as a part of the Norwegian Stroke follow-up registry.

The proxy form, which could be filled out by caregivers, was identical to the first 2 pages of the 3- and 12-month questionnaires. The proxy questionnaire included basic information about demographics and mRS scores at 12 months and was used to provide background information about the stroke cohort.

The questionnaire sets from both countries are included in the appendix.

Data from the questionnaire package regarding smoking, self-reported level of poststroke improvement, need for care, and satisfaction with treatment and rehabilitation were not used in this thesis.

2.4.2 Specific data retrieved from the national registries

Information about sex, age and pre-stroke living conditions, such as living alone or receiving help; stroke subtype; stroke severity; thrombolysis; thrombectomy; and length of stay (LOS) in a stroke unit, was obtained from the stroke registries in Norway and Denmark (Appendix 9).

Questions about met/unmet or no need for care or rehabilitation were collected from the Norwegian national follow-up stroke registry (Appendix 10).

2.4.3 Telephone interview at 3 months

The telephone interview at 3 months included a study-specific addition to the compulsory follow-up national stroke registry registration in Norway (Appendix 7) and was performed by the staff responsible for collecting national stroke registry data. In Denmark, due to the lack of follow-up by the national stroke registry, selected questions from the Norwegian follow-up registry and the same study-specific additions, including detailed rehabilitation data and questions about met/unmet or no need for care or rehabilitation, were collected within a month post stroke by a member of the study group.

2.4.4 Similarities and differences in data collection procedures in Norway and Denmark

The procedures followed in this study, e.g., data recording or collection procedures, were intentionally conducted in a similar manner but differed between the countries in some areas based on legal and practical reasons, which are outlined below.

Regarding study inclusion, we used the ICD-10 definition of ischemic and hemorrhagic stroke and had common exclusion criteria. The national registries, however, define stroke in different manners, as the Norwegian registry includes patients with stroke up to 28 days post stroke, whereas in Denmark, the time limit for registration in the stroke registry is 7 days (154). However, no Norwegian patient in the study was included later than one week post stroke.

The recruitment process also differed. In Norway, patients were recruited at the stroke unit or at the 3 months poststroke national registry follow-up by study personnel inviting patients to participate in the study. All Norwegian patients provided written consent.

In Denmark, study personnel received a list of patients with stroke from the national registry. These patients received a questionnaire. Those who responded to this questionnaire or answered the follow-up telephone interview at 3 months became consenting participants in the Danish part of the study. Only Norway has a national 3-month follow-up of National Stroke Registry data. To compensate for this difference, selected data from the 3-month follow-up in Norway were collected during the telephone interview at 3 months in Denmark.

The time span for inclusion was initially planned to be 15.03.14 through 31.12.15. Due to unforeseen delays in Denmark, the recruitment process did not start until 01.06.14. Both studies were terminated according to the plan at the end of 2015.

In the period from the 15.03.14 until 01.06.14, a total of 45 surviving Norwegian patients were recruited.

The telephone interview at 3 months included a study-specific addition to the compulsory follow-up national stroke registry registration in Norway and was performed by the staff responsible for collecting national stroke registry data. In Denmark, selected questions from the Norwegian follow-up registry and the same study-specific addition, including detailed rehabilitation data, were collected by a member of the study group

See Appendix 8 for the Danish version of the three-month telephone interview.

We had access to medical records to obtain supplementary data for consenting patients in Norway but not in Denmark.

The differences in the way questions were formulated in the two national stroke registries were adjusted for, and similar questions were selected. The study-specific questionnaire sets “Rehabilitation pathways, functioning and quality of life after stroke” were identical, as were the 3- and 12-month timepoints for assessment in the two countries.

Approval procedures differed between the countries, and approval by the Committee for Medical Research Ethics was claimed only in Norway.

2.5 Measurements

2.5.1 QOLIBRI-OS (Quality of Life after Brain Injury-Overall Scale)

This scale was originally developed as a short version of the 37-item QOLIBRI (Quality of Life after Brain Injury) Scale (155) for measuring patient-reported satisfaction with functioning and well-being after traumatic brain injury (128). The QOLIBRI-OS was validated by the study group (156) for patients with stroke in paper 1 and conducted in collaboration with the original author of the scale.

The original English version (128) of the QOLIBRI-OS items are as follows:
Overall, how satisfied are you now and including the past week:

- With your physical condition?
- With how your brain is working, in terms of your concentration, memory, thinking?
- With your feelings and emotions?
- With your ability to carry out day to day activities?
- With your personal and social life?
- With your current situation and future prospects?

Scoring on a Likert scale ranging from 1 to 5 (1-not at all, 2-slightly, 3-moderately, 4-quite and 5-very) yielded a total score range of 6-30, which was converted to a 0-100 percentage score (128).

In the present study, both the raw item scores and the overall sum scores were used.

Internal consistency measured with Cronbach's α revealed a value of 0.86 in patients after traumatic brain injury (128) and a similar value of 0.88 in patients with subarachnoid hemorrhage. The scale has good validity for patients with traumatic brain injuries (128).

In 2020, a version of the QOLIBRI-OS was transformed to utility scores for use in economic analyses was published (157). In this version, the item regarding the current situation and future prospects has been removed. A value set for assessing HRQOL among patients with TBI in Italy, the Netherlands and the United Kingdom has been derived.

2.5.2 Stroke Specific Quality of Life (SS-QOL)

The Stroke Specific Quality of Life (SS-QOL) scale (158) is a 49-item multidimensional questionnaire assessing the functional impact of stroke. The questionnaire was translated into Norwegian by the study group (112).

The SS-QOL assessed poststroke functioning across the following 12 domains: mobility, energy, upper extremity function, work and productivity, mood, self-care, social roles, family roles, vision, language, thinking, and personality. Items are scored on a Likert scale (range 1-5), with higher scores indicating better functioning. The SS-QOL overall score is most commonly used as the primary outcome; however, the domain scores are helpful for identifying specific areas that are affected by stroke (158). The reliability of the SS-QOL is good and has been investigated both in Norway (112) and in Denmark (159), with Cronbach's α 79-.93 and α=.81-.94, respectively. The construct validity of both the Norwegian (112) and Danish versions of the scale has been well supported (160).

Both sum scale scores and some domain scores were used in the validation study in paper 1.

2.5.3 EQ5D-3L

The EQ5D-3L, the EuroQol Five Dimensions Questionnaire (EQ-5D)(161) is a generic instrument developed to measure health outcomes and is often used in health-economic analyses.

The EQ5D-3L (161) is a three-level health-related quality of life (HRQOL) questionnaire comprising 5 items rating mobility, self-care, ability to perform daily activities, pain/discomfort, and anxiety and depression. Each dimension has 3 response categories: no problems (1), some problems (2) and severe problems (3). Patient-reported responses to items 1, 2 and 3 are combined into a three-digit number defining the level of health outcome, where 111 indicates the best and 333 the worst outcome. These digit numbers may also be converted to a single utility index using country-specific value sets (161).

Single item scores may also be used.

The scale is extensively used and has good psychometric properties (162). Reliability analysis shows Cronbach's alpha at .93 for patients with stroke (163), and the instrument appears to have acceptable concurrent and discriminant validity for the measurement of health-related quality of life after stroke (164).

The **EQ-VAS** (165) is a 0-100 visual analog scale intended to measure actual self-reported health status. The patient is asked to indicate their perceived HRQOL by marking one point on the vertical axis that measures worst to best imaginable health.

The scale has been shown to correspond both to the EQ5D (165) and to disease-specific instruments (166).

Both the EQ-5D and EQ-VAS were used in paper 1.

2.5.4 Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS), as originally published by Zigmond and Snaith (167) in 1983, is a widely used instrument that screens for symptoms of anxiety (7 items) and depression (7 items). The scale is favorable for use in patient samples, as it screens for nonvegetative mood-related symptoms that are less affected by somatic symptoms, such as fatigue or sleeping problems (168).

The HADS items are scored from 0 to 3, with higher scores indicating worse symptoms, and a total range of 0-21 for each subscale. A cutoff score of 8 is commonly used as an indication of anxiety or depression that may pass diagnostic threshold levels and require treatment(169).

The total score (HADS-14) can also be used as a global measure of psychological distress (170). The psychometric properties of the HADS are acceptable (171). Confirmatory factor analyses (CFA) in stroke groups confirmed separate assessments of anxiety and depression (172).

The questionnaire has been applied several times in Norwegian populations (173) and also in poststroke populations (174).

The HADS was used in all papers.

2.5.5 Modified Rankin scale (mRS)

The gross level of functioning was assessed using the modified Rankin scale (mRS), which is the most frequent outcome measure used in stroke studies (175).

The mRS is a clinician-reported measure of global disability widely used to evaluate poststroke outcomes. The scale consists of categories assessing the level of independence, ranging from completely independent to bedridden or death. The range of scores is between 0, representing no problems at all, and 5, which indicates total help dependency. An mRS score of 0-2 is often defined as a favorable outcome in stroke studies (176).

Convergent validity between the mRS and other disability scales has been well documented (177).

Numerous studies have demonstrated the construct validity of the mRS by its relationships to physiological indicators such as stroke type, lesion size, perfusion and neurological impairment (177).

Interrater reliability has been regarded as moderate (178).

The mRS scale with 6 categories was used in papers 1 and 3.

2.6 Assessing stroke severity

Stroke severity was defined within 24 hours after admission to the hospital. Data were collected from the national registries. In Norway, the National Institute of Health Stroke Scale (NIHSS) (179) is used to measure neurological impairment after stroke, while the Scandinavian Stroke Scale (SSS) (180) is the preferred scale to determine stroke severity in Denmark. Both scales grade common neurologic impairments, but they also differ in some clinical aspects. Only the SSS measures hand strength, while only the NIHSS measures neglect. No impairment measured with the SSS is indicated by a score of 58/58, while a score of 0/42 on the NIHSS is considered the optimal outcome.

The scales are regarded as equivalent (181).

In handling data from both Norway and Denmark, we chose to use the SSS, as data from the Danish National Stroke Registry were more complete than those in the Norwegian Stroke Registry. Missing Norwegian NIHSS scores, a which occurred in 40.9% of the sample, were retrospectively coded from medical records by an experienced clinician.

All conversions from NIHSS scores to SSS scores were made using the unadjusted mathematical model from Grey et al. (182), which was derived for interconversion between these two stroke scales.

Figure 3, made by Asger Roer Pedersen, statistician in the study group, indicates less matching between the NHISS and SSS raw scales in the highest and lowest parts of the scale.

To enhance interoperability, and since the patient population used to develop the interconversion model did not include persons with NIHSS scores 0-3 (182), and there were very scarce data in the most severe part of the scale defined as NIHSS scores above 15, we classified this part of the Norwegian patient population retrospectively by using medical records.

The SSS sum scores were divided into 4 categories: an SSS score of 0-14 indicated very severe stroke, 15-29 indicated severe stroke, 30-44 indicated moderate stroke and 45-58 indicated mild impairment post stroke.

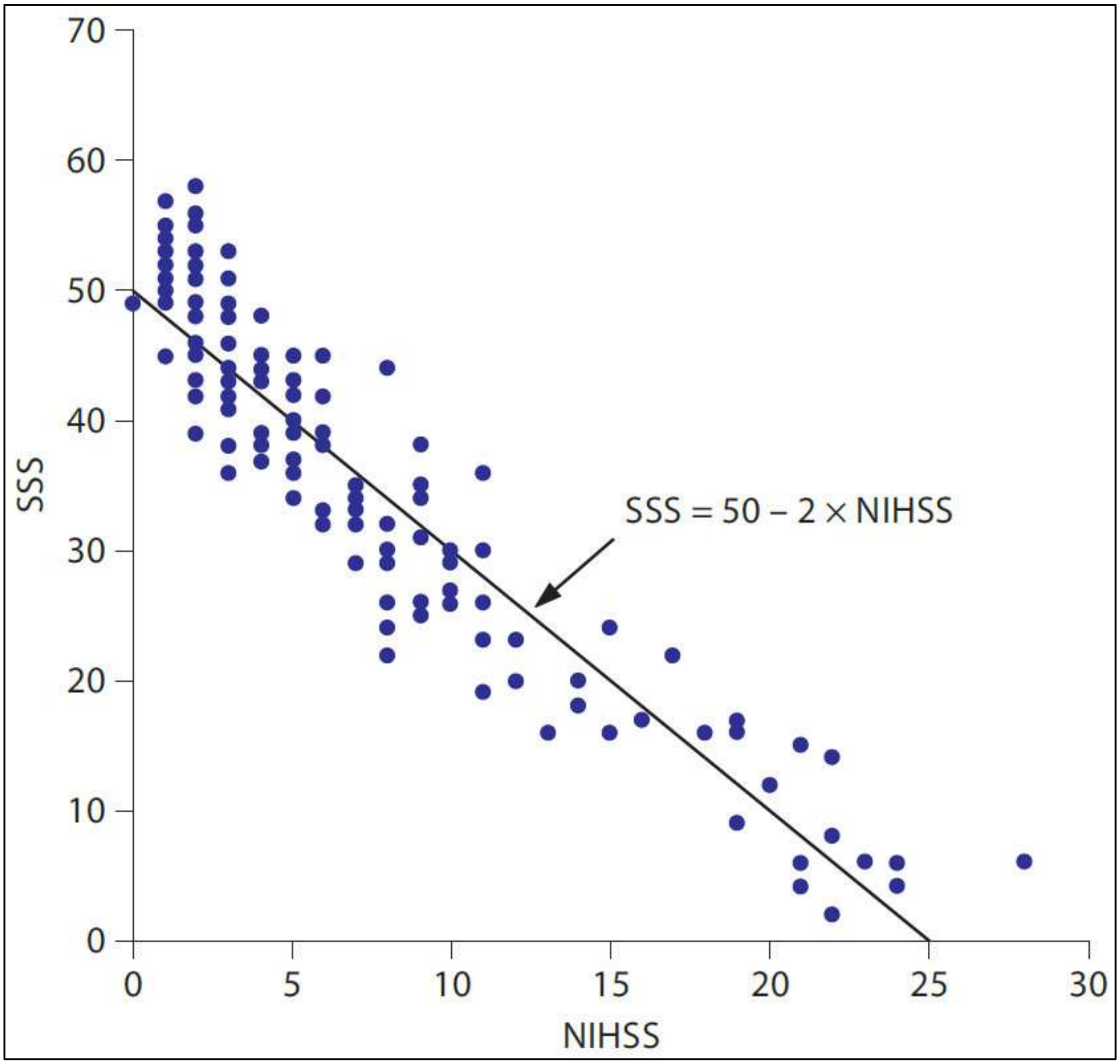


Figure 3: Correspondence between SSS and NIHSS scores in patients with stroke.

2.7 Assessing help and rehabilitation needs

Help and rehabilitation needs were assessed at 3 months post stroke using the following two questions from the Norwegian Stroke Registry follow-up questionnaire:

1. Have you received enough help after the stroke?
2. Have you received as much training as you wanted after the stroke?

Response options were yes (met need), no (unmet need), no need and unknown. Patients who answered one or both of these questions were included as participants. The term training in this context was used to refer to all rehabilitative therapy offered by physio, occupational therapists or speech therapists. The term help was used to refer to care provided by health professionals.

2.8 Unpublished analysis for the thesis

Data from papers 2 and 3 were combined to assess the relationship between rehabilitation needs (met, unmet or no needs for help and training) and QOLIBRI-OS scores.

Correlations between rehabilitation needs and HADS-A and HADS-D scores were explored.

National and regional registry data from 2015 were compared to the study cohort.

2.9 Statistical Methods

Statistical analyses, with the exception of factor analyses in paper 1, were conducted in IBM SPSS versions 23- 26. The descriptive statistics are presented as percentages, medians with interquartile ranges or means with 95% confidence intervals (CIs). Simple group difference testing based on continuous and categorical data was performed with independent t-tests and chi-square tests, respectively. Repeated measurements were performed with paired sample t-tests. Correlations between samples were investigated with Pearson’s (183) or Spearman's rank (184) correlation coefficients.

In the case of small sample sizes within contingency tables, Fisher’s exact test was used (185).

The distribution of the variables were visually examined using normal probability plots (186).

In the case of heavily skewed data, the Mann-Whitney U test was applied for group difference tests with continuous data.

2.9.1 Linear regression

Linear regression analysis (187) is a statistical method for estimating the degree of relationship between an independent (predictor) variable and a dependent (outcome) variable. Multivariable regression extends the linear model by adding multiple independent variables and assessing their unique contribution in explaining the outcome variable based on the correlation between the covariates.

Linear regression (paper 2) was specified hierarchically in four blocks (country; age, sex, prestroke social situation, dependency, and working situation; SSS, stroke subtype, thrombolysis, and LOS; HADS anxiety and HADS depression).

We report unstandardized beta coefficients because the QOLIBRI-OS score range of 0–100 is a well-established metric. The alpha level was set to .05 as a threshold for discarding null hypotheses ($p < .05$). The VIF (variance inflation)(188) estimate was consulted to examine whether the degree of multicollinearity between the predictors was within tolerable limits. The regression-based residual scores were examined with regard to normality and homoscedasticity.

Key assumptions of regression analyses are (i) relatively normally distributed residual scores, (ii) absence of significant nonlinear relationships (i.e., linearity), (iii) absence of heteroscedastic residuals (i.e., different precision at different levels of the outcome variable), and (iv) few or preferably no outliers or highly influential observations.

The explained variance of each block is reported as the adjusted R^2, which penalizes increasingly complex regression models by lowering the R^2 estimate.

2.9.2 Logistic regression

Logistic regression is a commonly used, robust and efficient method to study the effect of independent variables on a binary outcome. The outcome of the logistic regression is the odds ratio (OR), which is the odds of an event occurring given some risk exposure to the odds of the same event occurring in the absence of the risk exposure (189).

An OR of 1 means that the odds are the same in the two comparison groups, while an OR greater than 1 indicates that the event is more likely to occur in the exposed group than in the unexposed group.

Correspondingly, an OR less than 1 indicates that the event is more unlikely in the exposed group. A 95% confidence interval (CI) is routinely added to the OR estimate to indicate the degree of precision.

Logistic regression analyses (papers 2 and 3) are presented with both univariate (single independent variable) and multivariate (multiple independent variables) regression. An alpha level of <.05 was required to discard the null hypothesis.

Logistic regression typically requires a large sample size and is based on the following assumptions: (i) independent observations (lack of correlations between cases or observations), (ii) an acceptable low degree of multicollinearity between the independent variables, (iii) few or preferably no extreme observations (outliers) in the continuous predictors, and (iv) a linear relationship between the independent variables and the log odds of the outcome variable. All data fulfilled the key assumptions.

The results are presented as adjusted odds ratios (ORs). Model fit was investigated with the Hosmer and Lemeshow test to assess the agreement between the observed and predicted outcomes of our models. The degree of pseudo-explained variance is reported based on Nagelkerke's R^2.

2.9.3 Minimal clinically important difference

Minimal clinically important difference (MCID) scores are commonly used by clinicians and in research when determining patient response to treatment and to guide clinical decision-making during the course of treatment.

The MCID defined as the score calculated with the standard error of measurement (SEM) formula, i.e., $\mathrm{SEM} = \mathrm{SD}\sqrt{1 - \mathrm{r_{xx}}}$. The SEM indicates the minimum raw score change that reflects a true change beyond measurement error, thus avoiding interpreting change scores lower than the SEM score as reflecting a true change since measurement error is the prime reason for the observed change. A difference of at least one SEM has been used to define the MCID (190), but we chose to use stricter criteria by multiplying it by Z = 1.96 to improve the confidence intervals. Thus, a calculated SEM of six yields an MCID of 12 points for the total QOLIBRI-OS. Effect sizes were calculated with Cohen's d. A value below 0.5 was regarded as a small, 0.5-0.8 was considered a medium, and greater than 0.8 was considered a large effect size (191,192).

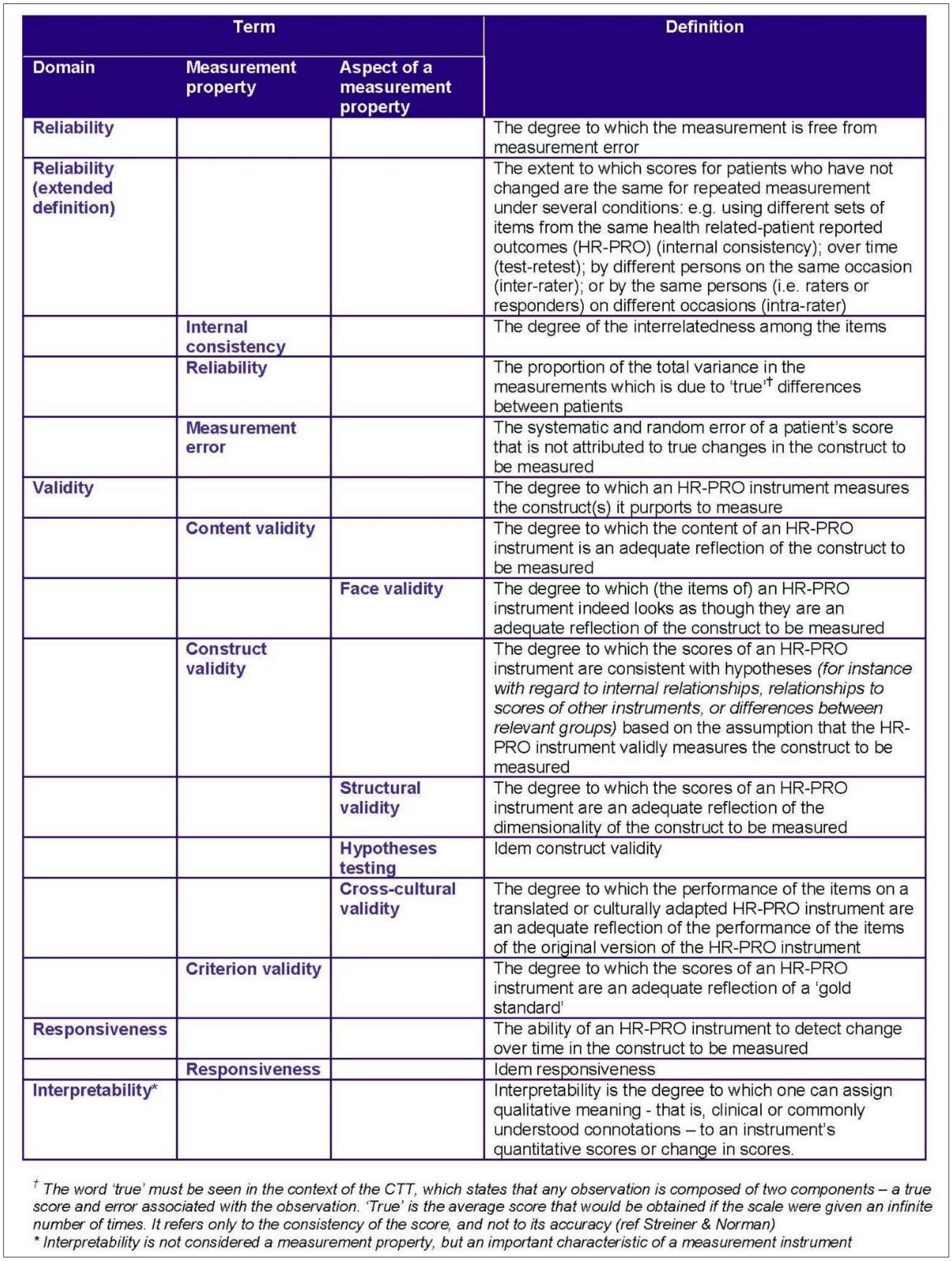
2.9.4 Psychometric analyses of QOLIBRI-OS (paper 1)

The Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) guidelines (193) were used as guidelines for the validation study.

The psychometric and classical test theory confirmatory factor analyses (194) were conducted in Mplus version 7.4 (Muthen & Muthen, 1998-2012).

See Table 2 for the COSMIN definition of reliability, validity and measurement properties.

Table 2: COSMIN definition of reliability, validity and measurement properties.



Term			Definition
Domain	**Measurement property**	**Aspect of a measurement property**	
Reliability			The degree to which the measurement is free from measurement error
Reliability (extended definition)			The extent to which scores for patients who have not changed are the same for repeated measurement under several conditions: e.g. using different sets of items from the same health related-patient reported outcomes (HR-PRO) (internal consistency); over time (test-retest); by different persons on the same occasion (inter-rater); or by the same persons (i.e. raters or responders) on different occasions (intra-rater)
	Internal consistency		The degree of the interrelatedness among the items
	Reliability		The proportion of the total variance in the measurements which is due to 'true'[†] differences between patients
	Measurement error		The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured
Validity			The degree to which an HR-PRO instrument measures the construct(s) it purports to measure
	Content validity		The degree to which the content of an HR-PRO instrument is an adequate reflection of the construct to be measured
		Face validity	The degree to which (the items of) an HR-PRO instrument indeed looks as though they are an adequate reflection of the construct to be measured
	Construct validity		The degree to which the scores of an HR-PRO instrument are consistent with hypotheses *(for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups)* based on the assumption that the HR-PRO instrument validly measures the construct to be measured
		Structural validity	The degree to which the scores of an HR-PRO instrument are an adequate reflection of the dimensionality of the construct to be measured
		Hypotheses testing	Idem construct validity
		Cross-cultural validity	The degree to which the performance of the items on a translated or culturally adapted HR-PRO instrument are an adequate reflection of the performance of the items of the original version of the HR-PRO instrument
	Criterion validity		The degree to which the scores of an HR-PRO instrument are an adequate reflection of a 'gold standard'
Responsiveness			The ability of an HR-PRO instrument to detect change over time in the construct to be measured
	Responsiveness		Idem responsiveness
Interpretability*			Interpretability is the degree to which one can assign qualitative meaning - that is, clinical or commonly understood connotations – to an instrument's quantitative scores or change in scores.

[†] *The word 'true' must be seen in the context of the CTT, which states that any observation is composed of two components – a true score and error associated with the observation. 'True' is the average score that would be obtained if the scale were given an infinite number of times. It refers only to the consistency of the score, and not to its accuracy (ref Streiner & Norman)*

* *Interpretability is not considered a measurement property, but an important characteristic of a measurement instrument*

Reprinted text from the Journal of Clinical Epidemiology, Volume 63/Issue 7, Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, Bouter LM, de Wet HC. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes, p.743. Copyright (2010), with permission from Elsevier dated 06.05.2021.

The COSMIN definitions define the optimal standards for the investigation of the psychometric properties of the instrument of interest.

The reliability of the questionnaire scale sum scores was examined with Cronbach's alpha as an indication of internal consistency and with test-retest associations as an indication of stability. Internal consistency values larger than 0.70 are generally recommended for research purposes (e.g., group comparisons), whereas values above 0.90 are desirable for individual clinical assessment (189). Item-total correlations between the QOLIBRI-OS items and its total score were examined, and values > 0.40 are preferable (195), as low item-total correlations may identify items contributing poorly to the reliability or the ranking of the patients.

The first 40 participants who answered at 12 months were asked to complete the retest in a 7- to 12-day period.

Test-retest reliability was evaluated with intraclass correlation coefficients (ICCs)(196,197) based on a two-way mixed model (i.e., treating items and subjects as fixed and random components, respectively). Both ICC absolute agreement and ICC consistency estimates were extracted for comparison purposes (197).

ICC consistency values > 0.75 were considered excellent.

Subsets of items are considered to be unidimensional if the variance in the items is primarily correlated to a single latent variable (198), which we examined using confirmatory factor analysis (CFA) (199).

CFA was conducted to examine the extent to which the QOLIBRI-OS fit a unidimensional model.

The maximum likelihood with robust standard errors (MLR) was applied, as the item variances were substantially nonnormal. Model fit was evaluated in terms of the root mean square error of approximation (RMSEA), standardized root mean square residual (SRMR), comparative fit index (CFI) and non-normed fit index (NNFI) (200). West et al. (200) suggested that RMSEA < 0.05, CFI > 0.95, NNFI > 0.90 and SRMR < 0.06 represent a well-fitting model, while CFI > 0.90, NNFI > 0.85, RMSEA < 0.08, and SRMR < 0.10 indicate a tentatively adequate model.

If these fit indices are within acceptable limits, the measurement model accounts well for the correlations between the actual observed patient data.

Validity has several aspects and is used to ensure that the instrument measures what it is intended to measure.

The QOLIBRI-OS was chosen based on the instruments´ ability to mirror a brain-specific condition, where items measuring cognitive function in addition to physical and emotional function are essential for content validity.

In developing the original QOLIBRI instrument, the international group of researchers (128) followed the principles listed in the COSMIN Risk of Bias checklist (Cosmin.nl).

To investigate construct validity (201), analyses of the a priori hypotheses (202) were tested using measures reflecting the construct to be measured from the questionnaire set. If a priori hypothesis tests showed correlations with the selected other validated measures in the presumed directions and magnitude, this was accepted as an indication of construct validity (202).

A complete cross-cultural adaption was not done (203,204), but forward and backward translation of the instrument from English to Norwegian was performed. Structural validity was investigated using confirmatory factor analysis. In the development of the QOLIBRI-OS scale (128), a Rasch analysis was performed showing, despite marginal misfits to the model, that the six items representing the QOLIBRI-OS could establish a Rasch scale (205).

2.10 Ethics

The study is based on the principles stated in the Helsinki Declaration regarding research involving human subjects (206) In Norway, the study was approved by the Committee for Medical Research Ethics, Health Region North (reference no. 2013/1472)(Appendix1). Approval from the Central Denmark Region Committees of Biomedical and Research Ethics (reference no. 202/2013) was not needed due to the study design.

Participation in an observational study represents no risk for the participants.

All participants received written information about the study before signing the consent form(Appendix 2).

A contact person in the research group was available to provide further information during the study period. The participants had the ability to withdraw from the study at any time.

Caregivers were invited to give consent on behalf of persons who, because of cognitive or communication deficits, were unable to sign themselves. Due to ethical considerations discussed by the study group, 25 persons in Norway with serious comorbidities were not asked to participate in the study.

Patients could have physical assistance filling in the questionnaire as long as they answered the questions themselves.

Data were stored a secure server at the University Hospital of North Norway, in line with the policy for secure storage.

3 Results

3.1 Patient sample

In total, 920 patients with first-ever stroke (518 in Norway and 402 in Denmark) were admitted to a stroke unit in the defined geographic regions during the inclusion period.

During the first 3 months post stroke, a total of 13% of both stroke cohorts died, resulting in 348 surviving patients in Denmark and 451 in Norway. At 12 months 81% of the cohort was alive.

The numbers of included patients in the different papers are given in flowcharts presented in Figure 4 and Figure 5. In the following, included patients from both countries are presented as the study cohort.

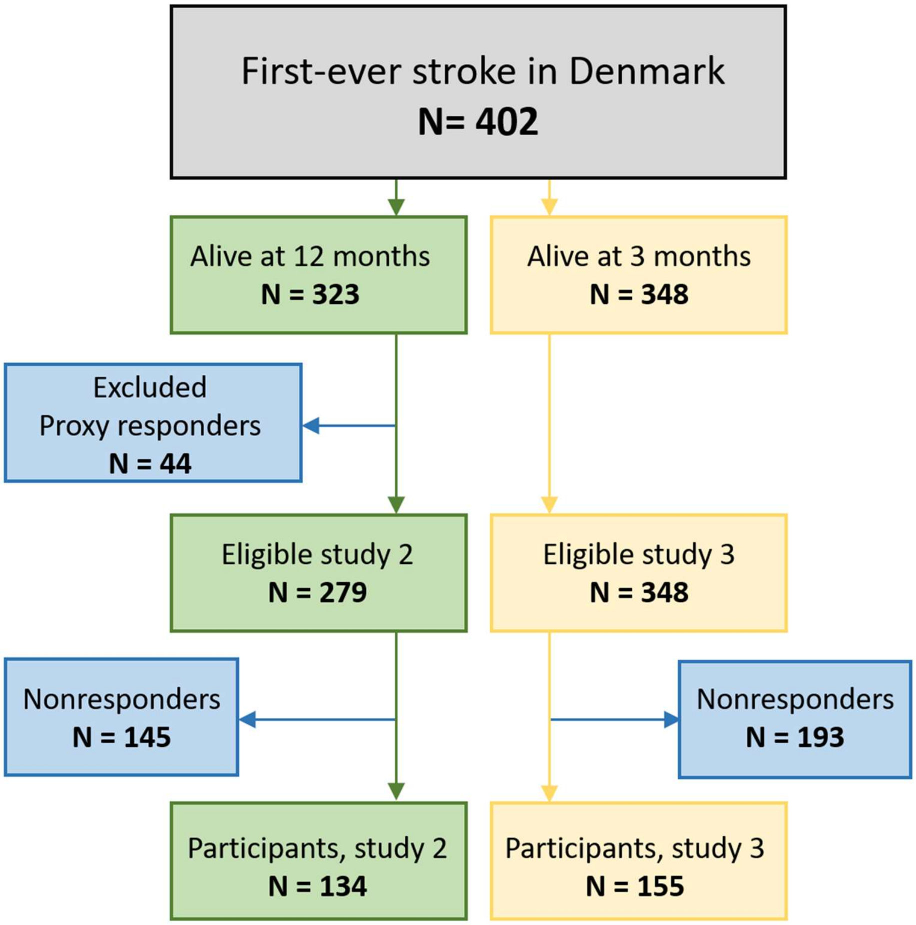


Figure 4: Flowchart for papers 2 and 3, Denmark.

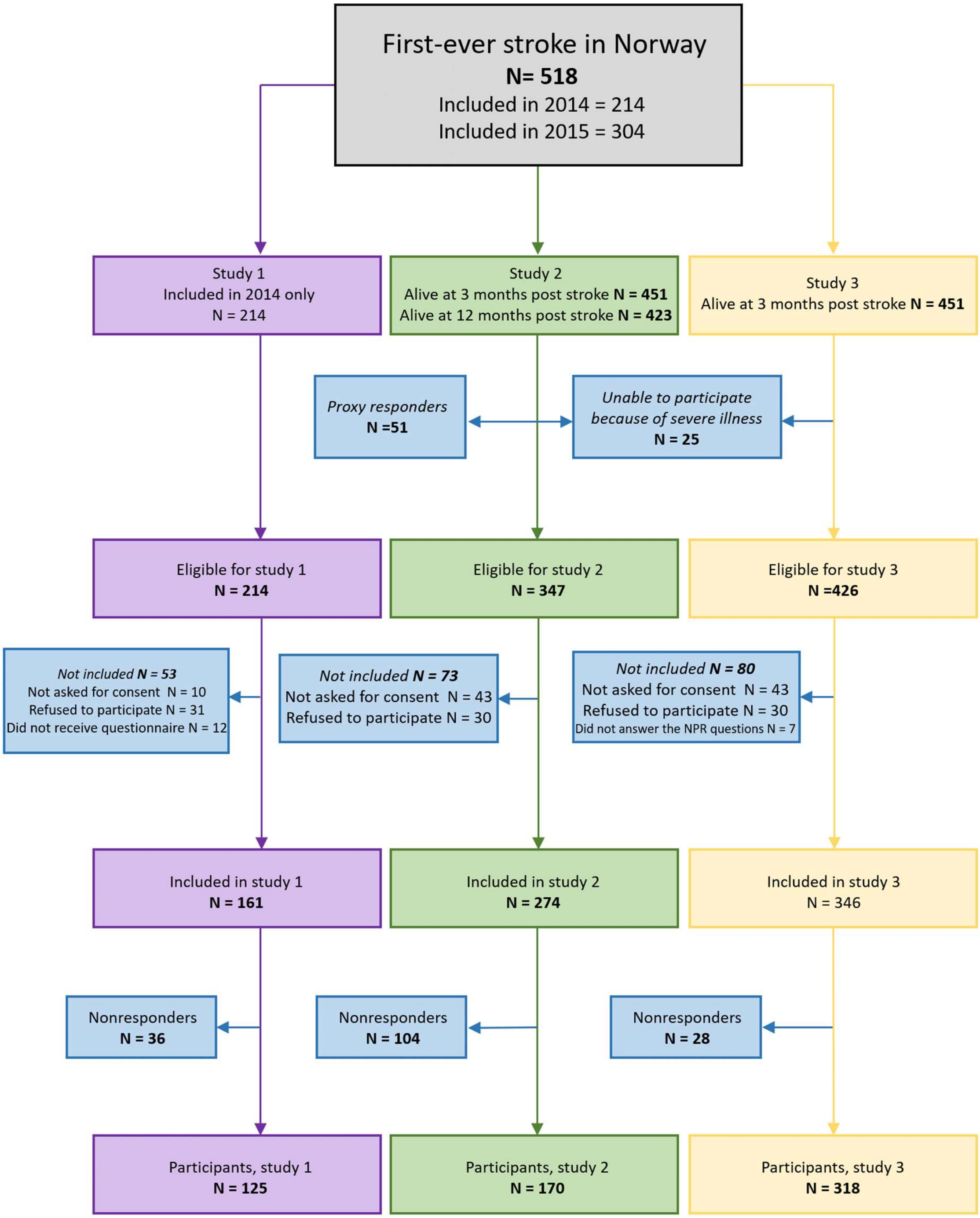


Figure 5: Flowchart for papers 1, 2 and 3, Norway.

3.2 Summary of papers

3.2.1 Summary of paper 1

Objectives: The aim of the study was to validate the patient-reported questionnaire QOLIBRI-OS, originally developed for patients with traumatic brain injury, in a population of patients with ischemic and hemorrhagic stroke.

Participants: A total of 125 patients with first-ever stroke in 2014 participated.

Mean age was 70,5 years, and 56% were men.

Design: Norwegian participants with stroke answered the QOLIBRI-OS questionnaire at 52 weeks post stroke. They also completed other validated questionnaires (HADS, SS-QOL, EQ5D and EQ-VAS) to assess construct validity. A total of 36 patients completed the QOLIBRI-OS at 54 weeks for a test-retest analysis.

Results: Missing responses on the questionnaire were low (0.5%). All items were positive skewed. No floor effects were present, whereas five out of six items showed ceiling effects. The summary QOLIBRI-OS score exhibited no floor or ceiling effects and had excellent internal consistency (Cronbach's α =0.93). All item-total correlations were high (0.73-0.88).

The test-retest reliability of single items varied from 0.74 to 0.91 and was 0.93 for the overall score. The intraclass correlation coefficient (ICC) estimates indicated that participants interpreted the response scale similarly at both measurement occasions.

The confirmatory factor analysis yielded an excellent fit for a five-item version that excluded the item on emotion and provided tentative support for the original six-item version. The convergent validity correlations were in the hypothesized directions, thus supporting the construct validity. The content validity of the QOLIBRI-OS for stroke would be further improved by adding an item measuring language and communicative skills and another item assessing motor function.

Conclusion: The QOLIBRI-OS questionnaire seems to be a suitable instrument for assessing satisfaction with functioning and well-being after hemorrhagic and ischemic stroke.

Study 1 provides background for the discussion of aim 1.

3.2.2 Summary of paper 2

Objectives**:** The objective of this study was to investigate levels of satisfaction with functioning and changes in health-related quality of life in a Norwegian and Danish cohort.

Participants**:** A total of 304 patients, 170 from Norway and 134 from Denmark, participated. The mean age was 68, 7 years, and 59% of the participants were men.

Design**:** The QOLIBRI-OS questionnaire was administered twice and was used to measure both levels of satisfaction and change from 3 to 12 months post stroke.

Results: Age, sex and stroke severity were comparable between the cohorts, whereas more Danish patients were working before the stroke (p=0.006). The difference in QOLIBRI-OS scores at three months was nonsignificant (p=0.08), but higher scores indicated a higher level of poststroke satisfaction in Norway at 12 months (p=0.02; Cohen´s d=0.26). Half of the participants experienced clinically important changes in QOLIBRI-OS scores between three and 12 months post stroke. Based on a minimal clinically important difference classification, 20% reported worse, 54% were unchanged and 26% reported better QOLIBRI-OS scores between three and 12 months. Logistic regression analysis revealed that age below 65 years predicted a negative change (OR=0.4, p=0.007). No variables predicted a positive change in HRQOL.

Conclusion: At 3 months, no difference in perceived satisfaction with functioning between the countries was observed. The Norwegian participants reported slightly better HRQOL at 12 months. There was no change in satisfaction at the group level, but almost 50% of the participants described clinically relevant changes from 3 to 12 months post stroke. Age below 65 years predicted a negative change. No variables predicted a positive change.

Study 2 provides a basis for the discussion of aims 2 and 3.

3.2.3 Summary of paper 3

Objectives: The objectives of the study were to examine patient-reported needs for health care and rehabilitation services in a cohort recruited from regions in two Nordic countries. The second objective was to assess the extent to which these needs were met or unmet three months post stroke and explored factors associated with met and unmet needs.

Participants: A total of 318 Norwegian and 155 Danish patients with first-ever stroke were included. The mean age was 71.1 years, and 57% were men.

Design: The participants answered questions from the Norwegian Stroke Registry about perceived met or, unmet or lack of need for help and training during the first 3 months post stroke.

Results: A total of 15% reported unmet needs, 52% reported met needs, and 33% reported no need for training.

Regarding the need for help, 10% reported unmet needs, 58% reported met needs and 31% reported no needs.

An unmet need for training was associated with lower functioning (OR=.32, p<.05) and more anxiety (OR=.36, p<.05). Patients reporting unmet needs for help more often lived alone (OR=.40, p<.05) and were more often depressed (OR=.31, p<.05).

Conclusion: Similar levels of met and unmet needs for training and help at 3 months after stroke were reported despite differences in the organization of the rehabilitation services.

Study 3 provides background for the discussion of aim 2.

3.3 Additional results exclusive to this thesis

As background information for the discussion of representativeness presented in the next chapter, a new table (Table 3) comparing process data and patient features was added. Data are presented as national data or regional data including all stroke patients in the selected geographical area. The national and regional data from both countries were obtained from national stroke registries in 2015. At the regional level, an average of results from the 3 Norwegian hospitals and for the two Danish municipalities is presented.

Table 3: Stroke data at the national and regional levels in Norway and Denmark in 2015.

Stroke data at national and regional level in Norway and Denmark in 2015 from national registry				
Data from national stroke registries	National registry data		Regional registry data	
	Norway	*Denmark*	*Norway* 30 municipalities	*Denmark* Randers Favrskov
Age, mean years (SD)[1] median years (distribution)	74,4 76 (19-104)	71 (13) 72 (18-105)	73,6 76	71 (13) 72 (20-104)
Admitted to hospital within 4 hours[2] post stroke (%)	44	46 (45-47)	41 (39-49)	42 (34-49)
Treated in a stroke unit (95% CI)[1]	91	93 (93-94)	87	89 (86-91)
Thrombolysis, proportion of patients with brain infarction, % (CI) [3]	18	15 (14-16)	18	20 (9-28)
Number of strokes in 2015, first-ever and recurrent	8538	11799	483	263[4]
Coverage, %	88	92	92	100

[1] The Norwegian stroke registry does not report 95% CI or SD for the variables.

[2] In Denmark, the proportion of patients admitted to hospital within 4,5 hours is reported

[3] In Norway, the proportion of thrombolysis among patients with brain infarction ≤ 80 years of age is registered.

[4] Only patients with ischemic stroke

Data in Table 3 were generated from the Danish stroke registry annual report 2015 (207) and National Norwegian stroke registry 2015 (27). The coverage of the Norwegian and Danish stroke registries is calculated as the fraction of individual cases of stroke recorded in the stroke registry compared to diagnosis registrations in the Norwegian Cardiovascular Disease Registry/The Norwegian Patient Register and in the Danish LPR (Landspasientregisteret), respectively (27,207).

The study included only first-ever strokes, whereas the registries also included recurrent incidents**.**

Table 4: Correlation between QOLIBRI-OS scores and HADS scores at 3 and 12 months.

Correlation between QOLIBRI-OS scores and HADS depression and HADS anxiety scores at 3 months and 12 months post stroke			
	QOLIBRI-OS Timepoint	Person's correlation coefficient	P
HADS Anxiety	3 months	-.62	>.001
HADS Depression		-.54	>.001
HADS Anxiety	12 months	-.64	>.001
HADS Depression		-.57	>.001

High QOLIBRI-OS scores indicate high HRQOL, and high HADS-A and HADS-D scores indicate psychological distress.

There was a highly significant negative correlation between the QOLIBRI-OS scores and HADS-A and HADS-D scores at both timepoints. Spearman's rho values provided identical results for the correlation between QOLIBRI-OS and psychological distress scores.

In dividing the QOLIBRI-OS score into high and low HRQOL, with a cutoff score of 52, the scores representing levels of anxiety and depression were approximately threefold higher for those reporting impaired HRQOL than those reporting high HRQOL.

Table 5: QOLIBRI-OS scores and rehabilitation needs at 3 months.

QOLIBRI-OS scores at 3 months and met, unmet or no rehabilitation needs for help and training					
Study 2		N (%)		QOLIBRI-OS sum scale scores (95% CI)	P
	Country N=304	134 (44)	Denmark	66.1 (62.1-70.2)	.08
		170 (56)	Norway	70.8 (67.7-73.9)	
Study 3	Training needs N=304	164 (54)	Met needs	67.7 (64.3-71.0)	<.001
		39 (13)	Unmet needs	49.8 (41.4-58.2)	
		102 (33)	No needs	74.3 (70.5-78.0)	
	Help needs N=304	171 (56)	Met needs	66.9 (63.5-70.3)	<.001
		28 (9)	Unmet needs	50.8 (41.3-60.4)	
		106 (35)	No needs	72.5 (68.9-76.4)	

Additional tables were made by combining data from papers 2 and 3 for the proportion of included patients who provided data on both the QOLIBRI-OS and rehabilitation needs. We had access to QOLIBRI-OS data for 304 of the 473 patients included in paper 3.

The purpose was to explore the relationship between perceived satisfaction and met, unmet and no need for help and training (Table 5). As shown in Table 5, there were significant differences in QOLIBRI-OS sum scores between those with unmet, met needs and no needs for training. Likewise, there was a significant difference in scores between those with unmet, met needs and no needs for help.

The relationships between HADS-A and HADS-D scores and met, unmet or no need for help and training and satisfaction with functioning was explored (Table 6). HADS data were available for 300 of the patients included in paper 3.

Table 6: HADS scores and rehabilitation needs at 3 months.

HADS scores and rehabilitation needs at 3 months							
Data source		N		HADS-A (95% CI)	P	HADS-D (95% CI)	P
Study 2	Country	116	Denmark	3.6 (2.9-4.3)	.77	2.8 (2.2-3.4)	.36
		184	Norway	3.5 (2.7-3.9)		3.2 (2.7-3.8)	
Study 3	Training	160	Met needs	3.6 (3.1-4.2)	.02	3.1 (2.6-3.7)	<.001
		39	Unmet needs	5.1 (3.7-6.5)		5.3 (3.8-6.8)	
		94	No needs	2.6 (1.9-3.3)		2.0 (1.4-2.9)	
	Help	169	Met needs	3.6 (3,1-4.1)	.01	3.2 (2.7-3.8)	.06
		48	Unmet needs	5.5 (3.7-7.3)		4.8 (3.0-6.4)	
		101	No needs	2.8 (2.1-3.6)		2.3 (1.7-3.0	

All differences in HADS scores between met, unmet and no need for help and training were significant, with the exception of the nonsignificant difference (p=.06) in depression scores between those with met and unmet needs for help.

The difference between the HADS depression scores in those with unmet needs for help and those with no need for help (p=.02) was significant.

These additional data provide the background for the discussion of aim 4.

4 Discussion

The discussion chapter starts with a presentation and discussion of structure, process and patient features, including representativeness, within the two selected regions. The results will be presented and thoroughly discussed in the outcome paragraph.

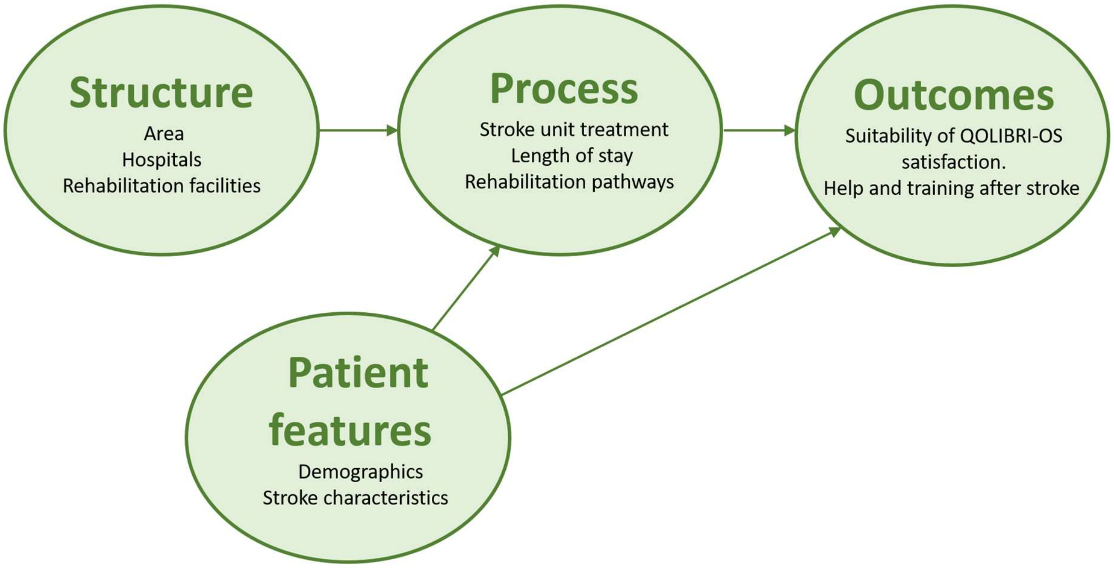


Figure 6: Study-specific modified Donabedian model

4.1 Structure

Rehabilitation research is hampered by a lack of shared insight into the optimal framework in which to offer rehabilitation (52). Studies on the effectiveness of stroke rehabilitation should incorporate contextual elements of the organization (208) to gain knowledge of elements crucial to offer the most professional and efficient rehabilitation service. A better understanding of structural conditions would also enable policy makers to optimize stroke treatment services (52).

Stroke rehabilitation structures and organizations vary considerably between countries (33,57) and even within countries (209). Comparisons between countries with different stroke structures are one possible way to reveal a deeper understanding of the relationship between structure and stroke outcomes (52).

By choosing well-defined regions in our study, it was possible to characterize both acute treatment and rehabilitation at a more precise level because of limited treatment options.

In the following paragraph, a detailed overview of similarities and differences in structures relevant to stroke in the Norwegian and Danish regions is provided.

During the last decade, juridical and political guidelines have changed the structures related to stroke in both Norway and Denmark. In Norway, the Coordination Reform Act was implemented in 2012 (210) and led to a new municipal health Care and Services Act (211). The political aim was to enact a guiding and coordinative reform using economic, juridical, organizational and professional tools to establish holistic patient processes and increase prevention and patient participation. Treatment should preferably be offered at the optimal time and place and as near to home as possible.

The Norwegian Coordination Act was built on the generalist principle, implying that every municipality, independent of size and resources, should offer the same range of services at the same quality (210). A law regulation from 2010 stated that patients have a right to assess a coordinated individual rehabilitation plan (212).

In Denmark, structural reform that merged municipalities into larger units was implemented in 2007 (213). In 2012, stroke care reform (214) was adopted that transferred the responsibility for rehabilitation of patients with mild and moderate functional deficits after stroke to the municipalities. As a consequence, the number of rehabilitation beds at the specialized level was reduced (215). The change in structure was mainly motivated by expectations of financial savings (215).

At the national level, both Norway and Denmark have public tax-financed health care systems, which included free access to general practitioners, hospital treatment, care and rehabilitation and subsequent inpatient or outpatient treatment in municipalities (216). There are therefore no financial obstacles at the individual level hampering stroke rehabilitation. At the systemic level, however, there are financial incentives to limit the length of stay in hospitals (217).

4.1.1 Treatment and rehabilitation facilities

Norway and Denmark follow well-established common principles for acute treatment and multidisciplinary rehabilitation in stroke units (60,218). The size of the stroke units in these studies differed, however, as all stroke patients in the Danish region were treated at one large stroke unit, covering a total of 1,3 million inhabitants.

In the Norwegian region, the treatment structure was decentralized to three smaller stroke units. The Danish region includes one of two highly specialized rehabilitation hospitals at the national level and other neurorehabilitation units. In Arctic Norway, a total of 2 in-hospital and 2 hospital-affiliated rehabilitation wards offer subacute inpatient rehabilitation. One of these rehabilitation units is organized at the regional level.

In both countries, professional responsibility for rehabilitation after stroke is divided between specialist health services and services provided at the municipality level. Hospitals offer rehabilitation at a specialized level reserved for patients with the most severe strokes in addition to a more comprehensive specialized inpatient multidisciplinary rehabilitation. In both country-regions, a proportion of stroke patients were treated in a neurosurgical unit.

At discharge from hospitals, all Danish patients receive a compulsory individual rehabilitation plan, which local professionals are obliged to follow. The Norwegian region has two ambulatory teams assisting selected patents in the transfer phase from hospital to home, but multidisciplinary rehabilitation at the municipal level in Norway varies according to local competence and capacity (16). Minor-scale inpatient rehabilitation, most often in the context of nursing homes, may be available.

The Danish region has established specialized multidisciplinary team-based neurorehabilitation at the municipal level, a service no regional Norwegian patients have access to.

In addition, both Favrskov and Randers have engaged a brain injury coordinator to ensure seamless, patient-oriented practice (219). In contrast to Norway, municipalities in Denmark often include job consultants and social workers as integrated parts of professional rehabilitation team efforts. The time span for patient follow-up is longer than customary practice in the Norwegian region.

The differences and similarities between the chosen regions are discussed in a paper from the study group (220); see also Table 1 in paper 3 for an overview of similarities and differences between the regions.

Danish patients, based on political decisions and professional guidelines, mainly receive rehabilitation at the municipal level, whereas, a higher proportion of patients seem to receive inpatient rehabilitation in Norway (221).

One aim of the legal guidance in the Norwegian Coordination Act was to transfer more responsibility for patient treatment, including rehabilitation, from the specialist level to the municipality level. Even so, to a large extent, the chosen region offers inpatient rehabilitation for patients at the specialist level at several units.

According to a report from 2016 by the government in the Office of the Auditor General, (222) which aims to control political and economic trustworthiness, the willingness to transfer patients with considerable needs from hospitals to treatment at municipal levels, even if competence is lacking at this level, may put patients at risk. It was also noted that individual rehabilitation plans secured a holistic course of rehabilitation to only a limited degree.

The Norwegian guidelines for stroke rehabilitation (223) recommend that all municipalities offer inpatient rehabilitation and day-based and home-based stroke rehabilitation. Due to a large number of municipalities with corresponding small stroke volumes, this is only possible at the inter-municipality level. At the municipality level, physiotherapists, occupational therapists and nurses represent the cornerstones of stroke rehabilitation.

Papers 2 and 3 provide a consistent picture of the types of rehabilitation offered, where the proportion of patients in Denmark who completed community-based rehabilitation was more than twice as high as that in Norway.

In our study, we had limited information about the precise types of community-based rehabilitation that were offered. We had access to rehabilitation data from the first three months post stroke, but no information about further rehabilitation courses. The described structure provides the framework available services within the two regions.

A minority of participating patients in both regions claimed an unmet need for both help and training (paper 3) post stroke, a finding that seems to indicate adequate capacity for professional follow-up. However, a major insecurity in considering total stroke rehabilitation capacity within the regions is the lack of information about the extent to which the nonparticipating patients perceived their rehabilitation needs fulfilled.

Capacity is only one of many prerequisites for meeting rehabilitation needs. Qualitative aspects such as competence and rehabilitation services adapted to the variety of patient symptoms are just as significant.

The main impression is that the juridical, economic and professional frameworks ensured sound treatment and rehabilitation structure in two regions with different areas and municipality sizes in the 2014-2015 period.

Our data was collected in 2014-2015. Since then, the Norwegian municipalities in the study have, to a certain extent, increased rehabilitation capacity and competence by establishing a few health houses for inpatient rehabilitation. Intermunicipality cooperation has been established to meet needs for rehabilitation. The level of inpatient rehabilitation services has slightly decreased.

In the Danish communities, based on information from the Danish part of the study group, some of the community-based rehabilitation services seemed to have been reduced during the period after the study.

4.1.2 National stroke registries in Norway and Denmark

For monitoring the national and regional quality of stroke treatment, national stroke registries are an essential (224) component of the structures related to stroke.

In Denmark, the Stroke Registry (154) was established in 2003. Stroke, TIA (transient ischemic attack) and subarachnoid hemorrhage are included in the Danish stroke registry. Reporting is mandatory by law for all hospitals (154). Data are collected from the acute disease phase.

The registry collects individual data on patients, analyzing 15 process quality indicators and 4 result indicators. A predefined level indicating good quality is stated for each variable.

In Norway, the National Stroke Registry was established in 2012 (27). The stroke registry is mandatory without the need for patient consent. Patients with hemorrhagic or ischemic stroke were included.

Data are collected from the acute phase and at three months post stroke. A total of 11 quality indicators, all process indicators, are defined as national quality indicators. For all indicators, the results are classified as low, medium or high quality (27).

Even though both countries have national quality indicators, the only common indictors across countries are the use of stroke units, the level of and door-to-needle time for thrombolysis and an assessment of swallowing function. These indicators, however, are not identical because of different age and time criteria. Although the registries have excellent coverage (Table 3) and are designed for the same purpose, the lack of common national quality indicators limits direct comparisons between countries. This represents a universal challenge, as international discrepancies in stroke registrations are reported to be striking (224,225).

If countries had a common stroke registry practice, or at least a common core set of identically defined variables, the individual data from national quality registries could contribute to a higher degree in the evaluation of the external validity of controlled studies.

4.2 Processes

Both regions have high and comparable levels of admissions to stroke units. Stroke unit treatment is the cornerstone among stroke procedures. Based on the categorization of teamwork by Karol (226) and personal knowledge of team structure in the included stroke units, teams are best defined as multidisciplinary. This model of teamwork, based on a study from the Sunnaas international network (33), demonstrated the best results in achieving improvements in ADLs in patients with stroke.

Surprisingly, regarding the geographic differences, the proportion of patients who were hospitalized in a stroke unit within the time limits for thrombolysis differed very little (Table 3). According to the national registries' annual reports from 2015, 39– 49% of all patients in the Norwegian region reached the hospital within a 4-hour period (27), while 42% of patients in Favrskov and Randers were hospitalized within 4,5 hours (207).

We did not calculate the proportion of patients arriving within the time limits in the study cohort.

In the study cohort, the proportion of patients who received thrombolysis between the regions was not significantly different (papers 2 and 3). Receiving thrombolysis did not seem to have an impact on either HRQOL at 3 months or met rehabilitation needs in our study. An efficient transport chain is a premise for achieving early admission to hospitals and the application of hyperacute treatment with thrombolysis. The use of thrombolysis is based on recommendations in the professional guidelines both Norway and Denmark have developed, providing detailed instructions on a normative level (79,223,227).

At national level in Norway, the median length of stay (LOS) in the hospital was 5, while the mean number of days in a stroke unit was 7,3 (27). The 3 hospitals included in Norway had a median LOS of 6, 6 and 4 days. We have no data on LOS at the national or regional level in Denmark.

In the study cohort (papers 2 and 3), there was a significant difference in LOS. The Danish patients had a median LOS of 2 days, compared to 4 (study 2) and 5 days (study 3) in Norway. The distribution of the indicator was wide (0-50 days), and the mean days were longer in both countries. Both countries have considerably shorter stays in acute hospitals due to stroke than the common neighboring country Sweden, where the LOS was 14 days in 2015 (228). Even though Denmark has all features defining a comprehensive stroke unit, the duration of only a 2-day median stay in the stroke unit may indicate that the stroke unit is in practice more similar to an acute stroke unit than to a comprehensive stroke unit. Denmark has, however, implemented compensatory guidelines with compulsory individual rehabilitation plans at discharge and established neurorehabilitation teams at the municipality level (229).

Short LOS requires well-organized rehabilitation pathways and a capacity at the next level to receive patients without time delay.

A qualitative study from our study group found Danish patients to be more satisfied than Norwegian stroke patients in the transfer phase (220).

The complexity of hospitals also matters, as a Swedish study found fewer barriers to organizing well-functioning stroke services in community-based hospitals than in university hospitals (230).

The transfer to rehabilitation is time-critical, as there is a strong association between early onset of rehabilitation and functional outcomes (87). Early rehabilitation also led to shorter lengths of stay compared to patients where admission to rehabilitation was delayed beyond 30 days (231).

Other Nordic studies (232,233) have shown that delays in transmission to the inpatient rehabilitation treatment level has a negative effect on outcomes for patients with TBI. In coordinating between levels, a variety of processes occur, as individual rehabilitation courses differ based on patient stroke complexity and severity. The courses are not necessarily linear, as patients could be moved to and from regional specialized rehabilitation services.

Both study 2 and study 3 found that Norwegian patients, to a larger extent than Danish patients, received inpatient rehabilitation after stroke unit discharge. Community-based rehabilitation was far more commonly used in Denmark. These observed processes are in line with the actual rehabilitation structure in the two selected regions.

We have detailed information about rehabilitation courses for both participants and non-responders among the included patients in Norway. Regarding the nonresponding proportion of Danish patients, we unfortunately have no information. This might lead to an underestimation of the use of inpatient rehabilitation in the Danish region. As nonincluded Danish patients were older and had more severe strokes, this might, however, represent a selection bias. Processes favoring community-based rehabilitation are, however, aligned with the politically chosen stroke structure in Denmark.

Future stroke processes in Norway will be influenced by the extended national stroke package (234) with a 3-month follow-up time currently being implemented. Within 7 days post stroke onset, patient rehabilitation course will be classified into one of four main trajectories: a) no rehabilitation, b) within specialized health services, c) ESD or d) community-based stroke rehabilitation.

The selection of the rehabilitation course will be based on medical assessment, NHISS scores, mRS scores and Barthel status at the stroke unit. The preferences of the patients will also be emphasized in the choice of trajectories.

4.3 Patient features

4.3.1 Comparing patients with stroke in Norway and Denmark

Careful selection of the population sample (235) is essential for answering research questions in observational studies.

When choosing the study population that live in two neighboring countries, we presumed the countries to be similar enough to make comparisons of courses of stroke and rehabilitative pathways meaningful. The study cohort was therefore compared both to the national level and the regional level, which included all patients with stroke from the defined geographical area.

4.3.2 National level

Truelsen et al. (236) estimated age-related stroke incidence and prevalence rates in several European countries in 2006, including Norway and Denmark. The results indicated a lower incidence of stroke in Norway among the youngest patients, whereas the incidence in the oldest cohort above 85 years old was higher in Norway, especially in men. The sex- and age-adjusted incidence rates of stroke in the age interval 65-74 years in Norway and Denmark were similar, with rates per 100,000 of 950 and 882 for men and 530 and 510 for women, respectively (236). These findings are in line with stroke incidence studies from Norway (8,237). For the age distribution at the national and regional levels, see Table 3. The regional age difference is similar to the national age difference. This finding is in accordance with a life expectancy difference of approximately two years for both men and women in favor of Norway (238).

In Norway, 46% of all patients with stroke in 2015 were women (27). In 2015, Norwegian female stroke patients were on average almost 6 years older than male patients (27).

Sex was not reported in the Danish registry (207).

4.3.3 Regional level

Table 3 provides an overview of national and regional stroke process indicators in Norway and Denmark. Overall, the results from the process indicators in the two regions seem in line with national standards. Both regions, however, had a lower proportion of stroke patients treated in a stroke unit than the national average. Compared to national quality standards, the patients from UNN had good to excellent goal achievement with the exception of the proportion of patients receiving thrombolysis within the time limit.

4.3.4 Study cohort

In our study, we chose geographical delimitation in two country-regions and intended to include all patients with defined stroke during a time span of 21 months. Using registered stroke in national stroke registries as the gold standard, we managed to include 45% of surviving Danish patients and 75% of all Norwegian patients in the study presented in paper 3.

In the study presented in paper 2, 41% of patients from Denmark and 49% of eligible Norwegian patients with stroke participated. This study in paper 2 made greater demands on the participants, as both 3- and 12-month questionnaires had to be completed. In line with the inclusion criteria, the complete study cohort had been treated in a stroke unit.

The Norwegian participants were older and had more severe stroke. The age difference, however, showed only borderline significance in study 2 (p =.07).

The SSS showed a difference in both studies across the two populations. These scores were, based on probability plot analysis, normally distributed in Norway but not in Denmark. This resulted in divergent interpretations depending on whether the mean or median was chosen as the outcome.

In study 2, mean SSS scores between the country-regions were similar (p=.12), while median SSS scores were highly significant. One Danish patient with an SSS of 10, corresponding to NHISS 24, was included in the study. Since we had no access to Danish medical data, we were unable to decide whether this low score was due to incorrect registration. Elimination of this patient from the analysis resulted in a significant mean SSS difference (p=.02) between Norway and Denmark. We, however, chose to keep this registered score in the analysis. The SSS is reported as the median in papers 2 and 3 because of nonnormality in Danish data.

The use of different stroke scales might be considered a confounder, but a recent prospective study has shown that the SSS is equally as good as the NIHSS in identifying outcomes defined as death or dependency (181). Using medical records to retrospectively define SSS scores was found to be reliable and useful for observational studies (239).

Hemorrhagic strokes, which indicate worse initial prognosis (240), were equally frequent in both countries (240), and this stroke subtype had a similar impact on SSS scores. The functional consequence of the initial stroke severity difference was nullified at 3 months, as the mRS scores were similar at 3 months (paper 3).

An age difference of approximately 28 months younger in the Danish population might explain lower stroke severity, as elderly patients tend to have more severe strokes (241).

The upper age quartile in Norway is 85 years, compared to 80 years for the 75% percentile in Denmark. Twice as many patients from Norway lived in institutions before the stroke. These findings might raise the question of whether there is clinical selection, where the oldest or most disabled persons pre-stroke are admitted to the hospital in Denmark to a lesser degree. We did not find any clinical support for this hypothesis. A Danish study from 2012 demonstrated increasing hospitalization rates for stroke in the last two decades (242), a tendency most likely unchanged during the time of the study.

In line with the age difference, a higher proportion of the Danish study cohort were working before the stroke (p =.006) (papers 2 and 3). At 3 months post stroke, there was no difference between countries in the proportion of patients working. The result was based on a small number of people who were working, which limits the interpretation.

4.3.5 Nonincluded patients and dropouts

A crucial question is to what extent the included patients are representative of the nonincluded patients from the selected area in the given timeframe.

We had access to the complete regional registry data in Denmark, which enabled us to compare demographics and stroke characteristics among the included and nonincluded patients.

Due to the described recruitment strategies, we were unable to differentiate the reasons for nonparticipation.

There were few dissimilarities between the included and nonincluded Danish stroke patients in study 3, as only the mean, not the median, SSS scores were significantly different. In the Danish part of study 2, the proportion of hemorrhagic stroke was significantly higher among nonparticipants than participants (p=.001), and more nonresponders lived alone before the stroke (p =0.01). Age was higher among non-participants with 71.3 versus 67.3 years (p=.01). Both mean and median SSS scores were higher among participants in study 2.

Danish rehabilitation data from the included patients or patients who, for some reason, were not included in the study could not be compared since these data were collected by telephone interviews.

For legal reasons, that is, due to a strict confidentiality policy, it is not permitted to report Norwegian stroke registry data from nonconsenting patients, with the exception of age and sex. In both studies, more Norwegian men than women were included, and the ages did not differ.

In Norway, we have a detailed overview of eligibility and inclusion; see the flowchart in figure 5. Administrative failures in not asking for consent and refusal to participate are noted.

Norwegian participants can therefore only be compared to consenting nonresponding dropouts.

Older age, lower SSS scores and a larger proportion of patients living alone indicated that the persons not included or not responding from both country-regions were more fragile, thus reducing the representativeness of the findings with regard to the oldest and most vulnerable among the patients.

Fortunately, the majority of patients with stroke had light or moderate symptoms post stroke.

According to the Norwegian Stroke registry, the majority of patients in 2015 had NIHSS scores between 0-5 (179), corresponding to SSS scores of 42-58.

In the selected Danish municipalities, the mean SSS score was 43 (SD=15), and the median SSS score was 48. The SSS cutoff differentiating moderate and light symptoms post stroke is 44, while SSS scores of 45-58 represent mild symptoms. A total of 55% of Danish patients in the regional cohort had mild symptoms, while 22% experienced moderate symptoms post stroke.

The included patients in both countries are therefore considered representative of the majority of patients with mild and moderate stroke severity in the selected regions. The correspondence between regional samples and the national average for patients with stroke increases the external validity, indicating that study results may be generalized (243) to other Nordic settings.

4.4 Outcomes

Evaluating treatment and rehabilitation outcomes requires understanding and consideration of similarities and dissimilarities in settings with different structures and procedures within health care systems, rehabilitation pathways, approaches and assessments and is essential for the interpretation of the results (244). The content and organization of rehabilitation vary within and between countries, reflecting the preferences, customs, traditions, and values of a society or community, which may have an impact on outcomes (33).

Outcomes, by and large, remain the ultimate validators of the effectiveness and quality of medical care. Outcomes should include the health circumstances most relevant to patients. They should cover both near-term and longer-term health and address a period long enough to encompass the ultimate results of care (245). The chosen outcome must be of value for the patient (50).

The outcomes of interest in this thesis were as follows:

- Suitability of the QOLIBRI-OS as an outcome measure for patients with stroke.
- Level of satisfaction as measured with the QOLIBRI-OS.
- Met and unmet needs for help and training after stroke.
- Change in satisfaction, measured with the QOLIBRI-OS, from 3 to 12 months post stroke.
- Correlation between the QOLIBRI-OS and unmet needs.

The consensus statements from the Stroke Recovery and Rehabilitation Roundtable in 2017 (246) defined the acute stroke phase from 1-7 days post onset, followed by an early subacute phase lasting until 3 months post stroke.

Aims 2 and 3 were derived from the early subacute phase and are presented with data on satisfaction and rehabilitation needs at 3 months post stroke. In this time frame, the available structures and implemented processes are of utmost importance as treatment and most rehabilitation services are being performed during this time.

Aim 4 covers the period from 3-12 months, which includes the late subacute phase lasting until 6 months, followed by the chronic phase.

4.4.1 Suitability of the QOLIBRI-OS as an outcome measure for patients with stroke

The following paragraph discusses aim 1.

In the first part of the discussion**,** the suitability of the QOLIBRI-OS as an outcome measure for patients with stroke will be discussed. Study 1 is not discussed in the context of structures, processes and patient features, as the validation study was performed only in Norway.

Methodologically, validation was performed according to COSMIN standards (193).

Clinically, an appropriate HRQOL measure should ideally be reliable, valid, responsive, precise and appropriate as well as feasible, interpretable and easy to complete (107,247–249).

To what extent does the QOLIBRI-OS questionnaire meet these eight compound requirements when applied to patients with stroke?

Reliability was investigated with internal consistency, which provides an estimate of the equivalence of sets of items from the same test (248) and test-rest reliability using intraclass correlation coefficients(197). The results indicated excellent reliability for patients with ischemic and hemorrhagic strokes, as Cronbach's alpha and ICC values were well beyond acceptable limits. The internal consistency of the QOLIBRI-OS overall score was excellent, with Cronbach's α=0.93 in patients with ischemic and hemorrhagic stroke.

The result was slightly higher than the result reported in the validation of the QOLIBRI-OS for patients with TBI (α=.86) (128) and for patients with subarachnoid hemorrhage (α=.88)(250).

Test-retest reliability was in line with the most commonly used stroke outcome measurement, the mRS (251).

Validity is, according to the COSMIN classification (table 2), divided into several subtypes, including content validity, criterion validity and construct validity.

Content validity assesses the extent to which the instrument measures the concept of interest. An instrument designed to assess brain conditions must address problems with cognition, emotions and physical condition and the social- and activity-based consequences of brain dysfunction.

Cognitive dysfunction is frequent and is most often characterized by deficits in attention, memory, orientation, executive function and language (252).

The question regarding cognitive ability in the QOLIBRI-OS is phrased as follows:

"Overall, how satisfied are you with how your brain is working, in terms of your concentration, memory, thinking?"

The question has no explicit specification for language difficulties, which is a limitation of the questionnaire. On the other hand, it is difficult, although not impossible (253), to create PROMs to be filled in by the patients with the most pronounced language limitations. Population-based studies of stroke survivors suggest that between a quarter and a third of patients have deficits that could complicate or even prevent them from completing a PROM instrument (254). This fact represents a selection bias common to all PROMs.

Physical consequences are common post stroke. Stroke is genetically associated with other diseases, such as heart disease and diabetes (255), and affects the immune system in a complex way (256). Patients and clinicians, however, most often regard sensorimotor sequelae, such as hemiparesis (257,258), coordination problems (259) and reduced balance (260), that affect activities of daily living as the prime physical consequences of stroke.

The QOLIBRI-OS question is “Overall, how satisfied are you with your physical condition?”

The question does not discriminate between sensorimotor sequelae post stroke and, for instance, lung problems, which may represent a problem with the specificity of the question. On the other hand, this broadly formulated question does include, for instance, neurological pain (261) or the common symptom post stroke fatigue (262).

Depression and anxiety (174,263) are very important predictors of HRQOL post stroke.

The QOLIBRI-OS question is “How satisfied are you with your feelings and emotions?” This question represents a linguistic challenge, as the Norwegian language does not distinguish between the terms feelings and emotions used in the original QOLIBRI-OS version for traumatic brain injury. In the forward and backward translation between English and Norwegian, our translation resulted in a slightly different version from the one used in Norwegian Center TBI (264). We translated the terms feelings and emotions into feelings and mood, whereas the TBI center chose the single term feelings.

In our opinion, the chosen terms feelings and mood should represent poststroke depression, anxiety and apathy. Our translation of the QOLIBRI-OS matches also the Danish translation of the questionnaire (see Appendix 4). Nevertheless, this item had the lower fit values in the confirmative factor analysis. The model fit of the six-item QOLIBRI-OS was considered fair, but removing the item measuring emotions increased the model fit to excellent. We retained all six items in the final model because the differences in the correlations regarding validity between the six- and five-item versions were negligible. The model fit may be caused by a translation problem, as the item has not been identified as problematic in other studies. Also question 1 differed slightly in the translation between our translation and the one used in TBI center study: How satisfied are you with your “physical health”/fysisk helse (our translation) compared to “physical condition”/fysisk tilstand (TBI center). This item did not, however, represent a problem in the CFA. In validating the QOLIBRI-OS for patients with traumatic brain injuries, the question about personal and social life was the sole item that was found to be problematic (205).

While the first three questions in the QOLIBRI-OS assess the direct impact of stroke on emotions, cognition and physical function, the next three questions partly operationalize the effect that these potential deficits have on activities of daily living, social interactions and perception of actual situations and the future. The consequences of reduced abilities and independence regarding activities of daily living (ADLs) are presumed to affect 25-50% of all stroke survivors (265) and are predictive for future need of care. Question five in the QOLIBRI-OS assesses satisfaction with personal and social life, including the important perspective (266) of participation in work. The last question aims to capture the patient's holistic perspective (267) on health-related quality of life post stroke. The sum scale of the QOLIBRI-OS score summarizes these crucial direct and indirect consequences of stroke.

The criterion validity of the QOLIBRI-OS was not analyzed due to the lack of a gold standard instrument for measuring satisfaction post stroke.

Construct validity for all items and sum scores (Table 2, paper 1) was tested against established measurements. The Spearman rank correlation coefficient (184), where +1/-1 demonstrates perfect correlation, was above 0,5 for all comparisons with the exception of physical function.

The correlations between the QOLIBRI-OS physical function scores and EQ5D mobility scale and SS-QOL scores were .31 and .44, respectively, probably because the QOLIBRI-OS item includes a broader range of functions, such as arm and hand functions, within the item.

The correlation between the sum scale QOLIBRI-OS total satisfaction scores and HADS total scores was negative, as expected, with the highest measured correlation of -.74. Other studies have also reported a highly significant correlation between psychological distress and reduced life satisfaction (127).

The responsiveness of the QOLIBRI-OS was measured in the study population at 3 and 12 months post stroke (paper 2). The instrument revealed a high responsiveness to change, as it detected clinically relevant changes among approximately 50% of the participants, although we applied a strict criterion to detect changes. Minimal clinically important difference (MCID) scores were calculated with the standard error of measurement (SEM) formula.

Precision in this context refers to the range and accuracy of the response categories (247). The QOLIBRI-OS is a Likert scale (268) with response options from not at all to very for every item, thus covering all relevant responses. Floor and ceiling effects may lead to reduced precision and the inability to identify true differences (107). Fortunately, the QOLIBRI-OS sum scale scores exhibited no floor or ceiling effects, though a modest ceiling effect (defined as > 15%) was observed in all items with the exception of the "physical condition" item.

Interpretability (193) is the degree to which one can assign clinical meaning based on values of the scales. The QOLIBRI-OS sum is transformed to a 0-100 scale, which increases the ability to interpret results. To increase the interpretability of the QOLIBRI-OS, the instrument has been compared to the SF-36 mental component summary norm-based scoring system (269).

Feasibility is the extent of effort, burden and disruption to staff and clinical care arising from the use of an instrument (247), while acceptability addresses how acceptable an instrument is for respondents to complete. The time to complete the QOLIBRI-OS was estimated to be well below 5 minutes. We found it very encouraging that the percentage of missing items was as low as 0.5% in an unselected stroke population.

The clinical burden to use the instrument is modest.

Finally, appropriability based on the study purpose must be considered. As satisfaction was our main outcome, the scale was highly appropriate.

At the time of the study planning, no short-form HRQOL questionnaire had been designed for patients with stroke. Subsequently, a short form of the well-established stroke impact scale was published (270) in a modified version of the SF-SIS with 8 items assessing stroke-specific function (271). The two short-form questionnaires have cognitive and emotional aspects, ADLs and social participation in common, but the SF-SIS in addition measures hand and leg strength, communication and balance. The content validity of the QOLIBRI-OS for stroke would be further improved by adding an item measuring language and communicative skills and another item assessing motor function.

The correlation between the SS-QOL sum scores and the QOLIBRI-OS sum scores was .71, demonstrating the relationship between function and satisfaction at 3 months in the study population. Optimal levels of function do not necessarily indicate 100% satisfaction with functioning and well-being, nor does optimal satisfaction measured with the QOLIBRI-OS indicate a complete lack of functional deficits.

Other studies have found lower correlations between satisfaction and function. In a study measuring function and stroke-specific satisfaction in the chronic phase, manual abilities and body functions were the best predictors of stroke patients' perceived satisfaction. However, this combination of factors predicted only 43% of the variation in the SATIS-Stroke measures (125).

In sum, the QOLIBRI-OS fulfills all eight clinical claims and can be classified as a valuable outcome instrument for satisfaction with functioning and well-being after hemorrhagic and ischemic stroke. However, it is a limitation that no general population scores of the QOLIBRI-OS have been published yet, yielding uncertainty about the distribution of satisfaction scores in a reference population.

4.4.2 Satisfaction with functioning in the early subacute phase

The paragraphs 4.4.2 to 4.4.5 discuss aims 2 and 3**.**

Satisfaction with functioning and well-being

What does the QOLIBRI-OS reveal about self-reported satisfaction after stroke?

Reporting "very satisfied" for all six items results in a maximum QOLIBRI-OS score of 100. At 3 months post stroke, the Norwegian cohort had a sum score of 70.1, while the Danish participants scored 66.1 sum scores (p=.08). How can this sum score be interpreted?

The original QOLIBRI-OS did not have a predefined level defining satisfaction corresponding to high or low HRQOL. However, the QOLIBRI-OS has been compared (272) to the SF-36 mental component summary norm-based scoring system (269).

For the QOLIBRI-OS, a score of < 52 coincides with low or impaired HRQOL (272). The percentage of cases in the sample that fell into the "impaired HRQOL" category was 36% for the mental component summary, 38% for the QOLIBRI total score, and 39% for the QOLIBRI-OS score (272).

Using a cut-off score of 52/100 for the QOLIBRI-OS sum score to create dichotomous categories with high HRQOL versus low HRQOL, we found that 77% of the study cohort scored beyond this level at 3 months post stroke.

In Norway, 81% of the cohort reported high HRQOL, compared to 73% among the Danish participants (p=.08). At the QOLIBRI-OS item level, satisfaction with cognition, emotions and ADLs was rated higher in Norway.

In the newly published version of the QOLIBRI-OS as a utility measurement (157), the largest weight increase for all attributes is seen from "slightly" to "not at all satisfied", resulting in the largest impact on health-related quality of life. "Not at all satisfied with how the brain is working" should receive the greatest weight in utility calculations.

The Norwegian cohort had significantly higher scores on satisfaction with cognition (p=.03) than the Danish cohort,

This finding may sound surprising, as the Norwegians were older and had more severe strokes. The mean age among participants in study 2 was lower than that in study 3, indicating that the oldest individuals in the study cohort participated to a lesser degree. Nevertheless, the Norwegians, with a mean age of 69.7 years, were 27 months older than their Danish neighbors (p=.07). The age difference also enhanced the risk of higher levels of preexisting cognitive deficits among the Norwegians (273).

Acquired cognitive impairment post stroke is common (274). A study reported reduced function in at least one cognitive domain in 55% of patients 3 months after ischemic and hemorrhagic stroke. Both memory deficits and poststroke dementia have been associated with older age (274). On the other hand, effective cognitive rehabilitation approaches have been reported for focal cortical deficits such as neglect and aphasia, but treatments for more diffusely represented cognitive impairment remain elusive (275). Satisfaction with cognitive function may not correlate with actual function. Older patients often have a living situation that involves less demand, thus minimizing the effects of cognitive problems. Loss of cognitive abilities has the most devasting effects on persons holding jobs or complex social roles (276,277). Unawareness of one's own cognitive limitations may also lead to overoptimistic assessments of one's own function (278). The self-rating of cognitive function is also modified by emotional status (279).

Emotions were also rated differently, with significantly lower scores among the Danish participants. A total of 27% of Danish patients with anxiety and an equivalent percentage with depression were classified in the category of low HRQOL, compared to 20% of the Norwegians. This finding is in line with studies reporting stroke survivors experiencing difficulty with cognition, depression and IADLs experiencing significantly lower life satisfaction than those without these functional limitations (280).

Recent reviews have shown that depression affects a third of all stroke patients and remains stable for years (82,101).

Major predictors of depression are disability, prestroke depression, cognitive impairment, stroke severity and anxiety. Lower quality of life, mortality and disability are independent outcomes of depression after stroke.

Norwegians also report more satisfaction with ADL function, despite older age, more severe strokes and a higher proportion of pre-stroke dependency. In fact, the Norwegian participants gave satisfaction with ADLs the highest score of all categories on the QOLIBRI-OS at both timepoints.

Rehabilitative effects resulting in improved ADL function in the first 3 months post stroke may possibly explain part of the relatively high levels of rated satisfaction.

The complex associations between cognitive function, emotions and ADL were illustrated in a study suggesting that improving depressive symptoms in stroke patients may accelerate functional recovery. Nevertheless, the level of physical functioning achieved post stroke is determined by neurological and cognitive factors, consistent with the evidence that improvement of depressive symptoms through therapeutic intervention is limited by cognitive impairment (281).

The participants from the two countries rated satisfaction with physical function, personal and social life and actual and future prospects at equal levels.

4.4.3 Rehabilitation needs in early subacute phase

In our study, we chose to operationalize rehabilitation needs after stroke by defining help and training as the crucial elements of needs. The term “training” in this context was used for all rehabilitative therapies offered by physiotherapist, occupational therapists or speech therapists. The term “help” was used for care and support in daily activities provided by nurses or health assistants. The formulation of the question, based on the Norwegian stroke registry, did not permit response options such as having partly met needs.

The way the questions are formulated in the National Stroke Registry was not, unfortunately, unambiguous; for instance, the term help did not differentiate between types of help and thus might encourage an interpretation that includes, for example, help from relatives. If some patients answered the question based on a different personal interpretation, this would have led to an overestimation of unmet needs that cannot be met by health services.

By simplifying the concepts of needs by using single questions about help and training, other elements of health needs, such as information needs, were not taken into consideration. The use of single-item measures is methodologically controversial and assumes, according to some authors, a homogenous underlying construct (282). Others have, however, compared single-item to multiitem scales measuring the same constructs and found comparable results (283,284). The patients reported relatively high levels of met needs for help and training post stroke.

A third of the cohort reported no need for training or help. When excluding this proportion, 78% of all persons reporting needs for training had these needs met, while the corresponding frequency for those with a need for help was 85%. There was no difference between the country-regions. An unmet need for training and for help was associated with different underlying factors of social, functional and psychological character. In contrast to a Swedish registry study at 12 months (285), age or stroke severity did not predict unmet rehabilitation needs.

Multivariate logistic regression analysis revealed that an unmet need for training was associated with lower functioning. Lower functional ability was also reported in a stroke study investigating unmet needs related to occupational therapy after discharge from the hospital (286). Unmet needs associated with increased poststroke disability seem to persist into the chronic phase (287), representing a major challenge in stroke care. Living alone seemed to enhance the risk of unmet needs for help in our study.

The other major factor associated with unmet needs was psychological distress. In multivariate logistic regression, anxiety and depression significantly predicted unmet needs for training and help, respectively.

The patients reporting low HRQOL had a 3-fold higher level of both anxiety and depression scores than the proportion with high HRQOL. Among the participants with impaired HRQOL, the mean score at 3 months was close to the cutoff score for the HADS defining anxiety or depression that may pass diagnostic threshold levels and require treatment. For patients with stroke, some authors (174) have found a cutoff level for HADS-A or HADS-D scores for treatment as low as 4 for both anxiety and depression. The odds for perceived met needs for training was reduced to .37 in the presence of anxiety. The odds for met needs for help with concomitant depression was correspondingly .38.

Reducing psychological distress might therefore reduce levels of unmet needs. On the other hand, it is plausible that the experience of an unmet need for help or training predisposes individuals to both anxiety and depression.

There are no comparable studies of unmet needs at 3 months post stroke. Studies at 6 and 12 months post stroke demonstrate great variability in unmet needs, which may stem from large differences in operationalization or use of measures, as well as differing contexts (288).

4.4.4 Correlation between satisfaction with functioning and rehabilitation needs

Satisfaction and need have some common features, as both are derived from the patient's expectations. Values and cultural adaptations also contribute to the idea of what encompasses a reasonable claim for a society to achieve satisfaction and having met needs. While satisfaction is completely subjective and can only be perceived and expressed by the individual, need involves both a subjective part and an objective dimension that can be defined by others. There is not necessarily consensus between the patient and, for instance, health professionals on how to handle a need.

By combining data from papers 2 and 3, we were able to calculate the correlation between satisfaction and needs for 304/473 (62%) of the included patients in paper 3 (see flowchart in Figure 4).

Table 5 presents the relationships between QOLIBRI-OS scores and the proportion of met, unmet or no need for help and training. The QOLIBRI-OS scores for those with met needs for help and training were in line with the scores of the total population in Norway and Denmark. The level of satisfaction for both samples was approximately a score of 67/100 on the QOLIBRI-OS. In contrast, those with unmet needs for help and training scored significantly lower at a level of 50/100 on the QOLIBRI- OS, which corresponds to impaired HRQOL (Table 5). This finding is interesting in light of the fact that 38% of the patients reporting an unmet need for training had an mRS score at 3 months of 0-1 (paper 3), indicating no or minimal functional loss. This somewhat surprising fact indicated that the mRS might not identify all the symptoms that patients expect help to solve. The unidentified unmet symptoms may be severe, resulting in perceived impaired HRQOL. A newly published study indicated that unmet rehabilitation needs among persons with TBI also had a negative influence on life satisfaction as long as 5 years after the injury (289).

The patients with no need for help and training reported significantly higher satisfaction (scores of 75/100 on the QOLIBRI-OS) than patients with met needs. Based on these data, there seems to be a very clear correlation between met or unmet needs and satisfaction but an even stronger correlation between a high level of satisfaction with functioning and well-being and no need for help or training.

4.4.5 Donabedian model of satisfaction and needs

Both satisfaction with functioning and met rehabilitation needs were equal between the country regions at 3 months. A majority of patients reported high HRQOL and met needs for help and training.

Do satisfaction and met needs require the same structures and processes to be optimally fulfilled?

The high level of fulfillment of needs for rehabilitation assumes a financial structure securing free rehabilitation for all patients and a structural capacity to offer sufficient rehabilitation services. Both country-regions met these requirements. In contrast, worldwide, the main reasons for the unmet needs for rehabilitation are the absence of or unequal geographical distribution of services within a country, lack of transportation, and unaffordability of the services (290).

Regarding processes, there seemed to be no clear association between the type of processes that we have recorded data for and the perception of unmet needs. Almost 50% of persons with an unmet need for training completed inpatient rehabilitation. The report of unmet needs may therefore refer to unmet needs regarding intensity or duration of training in the rehabilitation process or to unfulfilled aspirations of functional improvement. Patients may also experience unmet needs at the municipality level. Thrombolysis was less commonly performed in Norway.

Among the personal factors, the profound effect of psychological distress was demonstrated in papers 2 and 3.

The reported HADS-A scores were significantly higher among those reporting unmet needs than those reporting met and no needs for both help and training (Table 5). Regarding the HADS-D, the same pattern was observed, with the exception of a nonsignificant correlation between met and unmet need for help (Table 5). Dividing the study cohort into high- and low-HRQOL categories revealed 3-fold higher anxiety and depression levels among participants with impaired HRQOL. There was no difference between country-regions. The results of psychological distress in study 3 must be interpreted with caution because we only obtained HADS data from 64% of the population. A lack of data could have led to an underestimation of the effects of psychological distress.

Considering prestroke demographic and stroke characteristics, the cohort differed in favor of Denmark regarding age, stroke severity and level of prestroke dependency on help. Previous studies have found that unmet rehabilitation needs increase with age (285).

One might expect that these differences would give the Norwegian participants a lower chance for achieving equally favorable results post stroke. In contrast, there was borderline significance (p=.08) both for higher satisfaction and for a lower proportion of impaired HRQOL (p=.08) among the Norwegians. They also reported higher levels of satisfaction with cognitive function, emotions and ADLs.

Can these findings be attributed to differences between the regions in structure, processes or patient features?

Greater differentiation in structures and more favorable patient features would unambiguously point in the direction of higher satisfaction and less unmet needs among Danish patients. However, the equality in the results at the end of the early subacute phase leads to considerations regarding whether dissimilarities in stroke processes could explain the results by adding elements compensating for structure and patient features. LOS was longer in Norway, and inpatient rehabilitation was preferred to a much higher extent in Norway.

A longer stay in the hospital and inpatient multidisciplinary rehabilitation may enhance to a greater extent the realization of potential re-enablement of the best possible degree of independence and secure the process of resettlement (49) enough to compensate for the more severe strokes in Norway, thus increasing satisfaction and the level of met needs. The mRS scores at 3 months were also similar, indicating compensation for the initial, more severe stroke consequences.

4.5 Changes in satisfaction from 3 to 12 months

The following paragraph discusses aim 4.

Responsiveness, together with reliability and validity, constitute the “holy trinity” of necessary psychometric properties of health status instruments (291). The construct of responsiveness is, however, challenging as different theoretical definitions exist and a wide variety of operationalizations of magnitude by effect size indices are used in research.

We defined responsiveness as the sensitivity to detect a difference between two points in time.

A potential change may be of statistical, but not of clinical relevance, especially when analyzing large study samples. As stated in the methods chapter, we used MCID and applied a stricter criterion defining change. A magnitude of change equivalent to 12/100 in QOLIBRI-OS scores during the 9-month poststroke period was regarded as the minimum threshold for a clinically relevant change.

This difference in perceived satisfaction with functioning and well-being was not significant (*p*=.08) at 3 months but reached a significant level at 12 months (p=.02) because the Norwegians slightly but nonsignificantly improved their satisfaction scores to 71,7, while the Danish result was completely unchanged over time. The proportion of patients reporting high HRQOL also became significant, as 83% of Norwegians and 71% of Danish patients (p=.01) defined their satisfaction with functioning and well-being as good. The difference is however less than the defined MCID for QOLIBRI-OS. At the group level, no significant changes in sum scale scores were observed, neither for the individual country nor the total cohort. At the individual level, 20% of the participants reported less satisfaction, and 26% of the patients experienced a positive change in satisfaction. As the proportion of persons reporting higher satisfaction was almost identical to those reporting worse HRQOL, no overall change in satisfaction was observed.

We do not have rehabilitation data from the late subacute phase and chronic phase. Based on clinical knowledge, a very small proportion of patients receive inpatient rehabilitation beyond

3 months post stroke. Community-based rehabilitation, especially in the domain of help, sustains of course for the most severely affected patients into the chronic stroke phase. The minor but significant differences in favor of Norway at 12 months could not easily be explained by structure or processes, as the rehabilitative follow-up in the Danish municipalities was more long-standing, differentiated and patient-oriented. Structurally, the Danish region has the most differentiated rehabilitation services at both the hospital and municipal levels.

Among the personal factors, psychological factors, age and a higher proportion of patients working before the stroke in the Danish cohort may have contributed to the lack of increase in satisfaction observed among Norwegian participants at 12 months.

The presence of anxiety or depression plays a major role in this phase. Depression or anxiety did not significantly predict a worse HRQOL using logistic regression analyses, but increased psychologic distress correlated with less satisfaction with functioning and well-being at 12 months (Table 4) and might be part of the explanation for the dynamic individual courses reported in the study cohort. The total HADS scores at the group level were stable across timepoints, and no country differences were observed. Consistent with decreased, stable and improved satisfaction with functioning, the individual variations in perceived psychological distress, both better and worse, were nullified, thus leading to no change at the group level.

The frequency of depression in study 2, defined as a HADS depression score of ≥ 8, was 10% at both 3 and 12 months, which is considerably lower than that reported in a poststroke depression review (82).

The prevalence of anxiety was 15-16% in the period from 3 to 12 months post stroke, which was lower than the prevalence of anxiety post stroke reported in 2018 (144) but consistent with the overall pooled estimate of anxiety disorders assessed at 18% in an earlier poststroke review (146).

HADS anxiety scores at 12 months were also higher among persons under 65 years of age, either as a consequence or a cause of perceived worse HRQOL.

Comparing those with decreases in satisfaction to the proportion of stable HRQOL revealed that younger age (>65 years old) was the sole predictor of negative change. The perceived worse HRQOL in function and well-being among the younger proportion of the study cohort is not surprising, bearing in mind the substantial loss of social roles a stroke may represent for those under 65 years of age (276). Demanding role fulfilment, unsuccessful readjustment, or loss of working abilities (49) enhance the risk of experiencing declining satisfaction in the late subacute or chronic stroke phase.

No variables predicting improvements in QOLIBRI-OS scores were found.

At 12 months, 21% of the participants in our study cohort had QOLIBRI-OS scores of 52 or lower. This is a lower proportion of patients describing their HRQOL as impaired than what was found for patients with TBI (272) and SAH (292). The frequency of dissatisfaction with HRQOL in this study was unchanged over time. Although there is a common belief that stroke function is stable after 3 months, a Swedish study found a transition from ADL independence to dependence between 3 and 12 months post stroke among 1/6 of all patients and, most frequently, among women (293).

In light of this finding, the level of satisfaction at both 3 and 12 months must be regarded as good in our population. In comparison, another study demonstrated long-standing dissatisfaction one year post onset, correlating with activity limitations and restricted participation (147), where only 39% reported satisfaction with life as a whole.

Additionally, among patients with severe multiple traumas, longstanding loss of satisfaction has been reported (294).

On the other hand, individual coping strategies (295) and a well-functioning social network reduced the risk of impaired HRQOL.

Vulnerable patients with stroke may experience complex interactions between physical, cognitive and emotional deficits resulting in restrictions in ADLs and personal and social life, and loss of future prospects in subacute phase (246) is a reminder of the necessity of long-term follow-up of patients with stroke.

4.6 Methodical challenges and limitations of the studies

Comparing data from adjacent countries proved more difficult than anticipated due to differing legal restrictions regarding the use of patient data. The lack of follow-up data in the Danish stroke registry complicated data collection and caused a lower response rates, as we were obliged to contact all patients per telephone. The differences in described recruitment strategies with only indirect contact with potential patients most likely led to a lower number of participants included in Denmark. The dropout rate was amplified by our data collection procedure. In planning the study, no overlap of collected data between the questionnaire set, telephone interview and registry data was intended. See Table 1 for an overview of data and data sources. This decision, however, led to a lower inclusion rate, as we had limited possibilities to acquire complete data when one source of essential data was missing. This had the largest impact in Denmark, where access to medical records for the included patients was not permitted.

Data on anxiety and depression were collected in the questionnaire set. Partly because study 3 also included proxy responders, who answered only a few demographic questions in the questionnaire set, a total proportion of 36% of participants from both countries did not answer the HADS questionnaire in this study. The effects of psychological distress on the study population might have therefore been underestimated.

The missing proportion of Danish responders complicated the assessment of rehabilitation pathways. Missing data may not necessarily result in selection bias if the missing data are random. The statistical strength of the result will, however, be reduced. Bearing in mind that the nonparticipants in Denmark had lower SSS scores, indicating more severe strokes in both studies, one might suspect that the proportion of inpatient rehabilitation could have been underestimated in Denmark. We regard our findings representative of the proportion of patients with mild and moderate strokes. Due to selection bias, conclusions could not be drawn for the oldest and most severely affected patients with stroke in the two country-regions.

4.7 Study strengths

Despite the limitations listed above, we managed to include a large cohort of unselected patients, varying from 44% of elective Danish patients to 75% of Norwegians with first-ever stroke. All patients were followed from the acute phase until 12 months. The features of the patients and stroke characteristics were representative of both the regions and national stroke populations, thus increasing the external validity of the results. Our study was the first to investigate the QOLIBRI-OS in a stroke population. The instrument fulfilled psychometric claims for an HRQOL instrument adapted for individuals with ischemic and hemorrhagic strokes with mild and moderate stroke severity. Because of binational cooperation with locally anchored researchers and clinicians, we also had access to precise knowledge of both structures and processes influencing stroke treatment and rehabilitation.

4.8 Further research

A larger Scandinavian study based on both registry data and patient-reported data on function and satisfaction with functioning would be of value. Sweden provides acute treatment with a far longer LOS and more inpatient rehabilitation in comprehensive stroke units than Norway and, even more so, Denmark.

A comparison between the national structures and processes might reveal which stroke trajectories enable the best patient-reported outcomes, both in the early subacute and chronic phases.

In addition, we have unused data on satisfaction with health services (see Table 1) that could be combined with data on satisfaction with functioning and well-being from the QOLIBRI-OS. Increasing knowledge of the extent to which structure and processes in stroke treatment and rehabilitation influence perception of health-related quality of life could lead to further development of stroke pathways.

5 Conclusion

We explored the HRQOL instrument QOLIBRI-OS in an unselected group of first-ever stroke patients in regions in Norway and Denmark. The instrument demonstrated good psychometric properties and seems to be a suitable instrument for measuring satisfaction with functioning and well-being post stroke, although its content validity would improve even more if items measuring language impairments and sensorimotor function were added.

We regard satisfaction as measured with the QOLIBRI-OS to represent a valuable outcome instrument for the patient. The responsiveness of the QOLIBRI-OS enabled us to investigate changes in satisfaction over time. At the group level, no change in satisfaction from 3 to 12 months occurred. At an individual level, almost 50% reported clinically important changes in HRQOL over the observed time span. Younger patients were more susceptible to reporting worse outcomes at 12 months.

Regarding outcomes with respect to structures, processes, patient features and stroke characteristics enabled a more thorough analysis of possible differences between the country-regions.

The main impression from following a large proportion of patients in a region in Norway and Denmark was that both acute care and rehabilitation services are of good quality and promote opportunities for the majority of patients to achieve high levels of satisfaction. Using a dichotomous scale for high and low HRQOL, based on the QOLIBRI-OS cutoff score of 52/100, almost 80% of the population reported high HRQOL at 3 and 12 months.

The patients reported equal results for satisfaction and fulfillment of needs for help and training at 3 months, while the Norwegian population experienced better satisfaction with functioning and well-being at 12 months. The observed minor differences between the country-regions in perceived satisfaction may have been due to the choice of different procedures within the rehabilitation pathways.

Among the personal features, psychological distress had a major impact on outcomes. Anxiety and depression covaried with levels of HRQOL. Unmet rehabilitation needs were highly correlated with psychological distress and impaired HRQOL.

The expressed rehabilitation needs were to a large extent fulfilled due to well-adapted structure and processes. However, a fifth of the patients with stroke conveyed an unmet need for help and training with a correspondingly low HRQOL. Optimizing stroke structures and processes and implementing strategies to reduce psychological distress would enable a higher degree of fulfilment of rehabilitation needs and hence increase satisfaction.

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Paper 1

Guri Anita Heiberg, Synne Garder Pedersen, Oddgeir Friborg, Jørgen Feldbæk Nielsen, Henriette Holm Stabel, Nicole von Steinbüchel, Cathrine Arntzen, Audny Anke***. Can the health related quality of life measure QOLIBRI-Overall Scale be of use after stroke? A validation study***. Published in *BMJ Neurology* 2018; 18:98 https://doi.org/10.1186/s12883- 018-1101-9

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RESEARCH ARTICLE

Can the health related quality of life measure QOLIBRI- overall scale (OS) be of use after stroke? A validation study

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Abstract

Background: Brief measures of health-related quality of life (HRQOL) that assess both patient-reported functioning and well-being after stroke are scarce. The objective of this study was to examine reliability and validity of one of these measures, the patient-reported Quality of Life after Brain Injury–Overall Scale (QOLIBRI-OS), in patients after stroke.

Methods: Stroke survivors were examined prospectively using survey methods.
Core survey data ($n = 125$) and retest data ($n = 36$) were obtained at 3 and 12 months, respectively. Item properties (distribution, floor and ceiling effects), psychometric properties (reliability and model fit), and validity (correlations with established measures of anxiety, depression and HRQOL) of the QOLIBRI-OS were examined.

Results: Missing responses on the questionnaire were low (0.5%). All items were positively skewed. No floor effects were present, whereas five out of six items showed ceiling effects. The summary QOLIBRI-OS score exhibited no floor or ceiling effects, and had excellent internal consistency (Cronbach's α =0.93). All item-total correlations were high (0.73–0.88). The test-retest reliability of single items varied from 0.74 to 0.91 and was 0.93 for the overall score. The confirmatory factor analysis yielded an excellent fit for a five-item version and provided tentative support for the original six-item version. The convergent validity correlations were in the hypothesized directions, thus supporting the construct validity.

Conclusions: The brief QOLIBRI-OS is a valid and reliable brief health-related outcome measure that is appropriate for screening HRQOL in patients after stroke.

Keywords: QOLIBRI-OS, Stroke, Health related quality of life, Validity

Background

Strokes are associated with complex physical, cognitive and psychosocial consequences that pose challenges to valid long-term outcome assessments [1, 2]. Due to a combination of functional, psychological and social constraints, the use of patients reported outcomes (PROs) to assess progress following treatment is advocated [3, 4]. PROs also seek to ascertain patients' views of the severity of their symptoms and functional status [5].

Generic and disease-specific health related quality of life (HRQOL) instruments assess consequences of health conditions on quality of life comprising psychological, physical, social and daily-life domains [6]. Both generic and disease-specific scales are used following stroke [7–9].

A comprehensive evaluation of the available HRQOL measures found that generic scales had limited value due to their lack of specificity to particular conditions and low responsiveness to change [7]. In the past decade, the use of stroke-specific scales has increased [10].

Stroke-specific HRQOL measures should ideally be reliable, valid, responsive, precise and appropriate as well as feasible, interpretable and easy to complete [3, 11–13]. Examples of these types of measures are the Stroke-Specific Quality of Life (SS-QOL) scale [14] and the Stroke Impact

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Scale (SIS) [15], which both have shown good psychometric properties and been translated into several languages [16–18]. Although these scales adequately assess functional problems post-stroke, their comprehensive approach, i.e., inclusion of a large number of items covering multiple domains, reduce their feasibility in research and clinical use, especially for patients with cognitive deficits [19] or fatigue post-stroke [20]. A brief HRQOL measure could be useful for screening or in situations where the workload should be minimal. Additionally, a brief disease-specific version of the SIS with eight items has been developed [21], but this index does not address satisfaction, subjective functioning and subjective health status. Moreover, to compare conditions between patients with different disorders the measure has to be validated for use in several diagnostic groups.

In literature search of a suitable brief instrument assessing well-being, according to patient-reported satisfaction and important functional domains following stroke, the short Quality of Life after Brain injury Overall Scale (QOLIBRI-OS) [22] was identified as a possible option. This instrument was cross-culturally developed in six European countries between 2000 and 2010, and validated in more than 2000 patients after traumatic brain injury (TBI) [23].

The QOLIBRI-OS is a brief TBI-specific HRQOL index that addresses wellbeing and functioning [22]. The psychometric properties for the QOLIBRI-OS after TBI are satisfactory to good and are highly correlated with the 37 QOLIBRI scale (six subscales), indicating that a comparable construct is assessed [22]. The six items of the QOLIBRI-OS assess overall satisfaction with physical function, cognition, emotional status, ability to perform daily activities, personal life and social relationships, and satisfaction with the current situation and future prospects. A confirmatory factor analysis of the scale seem to support uni-dimensionality; however with some reservations as absolute fit seems clearly poorer (i.e., RMSEA = .07) than the relative fit (e.g., CFI = .98) [22]. QOLIBRI-OS has also been validated for patients with aneurysmal subarachnoid haemorrhage [24].

Stroke has important cognitive, emotional and physical clinical consequences that are similar to those of TBI, even though the health conditions differ in pathogenesis [25, 26]. Thus, the aim of this study was to investigate whether the QOLIBRI-OS is uni-dimensional and a reliable and valid measure of HRQOL post-stroke. To investigate its construct validity, we hypothesized positive correlations between the QOLIBRI-OS and the other HRQOL measures and negative correlations between the QOLIBRI-OS and psychological distress. In addition, concurrent relations of the individual QOLIBRI-items with relevant measures were explored.

Methods

This validation study is a part of a larger stroke study consecutively enrolling all patients, who were admitted to the stroke units of the University Hospital of Northern Norway (UNN) between March 2014 and December 2014.The inclusion criteria were in accordance with those of the National Stroke Registry. The exclusion criteria were age below 18 years, residence outside the hospital's region or foreign nationality. Patients with stroke related to brain malignancy, brain trauma or subarachnoid haemorrhage were excluded. A few patients who received acute stroke care in wards other than stroke units, due to the presence of other serious diseases, were also excluded. In total, 161 of 214 eligible patients with ischaemic or haemorrhagic stroke (ICD10 codes I.61 and I.63) consented to participate in the validation study, and 125 finally answered the questionnaire. While the response rate for eligible patients was 56%, the response rate for included consenting patients at 3 months was.

125 /161 = 78%. The flowchart in Fig. 1 shows more information on patient enrolment.

The study was approved by the Norwegian Regional Committee for Medical and Health Research Ethics (2013/ 1472).

Data collection

Patients were recruited during hospitalization in the stroke unit or by telephone within 3 months of discharge. Participants were asked to provide written consent. A local coordinator at all participating hospitals distributed the questionnaires by mail. Self-reported data were collected 3 months after stroke. Incomplete questionnaires were completed by filling in all missing items after an additional telephone interview. When up to two responses on any questionnaire were missing, mean imputation was performed. Questionnaires with more than 2 missing data points were excluded. Test-retest analysis of the QOLIBRI-OS was performed at 12-month follow-up due to the expected stability in functioning post-stroke [27] at this time point**.** The first 40 participants who answered at 12 months were asked to complete the retest in a 7- to 12-day period. Of these, 36 participants completed and returned the QOLIBRI-OS within the timeframe, which provides a response-rate of 90%. We conducted statistical tests (e.g., Student t- and chi-square tests) comparing the retest group (n = 36) with those not retested (n = 89), but no significant differences in any demographic characteristics or stroke severity emerged.

Demographic and stroke registry data

Information about age, gender, living condition and stroke was collected from the Norwegian Stroke Registry. Questions regarding education, marital status and work status

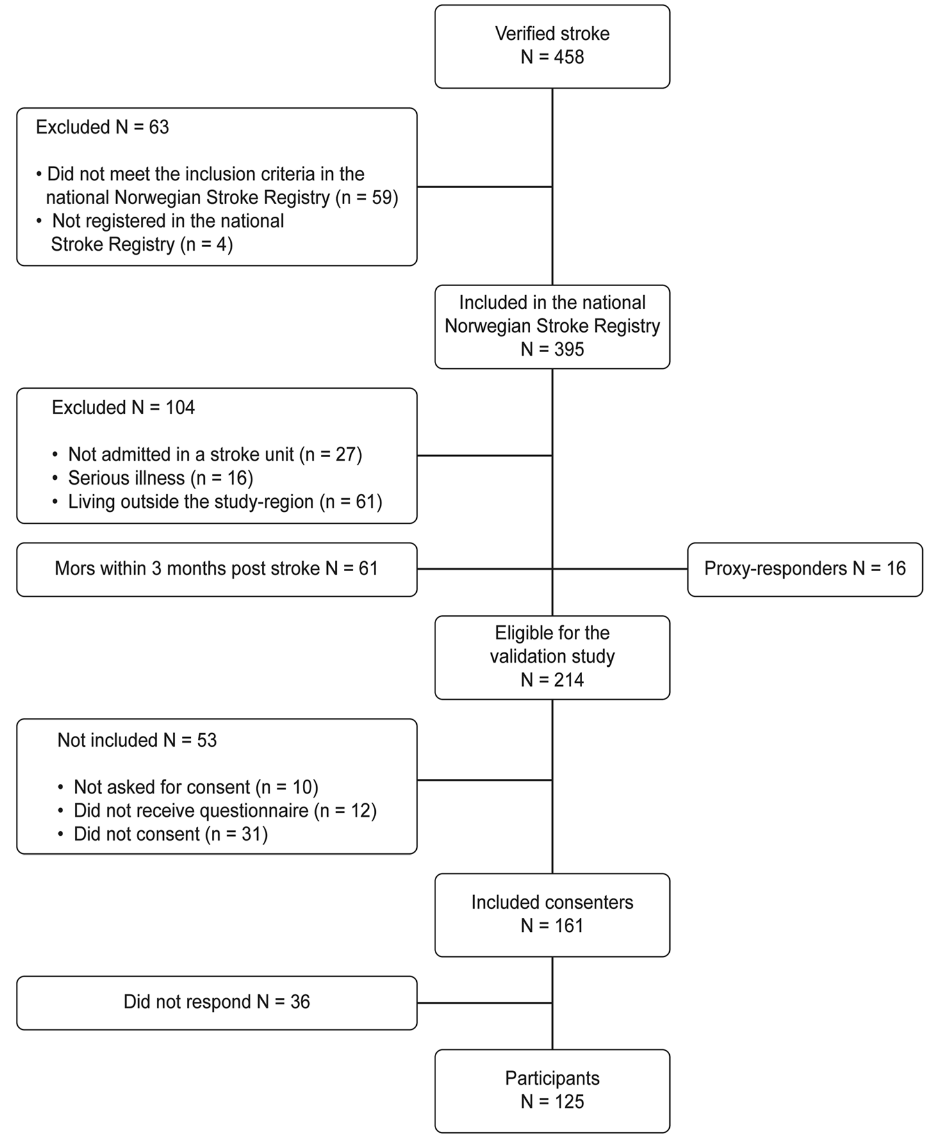

Fig. 1 Flowchart of persons with acute ischemic or hemorrhagic stroke registered during the recruiting period

were included in the mailed questionnaires, or were collected from the medical records after consent. Function was assessed with the Modified Rankin scale (MRS) [28], a clinician-reported measure of global disability widely used to evaluate post-stroke outcomes [28]. The scale consists of six categories assessing the level of independence, ranging from independent to bedridden or death. There is extensive evidence on the validity of the MRS [28]. In our study, the MRS was registered at 3 months after telephone interviews, as part of the national stroke registry registration.

Participants

Sociodemographic and clinical characteristics of the 125 participants are shown in Table 1. The average age was 70.5 years, and 62% were male. Approximately 50% of patients had less than 11 years of education, and three out of four had retired before stroke.

At 3 months after stroke approximately 75% lived at home without personal assistance. Compared to those who did not respond ($n = 36$), participants were 5 years younger and a larger proportion lived at home at 3 months. The participants and non-responders differed statistically significantly in age, MRS score at 3 months, and proportion living in an institution and in need of assistance. Gender and stroke subtypes were similar in both groups (Table 1).

Comparisons between participants and patients that were eligible for the validation study, but did not participate, were performed only for age and gender for ethical reasons. However, there were no statistically significant

Table 1 Sociodemographic and stroke characteristics of the participants and non-responders

	Participants *N* = 125	Non-responders *N* = 36	*P*-values
Age at time of stroke, Mean (SD)	70.5 (13.1)	75 (13.6)	< 0.05
Gender, n (%)			
Female	48 (38)	16 (44)	
Male	77 (62)	20 (56)	0.34
Stroke subtype, n (%)			
Ischaemic	113 (90)	31 (86)	
Haemorrhagic	12 (10)	5 (14)	0.33
Marital status at time of stroke, n (%)			
Married/cohabitant	80 (64)	16 (45)	
Widowed/single	45 (36)	20 (55)	< 0.05
Education, time of stroke, n (%)			
≤ 10 years (y)	60 (48)	–	
> 10	62 (50)	–	–
Unknown	3 (2)	–	
Living conditions at 3 months, n (%)			
Home, without assistance	92 (73)	12 (33)	
Home, with assistance	23 (19)	14 (39)	< 0.01[a]
Institution/residence for the elderly	10 (8)	10 (28)	
Work status at 3 months, n (%)			
Student/Unemployed/Working fulltime or part-time	23 (18)	3 (8)	0.77
Retired/ Sick-leave	102 (82)	33 (92)	
MRS at 3 months, n (%)			
0–1 no symptoms or significant disability	84 (67)	15 (42)	
2–3 slight or moderate disability	33 (26)	16 (44)	
4–5 severe disability	8 (7)	7 (14)	< 0.05[b]

[a] Significantly more responders than non-responders lived at home without assistance vs. at home with assistance/in institution at 3 months after stroke
[b] Wilcoxon signed rank test

differences in these demographic data between the participants and the patients who refused to participate or between those who, due to a administrate failure, were not contacted.

Measurements

The QOLIBRI-OS comprises six items that assess the degree of overall satisfaction with “Physical Condition”, “Cognition”, “Emotions”, “Ability to Perform Daily Activities”, “Personal and Social Life,” and “Current Situation and Future Prospects”. A Likert scale provides the following five response categories: not at all (score 1), slightly (score 2) moderately (score 3), quite (score 4), very (score 5) for each item [22]. Accordingly, item score range is 1–5 and sum score range 6–30.

Von Steinbuchel et al. [22] arithmetically converted the sum of all items to a percentage scale (0–100). In the present study, both the raw item scores and the overall sum score were used. The QOLIBRI-OS has demonstrated good internal consistency with a Cronbach’s α value of 0.86 in patients after TBI [22] and 0.88 in patients with subarachnoid haemorrhage. [24]. The QOLIBRI full scale (37 items) questionnaire has been examined in a Norwegian study of patients after TBI and showed metric properties supporting the reliability and factor structure. To date, the QOLIBRI-OS (6 items) has not been validated in Norwegian samples. The QOLIBRI-OS was translated into Norwegian in 2008 in accordance with recommended procedures and is used in a longitudinal international observational study (the European Union Study CENTER-TBI-HEALTH. 2013.2.2.1–1). [29, 30] The translation used in our study was slightly modified to improve language fluency, and checked with back translation by a professional translation service. According to a bilingual professional translator the semantic meaning in our Norwegian version express the meaning of the original English version.

The Hospital Anxiety and Depression Scale (HADS), originally published by Zigmond and Snaith in 1983 [31], is a widely used instrument that screens for non-vegetative symptoms of anxiety (seven items) and depression (seven items) [32]. The HADS items are scored from 0 to 3 with higher scores indicating worse symptoms. A cut-off score of 8 indicates a possible diagnosis of anxiety or depression [33]. The total score (HADS-14) can also be used as a global measure of psychological distress [34]. The HADS questionnaire has been applied several times in Norwegian populations [29], also post-stroke [35].

The EuroQol Five Dimensions Questionnaire (EQ-5D) [36] is a three-level generic HRQOL questionnaire comprising 5 items measuring the dimensions of mobility, self-care, ability to perform daily activities, pain/discomfort and anxiety and depression [37]. The levels are rated as 1, 2, or 3, indicating no (1), some (2), and considerable problems (3). Each dimension can be scored separately. The questionnaire includes the EuroQol Visual analogue Scale.

(EQ-VAS), which is a 0–100 visual analogue scale intended to measure actual self-reported health status from worst to best imaginable health [38].

The Stroke Specific Quality of Life (SS-QOL) scale [14] assesses the functional impact of stroke across 12 domains using 49 items and a five-point Likert scale where higher scores indicate better functioning. The SS-QOL measures energy, mood, family roles, language, mobility, self-care, social roles, thinking, personality, and upper extremity function, vision and work/ productivity. A sum score can be extracted from each domain. Separate domain scores are obtained from unweighted average of all items belonging to a particular domain, but the overall SS-QOL score is most often used as the primary outcome. The SS-QOL scale has recently been translated into Norwegian in accordance with recommended procedures [39, 40].

Validation study design

The construct and criterion-related validity of the QOLIBRI-OS were examined in a confirmatory factor analysis and as concurrent correlations with theoretically related measures, respectively.The instruments chosen represent different aspects like stroke specific health related functions in HRQOL-measures, generic health related quality of life instruments, single questions and instruments assessing anxiety and depression. Moreover, the criterion-related measures included in our study are validated in Norwegian samples.The convergent and divergent validity of the QOLIBRI-OS, as one specific type of criterion-related validity, were supported if the Spearman rank-order correlations with the HADS total and anxiety scales were negative and the EQ-5D and SS-QOL were positive. Such correlations were calculated for both the QOLIBRI-OS total and item scores. The direction of these a priori hypothesised correlations were based on the literature review in the introduction. According to the COSMIN guidelines [41], the overall construct validity is rated positively if the hypothesized relationships are specified in advance and supported in at least 75% of the reported results and based on a minimum of 50 patients.

Correlations above 0.50, between 0.31 and 0.49 and less than 0.30 were considered high, moderate and low, respectively [42]. Based on the literature review, we expected moderate to strong correlations between the QOLIBRI-OS and the criterion measures (see Table 2).The psychometric results from the current study were also used to re-evaluate the content validity of the QOLIBRI-OS, and discuss improvements.

Statistical and psychometric analyses

The Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) guidelines [41] were used as guidelines for this validation study. The psychometric classical test theory analyses were conducted in Mplus version 7.4 [43] whereas all other inferential analyses were conducted in IBM SPSS version 23.

Descriptive characteristics

The QOLIBRI-OS items were described in terms of means and distributional properties. The degree of floor and ceiling effects, as defined by more than 15% of responses in the extreme lower or upper categories of the scale, were reported [44].

Uni-dimensionality

A confirmatory factor analysis was conducted to examine the fit of the QOLIBRI-OS as a uni-dimensional model. The maximum likelihood with robust standard errors (MLR) was applied, as the item distributions were non-normal. Model fit was evaluated in terms of the root mean square error of approximation (RMSEA), the standardized root mean square residual (SRMR), the comparative fit index (CFI) and the non-normed fit index (NNFI) [45]. West et al. [45] suggest that RMSEA < 0.05, CFI > 0.95, NNFI > 0.90 and SRMR < 0.06 represent a well-fitting model, while CFI > 0.90, NNFI > 0.85, RMSEA < 0.08, and SRMR < 0.10 indicate a tentatively adequate model.

Reliability

Cronbach's α was used to investigate the internal consistency. A value larger than 0.70 is generally recommended for research purposes (e.g., group comparisons), whereas values above 0.90 is desirable for individual clinical assessment [46]. Correlations between QOLIBRI-OS items and its total score were examined (values > 0.40 are preferable) [44] to identify items contributing poorly to the reliability or the ranking of the patients. Test-retest reliability was evaluated with intra-class correlation coefficients (ICCs) based on a two-way mixed model (i.e., treating items and subjects as fixed and random components, respectively). Both ICC absolute agreement and ICC consistency estimates were extracted for comparison purposes [47]. ICC consistency values > 0.75 was considered as excellent.

Results

Item characteristics and data quality of the QOLIBRI-OS

The degree of missing QOLIBRI-OS data was below 0.5% (Table 3). Single items were moderately positively skewed. The QOLIBRI-OS total score did not show floor or ceiling effects according to the COSMIN criterion we used, whereas a modest ceiling effect (defined as > 15%) was observed in all items with the exception of one ("Physical condition"). All items robustly contributed to the overall QOLIBRI score, with all item-total correlations above 0.4 (ranging between 0.73–0.88).

Confirmatory factor analysis (CFA) of the QOLIBRI-OS

The model fit indicators of the hypothesized one-factor model were not universally good (robust $\chi^2_{df = 9} = 21.83$, $p = 0.009$). Although the relative fit indices were good (CFI = 0.972 and NNFI = 0.953), the important non-centrality index (RMSEA = 0.107) was poorer as opposed to the absolute difference in unexplained standardized residuals that were low (SRMR = 0.029). This model thus yielded mixed support. Removing a single item, i.e., item 3 ("Overall, how satisfied are you with your feelings and emotions?"), yielded a model with excellent universal fit (robust $\chi^2_{df = 5} = 3.47$, $p = 0.63$; RMSEA = 0; SRMR = 0.015; CFI = 1.0; NNFI = 1.0).

As shown in Table 3, the ICC of the individual QOLIBRI-OS items were high and ranged from 0.75 to 0.91, whereas the overall score had excellent stability, ICC = 0.93.

Internal consistency of the QOLIBRI-OS overall score was excellent (Cronbach's α = 0.93). We also calculated Cronbach's α after removing the item "feelings and emotions".

to observe changes in the internal consistency. In the resulting five-item scale, the Cronbach's α declined from 0.93 to 0.90.

Construct validity

As the results of the CFA were mixed, and as the authors considered the item in question (item 3) important for evaluations of HRQOL after stroke, additional correlation analyses were performed. First, the correlation between the five-item (after removing item 3) and six-item overall QOLIBRI-OS was 0.99. Second, the correlations between the HADS, EQ-VAS and the SS-QOL, and the five-and six-item QOLIBRI-OS yielded almost identical results.

Discussion

The results of this study indicated that the QOLIBRI-OS had excellent internal consistency, with slightly higher values than those reported in comparable studies after TBI and subarachnoid haemorrhage [22, 24]. All item-total correlations were high, and the items thus significantly contributed to a reliable ranking of patients. According to the COSMIN guidelines, floor and ceiling effects should not

Table 2 Construct validity of the QOLIBRI-OS at 3 months after stroke

Items	Measure for comparison	Correlation hypotheses	Spearman's Rho
1 Physical condition	SS-QOL sum mobility	High	0.44[a]
	EQ5D mobility	Moderate	0.31[a]
2 Cognitive function	SS-QOL sum thinking	Moderate to high	0.65[a]
3 Emotions	SS-QOL sum mood	High	0.66[a]
	HADS-total score	Moderate to high, negative	−0.70[a]
4 Daily activities	SS-QOL sum work	Moderate to high	0.62[a]
	EQ5D Usual activities	High	0.64[a]
5 Personal and social life	SS-QOL sum social role	Moderate	0.55[a]
	HADS total score	Moderate, negative	−0.61[a]
6 Current situation and future prospects	EQ VAS score	High	0.57[a]
	HADS anxiety scale	High, negative	−0.58[a]
Sum QOLIBRI-OS	HADS total score	High, negative	−0.74[a]
	EQ VAS score	Moderate	0.56[a]
	SS-QOL sum score	High	0.71[a]

EQ5D EuroQol Quality of Life Scale-5D, *HADS* Hospital Anxiety and Depression Scale, *SS-QOL* Stroke-Specific Quality of Life Scale
[a] Correlation is significant at the 0.01 level (two-tailed)

exceed 15% [41]. In our study population, the summary QOLIBRI-OS score had no floor or ceiling effects. Modest ceiling effects were observed for the individual items. Stroke populations are very heterogeneous, thus these ceiling effects are difficult to interpret. For instance, certain subgroups are expected to experience few or no cognitive symptoms [48], therefore, the 20% of persons in this study reporting optimal satisfaction with cognitive functioning (item 2) did not necessarily indicate a problem with the scale, but might rather represent a clinical feature of this population [19]. No other studies have specifically investigated ceiling effects for single items in the QOLIBRI-OS, but von Steinbuchel et al. [22] reported a positive skew for all items indicating positive HRQOL in patients with TBI.

The uni-dimensionality of the QOLOBRI-OS received mixed support, as reported by others [49]. Muehlan et al. [49] identified item 5 (personal and social life) as a potentially problematic item after TBI. In the present study the cause of the mixed fit was related to another item (item 3: feelings and emotions). Removing this item led to an excellent model fit for the resulting five-item QOLIBRI-OS. Nevertheless, we retained all items in the final model because the differences in the validity correlations between the six- versus the five-item versions were negligible. Because this item has not been reported as problematic in other studies, and as the model fit of the six-item QOLIBRI-OS in the present study may be considered as fair, future studies should confirm a problem with this particular item before considering its removal. The problem with item 3 could be related to the translation, which differs slightly from the Norwegian CENTER-TBI version. Norwegian language don't differentiate between the terms "«feelings" and "«emotion", hence there was a minor problem in back-translation from Norwegian to English. Therefore a Norwegian replication study containing some changes in wording may be performed, investigating whether the translation of the above mentioned item is inaccurate.

Validity of the QOLIBRI-OS

Analysis of the a priori hypotheses confirmed construct validity. All a priori hypothesis tests, apart from one hypotheses, showed correlations with the selected other measures in the presumed directions and magnitude (Table 2). The correlation between Physical condition and SS-QOL sum mobility was moderate 0.44, though hypothesised to be high.

The COSMIN criteria indicate that construct validity can be supported if the concurrent correlations with other criterion-related variables are in the magnitude and direction hypothesized or predetermined by the authors. The present results uniformly fulfilled the COSMIN criteria [44]. The lowest correlation was observed between the "satisfaction with physical condition" item and the EQ-5D "mobility" question; this finding is not surprising, as the EQ-5D assesses walking ability in isolation, thus overlooking upper arm function and general health [38]. The highest correlation was observed in a negative relationship between item 3 on the QOLIBRI-OS, "satisfaction with feelings and emotions", and the HADS total score, which assesses psychological distress [31]; this result is in accordance with previous findings [50]. Emotions contribute substantially to HRQOL, and the high correlation between the QOLIBRI-OS emotion item and mental distress supported maintaining this item, even though the CFA indicated that it might be potentially problematic.

Table 3 Psychometric properties of the QOLIBRI-OS in 125 participants post-stroke: missing, mean values, item-total correlations and floor and ceiling effects. Test-retest reliability in 36 participants

Item *N* = 125	Missing %	Mean (SD)	Corrected item-total correlation	Floor and ceiling effects (%)	Test-retest reliability *N* = 36
QOL1: Physical condition	0	3.47 (1.02)	0.74	5.6 12.6	0.81
QOL2: Cognitive function	0	3.58 (1.06)	0.73	2.4 20.0	0.87
QOL3: Emotions	0.8	3.58 (1.08)	0.85	3.2 20.8	0.80
QOL4: Daily activities	1.6	3.75 (1.11)	0.78	4.0 28.8	0.91
QOL 5: Personal and, social life	0	3.62 (1.19)	0.83	7.2 24.8	0.75
QOL 6: Current life and, future prospects	0	3.50 (1.09)	0.88	6.4 17.6	0.84
QOLIBRI-OS sum score	0.4	3.58 (0.93)		0.8 7.2	0.93

Score reliability as test-retest stability

The ICC was tested using both consistency and agreement methods. The results were nearly identical, indicating that the subjects provided rather identical responses. The test-retest stability was particularly high for the overall scale (ICC = 0.93), which is higher than in previously published studies (ICC = 0.81) [22]. This may relate to differences in time periods of assessment. In our study, all participants performed test-retest at 12 months, whereas in former studies of QOLIBRI-OS, test-retest was investigated from 3 months to 15 years post stroke.The test-retest stability of all single items were comparable excellent.

Summarized, the psychometric results of the QOLIBRI-OS administered after stroke in this study are comparable or better than the results determined after TBI and subarachnoid haemorrhage [22, 24].

Can single items be considered individual domains?

The literature is ambiguous about the use of single items [51] to assess HRQOL, as single items are less reliable and valid than sum scores. Nevertheless, other scholars have reported that the reliability of global questions regarding HRQOL might be adequate [52–54].

The EQ-5D [36] has scoring options that include the use of single items. In our study, all of the QOLIBRI-OS items appeared to be uniformly consistent. Means, item-total correlations and test-retest stability varied slightly between items and differed slightly from the results of the total QOLIBRI-OS scale. Moreover, the concurrent validity coefficients of the individual items were high, given the high correlations with criterion-related measures, such as the HADS and SS-QOL. A higher ceiling effect for single items compared to the total score can be expected because of more variation within sum scores. More patients after stroke are expected to have optimal function in one specific aspect assessed by the QOLIBRI-OS, than in all aspects.

Use of QOLIBRI-OS in patients after stroke?

For clinical and research purposes after stroke there is no single preferred choice of outcome measure yet [4]. We performed a literature search in PubMed from 2014 to 2016 and discovered that the MRS was by far the most commonly used outcome measure in stroke research studies published from 2014 to 2016. However, the MRS does not assess the patients' subjective perspectives of their health and wellbeing and is unable to differentiate between physical and cognitive sequelae, which is an important argument for including a patient reported outcome measure (PROM).

However, can the QOLIBRI-OS, which is a brief measure, collect substantial information about important HRQOL domains for patients after stroke? In our opinion, the QOLIBRI-OS assesses the major consequences of stroke. Compared to the SIS [55] the QOLIBRI-OS contains one item measuring satisfaction with physical condition but lacks detailed measurements of strength and hand function. The SS-QOL which has 49 items, also includes domains that assess vision and energy [14]. Both the SIS and SS-QOL address communication. The lack of measurement of communication abilities (speaking and understanding) presents, in our opinion, a weakness of the QOLIBRI-OS for use post-stroke. The lack of a specific communication component is likely due to the fact that the instrument was developed only with generalizing overall questions, and the communication aspect was included in the overall item assessing cognition. In addition, motor activity was assumed to be included in the item assessing satisfaction with the physical condition. However, in stroke, communicative and motoric problems are frequent specific problems [56]. Therefore, we suggest that two additional new items should be developed and added to the QOLIBRI-OS- For instance, an item from the QOLIBRI scale regarding satisfaction with language and communicative skills and one item assessing motor function could be included and the scale should then be re-validated in a comprehensive stroke population. For the time being, however, we recommend the use of the QOLIBRI-OS in patients after stroke because it provides a short, reliable and valid index of HRQOL after stroke.

Strengths and limitations of the study

The strengths of this study are that a major proportion of the unselected stroke population admitted to UNN in 2014 is included. Patients were recruited from stroke units and followed through early rehabilitation, in both hospital and community settings. Of the consenting patients, 78% responded to the main questionnaire, despite the broad inclusion criteria and no exclusion of patients with aphasia or cognitive problems. All patients responded during the same time period post-stroke. The data quality was excellent, and the results were consistent.

A significantly higher portion of non-responders was institutionalized. However, the absolute number of patients with considerable functional deficits post-stroke was low in both groups. A total of 14% of non-responders versus 7% of participants had MRS scores of 4 or 5. This finding may limit the validity of the QOLIBRI-OS in the most severely affected patients post-stroke. Due to Norwegian ethical rules, comparisons between consenters and non-participants are possible for the variables age and gender only, which may limit the representativeness of the results. Furthermore, this study did not evaluate responsiveness to change.

The sample size of 125 patients is less than the first original multinational study of the validity of the QOLIBRI-OS [22], which included 795 patients after

TBI and thus provided more substantial statistical evidence of the psychometric data quality. Our study is consistent with the sample sizes from other validation studies of HRQOL measures [18, 57].

Conclusions

The QOLIBRI-OS is a valid and reliable brief HRQOL measure that is appropriate for application to patients after stroke in research and clinical contexts.

Abbreviations

COSMIN: Consensus-based Standards for the selection of health Measurement Instruments; HADS: The Hospital anxiety and depression scale; HRQOL: Health related quality of life; MRS: Modified Rankin scale; PROM: Patients reported outcome measure; QOLIBRI: Quality of Life after Brain Injury; QOLIBRI-OS: Quality of Life after Brain Injury – Overall Scale; SIS: Stroke Impact Scale; SS-QOL: Stroke Specific Quality of Life

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Availability of data and materials

The dataset is available on request to the corresponding author.

Authors' contributions

GH, SGP and AA designed this study, analysed the data and were responsible for the overall decision-making in this study. GH and SGP collected all data. AA, OF and NVS contributed with supervision on the use of methods, analysis and interpretation of data. OF, JFN, HH, CA and NVS overlooked statistical analysis and interpretation. GH drafted the manuscript and all authors contributed to critical revision of the article. All authors read and approved the final manuscript.

Ethics approval and consent to participate

The Norwegian regional Ethical Committee health region North approved this study (2013/1472). All participants signed a written consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Paper 2

Guri Anita Heiberg, Oddgeir Friborg, Synne Garder Pedersen, Gyrd Thrane, Henriette Holm Stabel, Jørgen Feldbæk Nielsen, Audny Anke. ***Post-stroke health-related quality of life at 3 and 12 months post-stroke in a Central Danish and Arctic Norwegian Region: Satisfaction with functioning and predictors for change.*** J Rehabil Med. 2020 Sep 8;52(9):jrm 00096. doi: 10.2340/16501977-2716. PMID: 32735024

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ORIGINAL REPORT

POST-STROKE HEALTH-RELATED QUALITY OF LIFE AT 3 AND 12 MONTHS AND PREDICTORS OF CHANGE IN A DANISH AND ARCTIC NORWEGIAN REGION

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Objectives: **To investigate changes in health-related quality of life between 3- and 12-months post-stroke in a north Norwegian and a Danish region that organize their rehabilitation services differently, and to identify clinically relevant predictors of change.**

Design: **Prospective multicentre cohort study.**

Subjects: **In total, 304 patients with first-ever stroke (male sex 59%, mean age 68.7 years) participated from Norway ($n=170$) and Denmark ($n=134$).**

Methods: **The Quality of Life after Brain Injury-Overall Scale (QOLIBRI-OS) was administered twice to measure change in satisfaction with function and wellbeing.**

Results: **QOLIBRI-OS scores showed a small statistically significant difference in favour of Norway at 12 months post-stroke ($p=0.02$; Cohen's d = 0.26). Using a calculated minimal clinically important difference score of 12, 20% reported worse, 54% unchanged and 26% better QOLIBRI-OS scores between 3 and 12 months. Age below 65 years predicted a negative change (odds ratio (OR) 0.4, $p=0.007$).**

Conclusion: **In this population with mild and moderate stroke, QOLIBRI-OS scores were slightly higher in the Norwegian region. Approximately 50% of participants experienced clinically important changes in satisfaction with functioning and wellbeing between 3 and 12 months post-stroke. Younger age predicted negative change. This result could indicate increased rehabilitation needs over time in young patients and should be investigated further.**

Key words: stroke; HRQoL; QOLIBRI-OS; satisfaction; change.

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LAY ABSTRACT

This article compares experiences in satisfaction with functioning and wellbeing at 3 and 12 months between patients with stroke in a region in Denmark and a region in North Norway. Acute treatment of stroke in stroke units at hospitals is comparable in the 2 regions, but subsequent rehabilitation services differ. The Danish region had more organized municipality-based rehabilitation, while the North Norwegian region used more in-patient rehabilitation at specialized rehabilitation wards. In total, 170 patients from Norway and 134 from Denmark answered questionnaires about satisfaction with functioning and wellbeing at 3 and 12 months after stroke. At 3 months, patients reported comparable satisfaction, but after one year, the Norwegians were slightly more satisfied, especially with cognitive and emotional status. Change in satisfaction with functioning between 3 and 12 months was comparable between the 2 regions.

Stroke is the second leading cause of death and a major cause of disability (1). The concomitant physical, cognitive and psychosocial consequences post-stroke (2, 3) may affect daily life activities and participation in society (4). A valid approach to identify consequences may be using patient-reported outcomes (5) to assess health-related quality of life (HRQoL). The term HRQoL is adapted from the general concept of QoL by weighting subdimensions related to health more strongly (6).

Patient-reported stroke scales provide various multidimensional assessments, but few include aspects of patient satisfaction with functioning and future health expectations (7). The brief condition-specific 6-item Quality of Life after Brain Injury – Overall Scale (QOLIBRI-OS) has recently been validated in patients with stroke (8). Using QOLIBRI-OS at 3 and 12 months post-stroke provides the opportunity to examine changes in self-reported satisfaction with function and wellbeing between the subacute and early chronic phases following stroke. Identifying factors promoting positive and negative changes in satisfaction with function might be essential to improve subacute rehabilitation services (9).

The degree and direction of changes in satisfaction with life and function vary between studies. Generic measurements may show no change (10), an increase (11) or a decrease (12) in HRQoL. Both internal factors and external factors such as rehabilitation services contribute to satisfaction (13), but the relative

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importance in neighboring countries is unknown. A study (14) using the disease-specific Stroke Impact Scale at 3 and 12 months showed both clinically relevant improvements and declines across different domains. Bouffioulx et al.(15) used Satis-Stroke, a questionnaire developed to assess satisfaction with functioning. Significant improvements in satisfaction with activity and participation between the acute and post-acute phases overlapped with improvements in motor abilities, but there were no changes in satisfaction between the post-acute and chronic phases. A multi-centre study, including rehabilitation clinics in 7 countries, compared the concept life satisfaction after stroke using the generic instrument LiSat-11(10). Findings indicated that levels of satisfaction differed between clinics, while the longitudinal data during the first year indicated slightly improved satisfaction with mental health and life as a whole. However, no consistent predictors of change have been reported (10,14).

To reduce the burden of stroke, evidence-based medicine and rehabilitation are essential (16, 17). Acute treatment and rehabilitation in stroke units (16) are organized fairly similarly across Western Europe (18). However, the organization of subacute (19) rehabilitation services varies more substantially. In the Danish study region, multidisciplinary neurorehabilitation teams offer individualized and planned services to patients with stroke (20), whereas municipalities in northern Norway seldom provide multidisciplinary teams and seem to use inpatient rehabilitation to a larger extent (21, 22).

The study objectives were to: a) compare the QOLIBRI-OS scores between two country-regions with different organized subacute rehabilitation services, but comparable in terms of health service systems and cultural values, b) assess levels and rates of change following stroke, and c) identify any geographical, demographic, psychosocial or treatment-related factor that may be associated with any observed changes.

METHODS

Design

This study was a prospective, international, multicentre cohort study of consecutive patients with first-ever stroke living in predefined geographic areas in northern Norway and central Denmark. Patients were included when they were treated in stroke units and registered in the national Norwegian or Danish stroke registries. Data were collected acutely and at 3 and 12 months post-stroke.

Study areas

Participants were recruited from 30 municipalities served by the University Hospital of North Norway (UNN) and from 2 municipalities served by the University Hospital of Aarhus located in the Central Region of Denmark.

The population sizes were fairly comparable, with 138,455 and 185,289 people in the Danish and Norwegian regions, respectively. The UNN study admission area was 23 times larger than the Danish study area. In Denmark, stroke patients are admitted to a single university hospital serving 1.3 million inhabitants. In northern Norway, acute stroke treatment is provided at 1 of 3 stroke units in 3 different hospitals located 300 km apart, serving 35,000–100,000 inhabitants. In both regions, > 90% of all patients with stroke are admitted to stroke units. In Denmark, patients are transferred earlier to specialized community-based care, while northern Norwegian patients seem to be offered in-hospital rehabilitation more frequent in the early subacute phase after stroke (20).

Inclusion and exclusion criteria

The inclusion period was from March 2014 until the end of December 2015. All patients fulfilled the inclusion criteria of the national stroke registries, defined clinically according to the World Health Organization’s definition of stroke as acute ischaemic or haemorrhagic stroke in patients aged 18 years or above (International Classification of Diseases – 10th edition (ICD-10) diagnosis I.63 and I.61, respectively). Patients with subarachnoid haemorrhage were not included, as these patients are not part of the Norwegian stroke registry. Patients with stroke due to malignancy or head trauma were excluded.

Patients who died within the first year post-stroke were excluded. In addition, proxy responders, namely, a relative who had completed a short questionnaire on behalf of a patient, were excluded. A smaller number of patients in Norway (n=25) were not included due to severe comorbidity or a short expected remaining life-span.

Recruitment

Patients from the Norwegian region were recruited at the stroke units by direct contact, by telephone after discharge or by the hospital staff responsible for collecting and submitting consecutive data to the national Norwegian stroke registry. In Denmark, one of the authors (HHS) retrieved information from the Danish National Stroke Registry on patients with stroke living in the 2 defined municipalities. The patients received postal questionnaires and were subsequently informed by the same author about the study by telephone or letter. Those who responded to the posted questionnaires became consenting participants in the study.

Measurements acute, and at 3- and 12- months post-stroke

Acute. Norway and Denmark have mandatory national stroke registries that gather person-identifiable information about patients with acute stroke admitted to hospitals. Information on stroke subtypes, stroke severity, length of stay in stroke units (LOS), thrombolysis, age, sex and living conditions was collected from the national stroke registries. Demographic data are presented according to recommendations from the Stroke Recovery and Rehabilitation Roundtable (23).

Stroke severity was defined within 24 h after admission to the hospital. In Norway, the National Institute of Health Stroke Scale (NIHSS) was used to measure neurological impairment after stroke, while the Scandinavian Stroke Scale (SSS) (24) was used to report stroke severity in Denmark. We chose to use the SSS, as the data from the Danish National Stroke Registry (25) were more complete. The missing Norwegian NIHSS scores were retrospectively coded from medical records. Conversion of NIHSS to SSS scores was performed using an unadjusted mathematical model for interconversion (26). The SSS sum score is divided into 4 categories: 0–14 indicates very severe stroke, 15–29 severe stroke, 30–44 moderate stroke and 45–58 mild impairment post-stroke (24).

At 3 months. In Norway, the National Stroke Registry collected follow-up data 3 months after hospital admission from medical records or through a telephone interview with patients or relatives as proxy respondents. As Denmark has no regular follow-up stroke registrations, a telephone interview, with selected questions from the Norwegian follow-up registry, was performed at 3 months post-stroke to acquire similar data from both countries.

The information on the course of rehabilitation following stroke unit care was collected by telephone interview in both study regions. Based on this information, the first rehabilitation received was classified as in-patient, community-based or no rehabilitation given.

At 3- and 12-months post-stroke. The participants completed a postal questionnaire containing QOLIBRI-OS and the Hospital Anxiety and Depression Scale (HADS).

The QOLIBRI-OS (27) is a HRQoL measure of satisfaction with function and wellbeing specifically tailored to patients with brain conditions (27). The 6 items assess the degree of patients' self-reported overall satisfaction with "Physical Condition", "Cognition", "Emotions", "Ability to Perform Daily Activities", "Personal and Social Life," and "Current Situation and Future Prospects". A Likert scale provides the following 5 response categories for each item: not at all (score 1), slightly satisfied (score 2), moderately satisfied (score 3), quite satisfied (score 4), and very satisfied (score 5) (27). Thus, the item score range is 1–5, and the total score range is 6–30. The total score is arithmetically converted to a scale score between 0 and 100, where 100 is the optimal score. The questionnaire is validated for traumatic brain injury (27), subarachnoid haemorrhage (28) and stroke (8). A previous psychometric analysis of the QOLIBRI-OS in the same stroke study population showed high internal consistency (Cronbach's $\alpha=0.93$) (8).

The HADS is a widely used screening instrument for symptoms of anxiety (HADS-A) and depression (HADS-D). The scale range is 0–21 for both the anxiety and depression subscale. Scores of 8 or above in either subscale indicate a possible clinical condition of anxiety or depression (29).

Ethics

The Norwegian Ethical Committee Health Region North approved the study (2013/1472).

In Denmark, approval was obtained from the Danish Data Protections Agency (reference no. 1-16-02-363-14).

Statistical analysis

All statistical analyses were conducted using IBM SPSS 25. Descriptive data are presented as means and confidence intervals or percentages. A simple imputation of scale scores was used (mean replacement) when 1 or a maximum of 2 items was missing on the QOLIBRI-OS and HADS. Differences between continuous and categorical data were examined with independent or paired sample t-tests and χ^2 tests, respectively. Severe deviations from normal distribution assumptions were examined visually using P-P plots. The LOS and the Danish SSS scores were non-normally distributed; thus, we examined differences between SSS categories with χ^2 tests, and the median and interquartile range (IQR) are reported for LOS.

The included explanatory variables were based on the referred literature and discussions in the research group and were the following: country-region, age, sex, pre-stroke demographics (living alone, working, education, independence), SSS, stroke subtype, thrombolysis, LOS, HADS-A and HADS-D.

Minimal clinically important difference (MCID) scores were calculated with the standard error of measurement (SEM) formula, i.e. . The SEM indicates the minimum raw score change that reflects a true change beyond measurement error, thus avoiding interpretation of a change score below the SEM score as reflecting a true change when measurement error is actually the primary reason for the observed change. A difference of at least 1 SEM has been used to define the MCID (30), but we chose to use stricter criteria by multiplying it by $Z=1.96$ to improve the confidence intervals. Thus, a calculated SEM of 6 yields an MCID of 12 scale scores for the total QOLIBRI-OS. Effect sizes were calculated with Cohen's d. A value below 0.5 is regarded as small, 0.5–0.8 is considered medium, and greater than 0.8 is considered a large effect size (31).

A multiple linear regression analysis was conducted to examine predictors of change in QOLIBRI-OS sum scores as the outcome, defined as the QOLIBRI-OS score at 12 months minus the QOLIBRI-OS score at 3 months. We report unstandardized beta coefficients because the QOLIBRI-OS scale range of 0–100 is well-established (27). The explained variance of each block is reported as the adjusted R^2. Multicollinearity was checked with the variance inflation (VIF) estimate with a cut-off of 10, and the residual scores were examined for normality and homoscedasticity.

Two additional logistic regression analyses were conducted to examine predictors of decline and improvement in QOLIBRI-OS scores based on the MCID scores (with "no change" as the reference). Using MCID, change was defined as reliably negative or positive if change in QOLIBRI-OS scale scores decreased or increased by a minimum of 12 scale scores, respectively. The results are presented as adjusted odds ratios (OR). Model fit was investigated with the Hosmer and Lemeshow test to assess the agreement between the observed and predicted outcomes of our models. The degree of pseudo-explained variance was reported according to Nagelkerke's R^2.

RESULTS

The descriptive data for the 2 cohorts are provided in Table I. A total of 304 patients with complete QOLIBRI-OS data at 3- and 12-months post-stroke were included as participants in the study; see the flowchart (Fig. 1) following the STROBE criteria.

Dropout analysis

In total, 746 surviving persons with stroke (Norway, $n=423$; Denmark, $n=323$) were potentially eligible. Among them, 553 persons consented, but 249 of these persons were defined as non-participants as they did not complete the QOLIBRI-OS at both 3 and 12 months.

Analysis of representativeness was performed in 2 steps (Fig. 1). First, eligible persons not included from the Norwegian region because they did not consent ($n=73$) were compared with the 170 Norwegian participants. Age did not differ significantly, but

Table I. Pre-stroke demographics, treatment and stroke-specific characteristics

Questionnaire	All patients *n* = 304	Norwegian patients *n* = 170	Danish patients *n* = 134	*p*-value
Age, years, mean (95% CI)	68.7 (67.4–70.0)	69.7 (68.0–71.5)	67.3 (65.3–69.3)	0.07
18–55 years, *n* (%)	45 (15)	22 (13)	23 (17)	0.25
56–74 years, *n* (%)	161 (53)	87 (51)	74 (55)	
≥75 years, *n* (%)	98 (32)	61 (36)	37 (28)	
Sex, *n* (%)				
Male	181 (59)	101 (59)	80 (59)	1.0
Female	123 (41)	69 (41)	54 (41)	
Education > 11 years, *n* (%)	161 (53)	100 (59)	62 (46)	0.02
Living alone, *n* (%)	87 (29)	57 (34)	30 (23)	0.05
Working, *n* (%)	91 (30)	39 (22)	52 (36)	0.006
Need assistance, *n* (%)	24 (8)	16 (10)	8 (6)	0.39
Ischaemic stroke, *n* (%)	286 (94)	161 (98)	125 (93)	0.60
Total SSS, median (IQR)	49 (12)	47 (11.5)	52 (12)	
Very severe SSS, *n* (%)	3 (1)	1 (0.4)	2 (1.5)	0.08*
Severe SSS, *n* (%)	10 (3)	5 (3)	5 (4)	
Moderate SSS, *n* (%)	77 (25)	52 (31)	25 (19)	
Mild SSS, *n* (%)	212 (71)	112 (66)	100 (75)	
Thrombolysis, *n* (%)	50 (16)	23 (14)	27 (20)	0.12
Length of stay in stroke unit, days, median (IQR)	3 (4)	4 (4)	2 (2)	0.001
Telephone interview	*n* = 255	*n* = 170	*n* = 85	
In-patient rehabilitation, *n* (%)	68 (27)	56 (32)	12 (14)	0.001
Community-based rehabilitation, *n* (%)	67 (26)	29 (18)	38 (45)	
No rehabilitation after discharge from stroke unit, *n* (%)	120 (47)	85 (50)	36 (42)	

*Mild SSS compared with moderate, severe and very severe SSS. SSS: Scandinavian Stroke Scale; IQR: Interquartile range.

participants were more frequently men (63% vs 41%, respectively, $p=0.004$). Second, the included participants from both countries ($n=304$) were compared with non-participants ($n=249$).

Non-participants in both countries needed more often help pre-stroke ($p=0.04$), and had more severe strokes, with an SSS score of 45 (best score=58, standard deviation (SD) 12), while participants scored 48 (SD 11) ($p=0.003$). The percentage of haemorrhagic stroke was higher among non-participants (14% vs 6%; $p=0.001$). Age, sex and marital status were similar among participants and non-participants in both countries.

Demographics, stroke characteristics, mental health and treatment

The descriptive data for the 2 cohorts are presented in Table I. There were no significant differences between Norwegian and Danish participants in age, sex or stroke severity. However, the Norwegian participants tended to have more severe strokes. The country-regions differed significantly in terms of pre-stroke years of education and pre-stroke work status (Table I). An analysis of changes from the time of the event to 12 months post-stroke showed that the proportion of patients living in their own home without needing assistance decreased from 90% to 81% in the Norwegian region and from 94% to 83% in the Danish region. At 12 months post-stroke, 20% of northern Norwegian and 31% of Danish participants were employed. The number of those who had worked prior to the stroke decreased by 3% and 8%, respectively.

Data on in-hospital, community-based or no rehabilitation are presented in Table I. As indicated, the participants received more in-patient rehabilitation in northern Norway and more community-based rehabilitation in Denmark. The rehabilitation data must be interpreted with caution, as only 63% of the Danish population responded to this part of the survey, while all Norwegian participants answered these questions. Neither the HADS score at 3 and 12 months nor the HADS change scores differed significantly between the regions.

Country differences and changes in QOLIBRI-OS scores

Participants in both countries had a mean QOLIBRI-OS total score >65 (maximum 100) (Table II).

The total QOLIBRI-OS score was not significantly different between the Norwegian and Danish regions at 3 months post-stroke ($p=0.08$), but Norwegians had significantly higher scores at 12 months post-stroke ($p=0.02$) (Table II and Fig. 2). The pre-existing country differences increased slightly, but the difference in the total QOLIBRI-OS score was small (Cohen's $d=0.26$).

On the QOLIBRI-OS item score level, the effect sizes of the country differences were $d=0.41$ for cognitive function, $d=0.28$ for daily activity and $d=0.23$ for emotions. The rate of change in the total QOLIBRI-

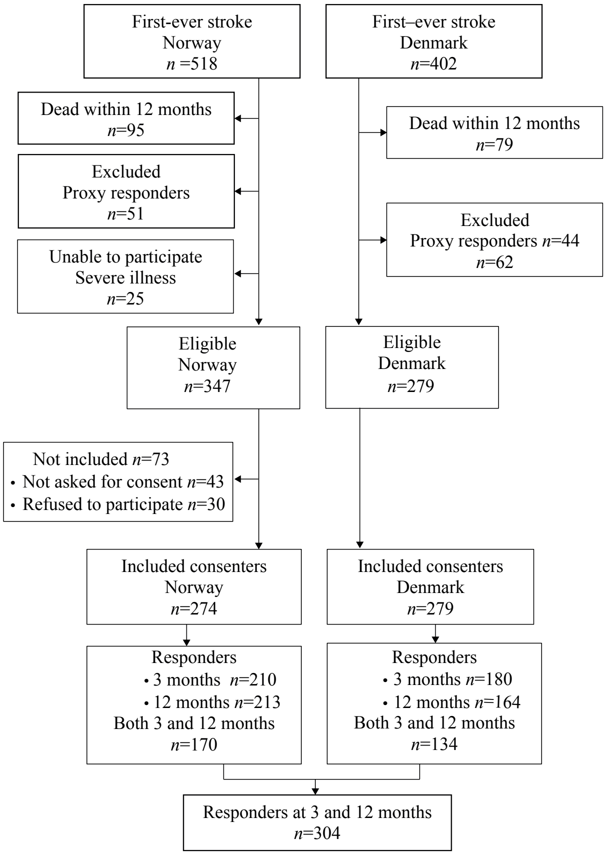

Fig. 1. Flowchart of the study.

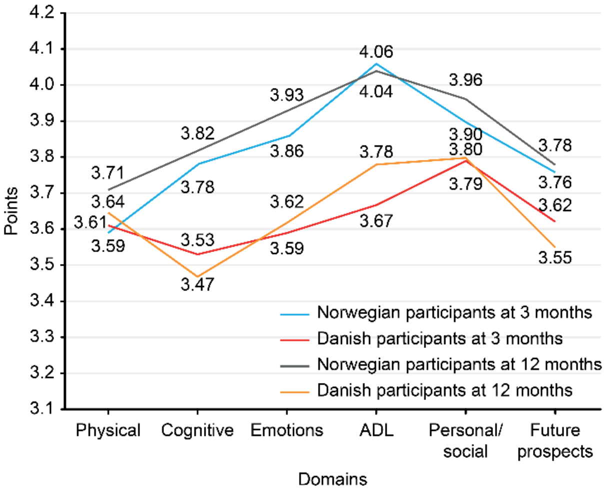

Fig. 2. QOLIBRI-OS item and scale scores at 3 and 12 months in Norway and Denmark.

OS scores from 3 to 12 months after stroke was not significant when examined separately in the country-regions (Fig. 2); thus, the rate of change between the country-regions was also not significant ($p=0.66$).

Prediction of change in continuous QOLIBRI-OS scores

Linear regression analysis with the QOLIBRI-OS change score as the dependent variable revealed that all predictors were non-significant (Table III). The residuals were normal and homoscedastic, and the multicollinearity was negligible, as the VIF ranged between 1.0 and 1.7. Moreover, the test score reliability for the QOLIBRI-OS was excellent at both 3 and 12 months (0.92 and 0.93, respectively).

As an alternative approach, minimal clinically important change scores were constructed. Using an MCID score of 12, patients were classified into 3 groups: no change (54%), worse (20%) and improved (26%). A logistic regression analysis with "no change" as the reference and the same predictors as those in the linear regression analysis indicated a sole predictor: age below 65 years predicted a negative change status (OR 0.4, $p=0.007$) (Table IV). An MCID decline was observed among 29% of those below 65 years of age, compared with 16% for those above 65 years of age. Nagelkerke's R^2 was 0.12.

No variables predicted a positive change. There were no significant differences between the country-regions in the worse, unchanged or improved clinical course distributions.

Table II. Quality of Life after Brain Injury-Overall Scale (QOLIBRI-OS) items and scores at 3 and 12 months

	3 months			12 months		
QOLIBRI item	Norway Mean (95% CI)	Denmark Mean (95% CI)	*p*-value	Norway Mean (95% CI)	Denmark Mean (95% CI)	*p*-value
Physical	3.62 (3.47–3.78)	3.60 (3.43–3.65)	0.90	3.70 (3.54–3.86)	3.65 (3.47–3.83)	0.60
Cognitive	3.81 (3.66–3.95)	3.53 (3.34–3.75)	0.03	3.82 (3.67–3.96)	3.46 (3.28–3.64)	0.002
Emotional	3.88 (3.73–4.03)	3.60 (3.42–3.79)	0.02	3.92 (3.78–4.06)	3.62 (3.43–3.81)	0.01
Activities	4.09 (3.95–4.23)	3.65 (3.48–3.83)	0.001	4.04 (3.88–4.19)	3.80 (3.60–3.95)	0.02
Social/personal	3.93 (3.77–4.09)	3.80 (3.62–3.97)	0.30	3.95 (3.81–4.10)	3.80 (3.61–3.98)	0.18
Actual/future prospects	3.79 (3.65–3.93)	3.62 (3.40–3.80)	0.20	3.76 (3.61–3.91)	3.54 (3.35–3.74)	0.20
Total (0–100)	70.8 (67.7–73.9)	66.1 (62.1–70.2)	0.08	71.7 (68.7–74.1)	66.1 (62.1–70.1)	0.02

Table III. Unstandardized beta (β) coefficients for predictors of change in the Quality of Life after Brain Injury-Overall Scale (QOLIBRI-OS) score between 3 and 12 months according to the multiple regression analyses

Variables	Block 1 Unst. β coeff. (95% CI)	Block 2 Unst. β coeff. (95% CI)	Block 3 Unst. β coeff. (95% CI)	Block 4 Unst. β coeff. (95% CI)
Country	−2.08 (−6.02–2.11)	−2.16 (−6.46–2.09)	−3.33 (−8.01–1.36)	−3.22 (−7.90–1.46)
Age		0.14 (−0.98–3.70)	0.15 (−0.83–3.88)	0.14 (−0.087–3.86)
Sex		3.31 (−1.19–7.74)	3.09 (−1.56–7.49)	2.58 (−2.01–7.18)
Living alone pre-stroke		0.76 (−4.14–5.67)	0.47 (−4.51–5.46)	0.45 (−4.52–5.42)
Working prior to stroke		−2.45 (−8.37–3.46)	−2.32 (−8.23–3.57)	−2.71 (−8.63–3.19)
Dependent pre-stroke		−7.60 (−15.30–0.45	−6.53 (−14.47–1.40)	−6.86 (−14.80–1.08)
Scandinavian Stroke Scale (SSS)			0.16 (−0.08–0.39)	0.16 (−0.79–0.40)
Stroke subtype			−7.56 (−16.57–1.44)	−7.8 (−16.86–1.21)
Thrombolysis			−2.37 (−8.31–3.57)	−2.5 (−8.96–3.49)
Length of stay in hospital			−0.24 (−0.94–0.45)	−0.25 (−0.94–0.45)
HADS anxiety				−2.01 (−8.14–4.12)
HADS depression				6.9 (−0.80–14.63)
Adjusted R square	0.001	0.003	0.006	0.011

HADS: Hospital Anxiety and Depression Scale; Unst. β coeff.: Unstandardized β coefficients.

Table IV. Uni- and multivariate logistic prediction models with positive or negative change in health-related quality of life (HRQoL) as outcome (unchanged as reference)

			Univariate			Multivariate		
Demographic variables and stroke characteristics	Decline, *n* = 61	Unchanged, *n* = 165	OR	95% CI	*p*	OR	95% CI	*p*
Country, *n* (%)								
Norway	30 (25)	92 (75)						
Denmark	30 (29)	73 (71)	1.59	0.75–3.40	0.23			
Treated with thrombolysis, *n* (%)	9 (24)	28 (76)	1.26	0.51–3.12	0.61			
Anxiety, HADS ≥8, *n* (%)	13 (38)	21 (62)	1.69	0.64–4.46	0.28			
Depression, HADS ≥8, *n* (%)	4 (22)	14 (78)	0.64	0.15–2.68	0.54			
Age, years, *n* (%)								
< 65 years	27 (39)	42 (61)						
> 65 years	33 (21)	123 (79)	0.36	0.231–797	0.007	0.430	0.231–797	0.007
Sex, *n* (%)								
Male	39 (28)	101 (72)						
Female	22 (26)	64 (74)	1.02	0.49–2.12	0.95			
Education >11 years, *n* (%)	32 (27)	88 (73)	0.88	0.44–1.76	0.71			
Living alone pre-stroke, *n* (%)	19 (32)	41 (68)	1.15	0.51 –2.61	0.72			
Dependent on help pre-stroke, *n* (%)	6 (33)	12 (67)	1.30	0.39–4.29	0.66			
Working prior to stroke, *n* (%)	20 (30)	47 (70)	1.57	0.61–4.01	0.34			
Stroke subtype haemorrhagic, *n* (%)	2 (20)	8 (80)	3.54	0.59 –21.4	0.17			
LOS in stroke unit, median (IQR), days	3 (5)	2 (4)	0.93	0.86–1.01	0.07			
Scandinavian Stroke Scale SSS, median (IQR)	49 (12)	49 (12)	1.01	0.09–1.04	0.58			

HADS: Hospital Anxiety and Depression Scale; LOS: length of stay; IQR: interquartile range; OR: odds ratio; 95% CI: 95% confidence interval.

DISCUSSION

This study investigated satisfaction with functioning and wellbeing, as measured by the QOLIBRI-OS instrument, in 2 neighbouring country-regions that used similar acute treatment strategies, but organized sub-acute stroke rehabilitation services differently. At 12 months post-stroke, there was a slight difference in the QOLIBRI-OS score in favour of participants from the northern Norwegian region compared with participants from Denmark. Approximately half of the participants reported substantial clinical changes in the QOLIBRI-OS according to the MCID classification. Several predictors of MCID change were examined and it was found that age below 65 years was the sole predictor of risk of decline in satisfaction with functioning from 3 to 12 months post-stroke, whereas no predictors explained positive changes. These findings indicate that organization of subacute rehabilitation services had a minor impact on satisfaction with function and wellbeing in patients with mild and moderate strokes, as measured by QOLIBRI-OS. Patients below 65 years old were more likely to experience a decline in satisfaction, probably related to the loss of more complex activities and social roles or to higher expectations of functioning in general (22).

QOLIBRI-OS scores in the Norwegian and Danish regions

Comparable outcomes were found for the QOLIBRI-OS at 3 months post-stroke, as well as a clinically minor, but significant, difference between the country-regions in favour of the Norwegian Arctic Region at 12 months post-stroke. The dissimilarities were significant for items measuring cognition, emotions and activities of daily living. Cultural differences reflecting different expectations for health-related quality of life between the regions may play a role in explaining the slightly higher levels of satisfaction with functioning among Norwegians, although other studies did not find convincing signs of cultural influences that could explain the unequal life satisfaction (13).

Several other studies have compared HRQoL after stroke across countries. Ayis et al. (32) reported patient differences in HRQoL among 5 European populations that could not be explained by stroke severity or sociodemographic factors. Others (18) have found differences in patient-reported outcomes after stroke associated with how factors in stroke rehabilitation impose constraints that may cause disincentives for the rehabilitation process. In addition, Sprigg et al. (33) reported considerable differences in physical and emotional QoL (based on the Short Form-36) between regions and countries in Europe that persisted after adjusting for prognostic case mix and care quality variables. Langhammer et al. (13) found significant unexplained differences in life satisfaction when comparing rehabilitation units in 7 countries.

One reason for the small differences in HRQoL as revealed in our study may be that prior studies compared countries with more underlying differences in socioeconomic or healthcare systems than the Scandinavian countries. The health systems in Nordic countries are tax-financed, offering equal healthcare services to all inhabitants (34). Even though Norway has implemented the Coordination reform, advising early transfer of patients from hospital to community-based rehabilitation and care, northern Norwegian patients in this study seemed to be treated with in-hospital rehabilitation to a greater extent than the Danish patients. A likely reason may be that many smaller municipalities do not have the facilities or staff competence to offer subacute stroke rehabilitation. Regarding self-reported satisfaction with functioning and wellbeing as measured by QOLIBRI-OS, this study indicates that the organization of rehabilitation in Denmark, with its specialized multidisciplinary, community-based teams that reflect the principles of early supported discharge (ESD) (35), should be investigated further to assess effects compared with those of other subacute rehabilitation services.

Change in satisfaction with functioning and wellbeing from 3 to 12 months

The rate of change in QOLIBRI-OS scores from 3 to 12 months was not significant for either country or different between Norway and Denmark. A lack of change post-stroke coincides with other studies using change in self-perceived health-related functioning post-stroke as the outcome (4, 10). However, the degree of individual changes in wellbeing and satisfaction with functioning were substantial, as almost 50% of the patients reported a clinically significant change in the QOLIBRI-OS. This magnitude of clinically meaningful changes in either direction is in accordance with a study by Guidetti et al. (14) examining changes using the Stroke Impact Scale score during a similar follow-up period as that in the present study. The substantial degree of individual changes in wellbeing and satisfaction with functioning is interesting because it may involve long-term changes in rehabilitation needs. This finding indicates that patients should be followed for a longer period to identify vulnerable patient groups experiencing functional declines that may hamper their HRQoL.

Predictors of change in QOLIBRI-OS scores

Several predictors of MCID change were examined, such as country, demographic factors, stroke characteristics, LOS and psychological factors. Psychological factors contributed strongly to HRQoL (36), but they did not contribute to changes in the QOLIBRI-OS score in the present study, a finding that is in accordance with a study by Donnellan et al. (36). However, age below 65 years was the sole predictor of negative change, whereas no predictors explained positive change in QOLIBRI-OS scores.

White et al. (10) found positive change in HRQoL between 3 and 12 months among younger persons in a stroke cohort study. In contrast, we observed that younger patients were more susceptible to negative changes in HRQoL. Some of the younger patients may experience unfulfilled aspirations of returning to work after stroke, resulting in significantly decreased subjective wellbeing and life satisfaction (37). They may also experience more demands across several life areas compared with older patients, resulting in the observed increased risk of decline in wellbeing and satisfaction with functioning (38). Comparably, a systematic review (3) revealed a negative impact on family relationships, sexual life, economy and leisure activities among patients with stroke below 65 years old. Moreover, a Swedish twin study by Harris et al. (39) reported that genetic factors contributed more to perceived satisfaction with health among those older than 65 years of age, whereas the satisfaction of younger individuals with health was more strongly related to environmental factors.

Based on our findings, we recommend that rehabilitation services pay attention to younger patients with stroke, as they are more prone to perceiving a decline in satisfaction with functioning and health during the first year post-stroke.

Strengths and limitations

The observational design of this study allowed the tracking of patient satisfaction and functioning to be compared between these 2 country-regions. The number of participants in the present study was high compared with that in previous similar studies (4, 10). The recruitment process differed between the 2 countries, but every stroke survivor fulfilling the inclusion criteria in the predefined area and time period was asked to participate, apart from 25 Norwegian patients who had severe dementia or were terminally ill. It was not possible to exclude Danish patients at the beginning of the study, but it is not likely that Danish patients in an equivalent situation would have been able to participate in the study. The participants differed significantly only in education and proportion working.

The findings of this study may not be representative of populations with more severe stroke severity. Analyses revealed some selection biases, as non-participants more often had haemorrhagic strokes, severe strokes and needed help pre-stroke.

Retrospective coding of some Norwegian stroke severity data may represent a limitation, but studies have found adequate reliability of SSS data coded from medical journals (40).

Furthermore, the results from regional studies may not be representative of the national situation.

Conclusion

Minimal differences in patient-reported wellbeing and satisfaction with functioning measured with QOLIBRI-OS between the investigated regions in Arctic Norway and Central Denmark were found, despite different sub-acute rehabilitation organization after stroke. No overall change in satisfaction from 3 to 12 months post-stroke was found; however, being younger than 65 years increased the risk of a decline in satisfaction with functioning and wellbeing.

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Paper 3

Guri Anita Heiberg, Cecilie Røe, Oddgeir Friborg, Synne Garder Pedersen, Henriette Holm Stabel, Jørgen Feldbæk Nielsen, Audny Anke. ***Factors associated with met and unmet rehabilitation needs after stroke:*** A multicentre cohort study in Denmark and Norway. J Rehabil Med. 2021 Apr 13. doi: 10.2340/16501977-2828 PMID: 33846761

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ORIGINAL REPORT

FACTORS ASSOCIATED WITH MET AND UNMET REHABILITATION NEEDS AFTER STROKE: A MULTICENTRE COHORT STUDY IN DENMARK AND NORWAY

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Objectives: **To examine patient-reported needs for care and rehabilitation in a cohort following different subacute pathways of rehabilitation, and to explore factors underpinning met and unmet needs.**

Design: **Observational multicentre cohort study.**

Patients and methods: **A total of 318 Norwegian and 155 Danish patients with first-ever stroke were included. Participants answered questions from the Norwegian Stroke Registry about perceived met, unmet or lack of need for help and training during the first 3 months post stroke. The term "training" in this context was used for all rehabilitative therapy offered by physiotherapists, occupational or speech therapists. The term "help" was used for care provided by health professionals. [AQ1]**

Results: **Need for training: 15% reported unmet need, 52% reported met need, and 33% reported no need. Need for help: 10% reported unmet need, 58% reported met, and 31% reported no need. Participants from both Norway and Denmark had similar patterns of unmet/met need for help or training. Unmet need for training was associated with lower functioning, (odds ratio (OR) = 0.32, $p < 0.05$) and more anxiety (OR = 0.36, $p < 0.05$). Patients reporting unmet needs for help more often lived alone (OR = 0.40, $p < 0.05$) and were more often depressed (OR = 0.31, $p < 0.05$).**

Conclusion: **Similar levels of met and unmet needs for training and help at 3 months after stroke were reported despite differences in the organization of the rehabilitation services. Functioning and psychological factors were associated with unmet rehabilitation needs.**

Key words: stroke; rehabilitation; unmet needs; rehabilitation pathways.

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LAY ABSTRACT

The aim of this study was to examine patient-reported needs for care and rehabilitation among selected patients with stroke in Norway and Denmark. A total of 318 Norwegian and 155 Danish patients with first-ever stroke were included. Participants answered the following 2 questions from the Norwegian Stroke Registry: Have you received enough help after the stroke? Have you received as much training as you wanted after the stroke? The term "training" in this context was used for all rehabilitative therapy offered by physio-, occupational or speech therapists. The term "help" was used for care provided by health professionals. Levels of anxiety and depression were investigated. With regard to training needs, 15% of all participants reported unmet needs, 52% reported that their needs had been met, and 33% reported that they had no need for training. Regarding the need for help, 10%, 58% and 31% reported unmet needs, that needs had been met, and that they had no need for care, respectively. Participants in the 2 countries had similar patterns of unmet/met needs for help or training. Unmet need for training was associated with low function and anxiety. Patients reporting an unmet need for help more often lived alone and were more often depressed. There was no difference in met or unmet needs between Norwegian and Danish participants. Different rehabilitative follow-up after stroke did not affect levels of met and unmet rehabilitation needs. Health services should pay special attention to patients at risk, including those who are anxious or depressed, live alone or have functional deficits after stroke.

Stroke is a major cause of death, with an increasing number of patients affected worldwide (1). Stroke survivors often have varying degrees of physical, psychosocial and cognitive disabilities, which may substantially affect their functional ability in daily and working life (2). Treatment offered by specialized stroke units (3), inpatient multidisciplinary rehabilitation teams (4) and community-based rehabilitation services adapted to patients' home environment (5) are key elements to successful rehabilitation. At all intervention levels, the identification of patients' individual needs is crucial for the optimization of rehabilitation outcomes. The definition of a need is, however, not unambiguous (6). A pragmatic approach is to adopt the most commonly used definition of healthcare needs and define rehabilitation needs as the needs that can be fulfilled by rehabilitation interventions and services (7). From the patient's perspective, a need represents the perception of a situation

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in which help or support is desired. If adequate help is not offered, the provision of services does not fit the needs, gaps occur and needs become unmet (8).

A perceived need for therapy, comprehensive care, pscyhological support or information are examples of commonly reported unmet needs post-stroke (9).

Unmet rehabilitation needs may persist for years after stroke (10). According to a UK study, they are more often reported by people with disabilities, those belonging to ethnic minorities, and those living in the most deprived areas (10). According to a recent systematic review of 19 studies, mostly cross-sectional in design, 74% of stroke survivors experienced at least one unmet need. The studies revealed heterogeneous levels of unmet needs, ranging between 5% and 40% for care and between 2% and 36% for therapy (9). In most studies, unmet needs were assessed by using different multi-item questionnaires, such as the Longer-term Unmet Need after Stroke (11) and the Greater Manchester Stroke Assessment Tool (12), or by the self-report of long-term needs after stroke (10).

In a Swedish registry study evaluating perceived unmet or partly met rehabilitation needs with a single question, 21.5% of patients reported unmet needs one year after stroke. Important underpinning factors were older age, dependency on others, pain and depressive/affective symptoms (13).

Rehabilitation practices are formulated and enacted in a cultural and historical context aligned to the development of healthcare services (14). Specialized stroke rehabilitation is integrated in the public healthcare systems in Nordic countries (15), but, whereas the Norwegian study region mainly emphasizes inpatient rehabilitation, the Danish region has developed an additional and more specialized, community-based rehabilitation programme (16). Although some studies have reported different rehabilitation pathways in the early subacute phase of stroke (17), no previous studies have, to our knowledge, compared unmet needs post stroke in participants with different subacute rehabilitation pathways.

The primary aim of this study was to examine patient-reported needs for healthcare and rehabilitation services in a cohort with different rehabilitation pathways recruited from 2 Nordic country-regions. Secondary aims were to assess to what extent these needs were met or unmet 3 months post stroke and to explore factors associated with met and unmet needs.

METHODS

Participants

Danish patients were included if they were: (*i*) diagnosed with a first-ever stroke using the World Health Organization (WHO) International Classification of Diseases, version 10 (ICD-10) (code I.I61, I.I63); (*ii*) admitted to the stroke unit at Aarhus University Hospital (AUH); (*iii*) ≥18 years old; (*iv*) living in either the Favrskov municipality or the Randers municipality, with 47,655 and 90,800 citizens, respectively, located in the Central Region of Denmark (5), from 1 June 2014 to 31 December 2015.

Norwegian patients were included if they were: (*i*) diagnosed with a first-ever stroke; (*ii*) admitted to 1 of 3 stroke units of the University Hospital of North Norway (UNN); (*iii*) ≥18 years old; and (*iv*) living in 1 of 30 municipalities in the hospital catchment area in the northern region of Norway, with a total of 190,000 citizens (5), from 20 March 2014, until 31 December 2015.

The study flowchart, following the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria (18), is shown in Fig. 1. The response rates for eligible patients were 76% and 45% in Norway and Denmark, respectively.

Help and rehabilitation needs

Help and rehabilitation needs were assessed at 3 months post stroke using the following 2 questions from the Norwegian Stroke Registry follow-up questionnaire:

1. Have you received enough help after the stroke?
2. Have you received as much training as you wanted after the stroke?

Response options were yes (met need), no (unmet need), no need, and unknown.

Patients who answered one or both of these questions were included as participants.

The term "training" in this context was used for all rehabilitative therapy offered by physiotherapists, occupational or speech therapists. The term "help" was used for care provided by health professionals. [AQ2]

Acute treatment and rehabilitation of stroke in 2 regions of Denmark and Norway

Both countries have public-tax-financed healthcare systems, including free access to general practitioners, hospital treatment, care and rehabilitation and subsequent inpatient or outpatient treatment in the municipalities (19).

Norway and Denmark follow well-established common principles for acute treatment, including multidisciplinary rehabilitation in

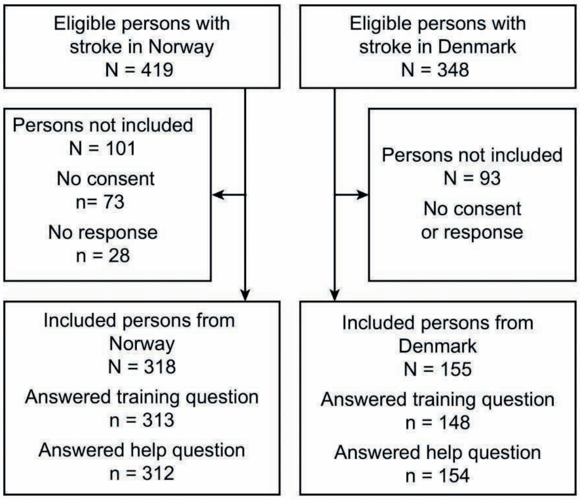

Fig. 1. [AQ5]

stroke units (20, 21). According to their national stroke registries, more than 90% of all patients with stroke in Denmark and Norway receive treatment in a stroke unit. However, the size of stroke units differs in these countries, as, in Denmark, all stroke patients in the region were treated at a single large stroke unit, whereas in Norway, the treatment structure was decentralized, with 3 stroke units. The average [AQ3] number of inhabitants in the municipalities in the Arctic North is also far lower than that in the region in Denmark.

Following discharge from stroke units, a higher proportion of patients in Norway appear to receive inpatient rehabilitation (16). The Danish region had specialized multidisciplinary team-based neurorehabilitation available at the municipal level, while this service was scarce in the northern Norwegian region.

All Danish patients receive a compulsory individual rehabilitation plan at discharge, while rehabilitation at the municipal level in Norway varies according to local competence and capacity (16). Individual rehabilitation plans may be adapted for younger patients with stroke in Norway, but seldom for elderly patients.

Table I gives an overview of rehabilitation services provided after discharge from stroke units.

Assessing stroke severity

Stroke severity was recorded at baseline within 24 h after admission to the hospital. Data were collected from the national registries. In Norway, the National Institute of Health Stroke Scale (NIHSS) (22) is used to measure neurological impairment after stroke, while the Scandinavian Stroke Scale (SSS) (23) is the preferred scale to determine stroke severity in Denmark. In dealing with data from both Norway and Denmark, the authors chose to use the SSS, as data from the Danish National Stroke Registry (24) were more complete than those in the Norwegian Stroke Registry. Primary missing Norwegian NIHSS scores were retrospectively coded from medical records. All conversions from the NIHSS to the SSS were made by one experienced clinician using the unadjusted mathematical model of Gray et al. (25), which was derived for interconversion between these 2 stroke scales.

The SSS sum score is divided into 4 categories: an SSS score of 0–14 indicates very severe stroke, 15–29 indicates severe stroke, 30–44 indicates moderate stroke, and 45–58 indicates mild impairment post stroke.

Recruitment and data collection

Patients from the northern Norwegian region were asked for consent at the stroke unit or by mail [AQ4] within 3 months after stroke. In Denmark, a health professional retrieved information on patients with stroke directly from the Danish National Stroke Registry. The patients were informed about the study by telephone or letter. Those who responded became consenting participants in the study.

Both Norway and Denmark have mandatory national stroke registries that aim to acquire person-identifiable information about patients with acute stroke admitted to hospitals. The registries contain information about risk factors prior to stroke and hospital treatment in the acute stage of stroke.

In Norway, information is also collected through a follow-up questionnaire administered by telephone interview at 3 months after hospital admittance and input into the National Stroke Registry. The telephone interview was performed by professionals at the stroke units in Norway and by the study personal in Denmark. As Denmark has no regular follow-up stroke registries, selected questions from the Norwegian follow-up registry were collected by telephone interview in Denmark at 3 months post stroke, in order to acquire similar data from both countries.

This study has 3 data sources: the National Stroke Registry, telephone interviews and study-specific postal questionnaires at 3 months post stroke.

Stroke registry data: information about age; sex; pre-stroke living conditions, such as living alone or receiving help; stroke subtypes; stroke severity; thrombolysis; and length of stay (LOS) in stroke units were collected. Met/unmet need status and no need for care or rehabilitation were assessed with the 2 questions concerning help and training presented earlier.

Telephone interview at 3 months post stroke. Pre-stroke data on working status and dependency on help in activities of daily living were obtained. In addition, patients from both countries answered study-specific questions regarding rehabilitation services after stroke unit treatment. Rehabilitation was classified into 3 categories (in-hospital, community-based or no rehabilitation) according to the first type of rehabilitative follow-up the patient received immediately after discharge from the stroke unit.

The level of functioning was assessed using the modified Rankin scale (mRS) (26), a clinician-reported measure of global disability widely used to evaluate post-stroke outcomes. The scale consists of categories assessing the level of independence, ranging from completely independent to bedridden or death. There is extensive evidence on the validity of the mRS (26).

Questionnaire at 3 months post stroke: mental health status was assessed using the Hospital Anxiety and Depression Scale (HADS) (27). The HADS is a widely used screening instrument for symptoms of anxiety (HADS-A) and depression (HADS-D). The scale is favourable, as it is relatively less affected by common somatic symptoms not related to affective symptoms, such as fatigue or sleeping problems (28). The scale range is 0–21 for both subscales, with a cut-off score of 8 being indicative of anxiety or depression possibly needing treatment.

Table I. Rehabilitation services after discharge from stroke units in the selected regions in Norway and Denmark during the study period

Rehabilitation services	Denmark	Norway
In-patient specialized neurorehabilitation	Yes	Yes
In-patient hospital-linked rehabilitation units outside the hospital, less specialized in neurorehabilitation	Yes	Yes
In-patient rehabilitation nursing home and other in-patient rehabilitation location in the municipality	Yes	Yes
Ambulatory consulting team at the specialist level	Yes	Yes
Specialized neurorehabilitation team at the municipality level	Yes	No
Out-patient specialized day rehabilitation	Yes	No
Community-based day rehabilitation at a centre	Yes	No
Out-patient rehabilitation in private physiotherapy clinic	Yes	Yes
Home-based rehabilitation		
Provided by home help	Yes	No
Provided by therapists	Yes	Yes
Brain injury coordinator in municipalities	Yes	No
Job consultants	Yes	No
Compulsory rehabilitation plan at discharge from stroke unit	Yes	No

Ethics

In Denmark, approval was obtained from the Danish Data Protections Agency (reference number 1-16-02-363-14), while in Norway, the study was approved by the Committee for Medical Research Ethics, Health Region North (reference number 2013/1472).

Statistical analysis

All statistical analyses were conducted in IBM SPSS 26. Descriptive statistics are presented as percentages, medians with interquartile ranges (IQR) or means with 95% confidence intervals (95% CI). Simple group difference testing based on continuous and categorical data was performed with independent t-tests and χ^2 tests, respectively. The distributional properties of the variables were examined visually using P-P plots. In the case of heavily skewed data, the Mann–Whitney U test was applied.

Multivariable logistic regression analyses

The study had 2 outcome variables: (1) patients reporting needs for help; and (2) patients reporting needs for rehabilitation training. Both outcome variables had 3 response options: (a) needs met, (b) needs unmet, and (c) no needs stated. Logistic regression analyses were conducted for each of the outcome variables to identify predictors of needs. This analysis combined categories (a) and (b) (met + unmet needs) relative to category (c) as the reference (no needs).

Two additional logistic regression analyses were conducted comparing the subgroups reporting such needs, specifying category (a) (met needs) with category (b) as the reference (unmet needs). As the current study was exploratory rather than hypothesis-testing, non-significant variables were removed using the backward procedure (excluded if $p>0.05$.). All final models were adjusted for country, age and sex.

The included potential explanatory variables were based on the reference literature and on discussions held by the research group. These were country (Norway/Denmark), age ($<65/\geq 65$ years), sex (male/female), living alone (yes/no), working (yes/no), dependent on help pre-stroke (yes/no), SSS score, stroke subtype (cerebral bleeding/ischaemic stroke), thrombolysis (yes/no), LOS, HADS-A scores ($<7/\geq 8$), HADS-D scores ($<7/\geq 8$), mRS scale scores (0–2/3–5), and type of rehabilitation after discharge from the stroke unit (inpatient, community-based, or no rehabilitation (no/yes)).

In the multivariate analysis of rehabilitation services, no rehabilitation was the reference category. The reference category of the dichotomous variables is the last variable within parentheses.

All analyses were also performed without the HADS to investigate whether a lower number of respondents had an impact on the results. As no substantial difference was observed, we chose to keep the HADS within the analyses.

The effect sizes of the predictors are given as odds ratios (ORs) with 95% confidence intervals (95% CIs). An alpha level of <0.05 was required to discard the null hypothesis.

The degree of multicollinearity was checked using the variance inflation factor (VIF: range 0 to infinity) and the tolerance statistic (range: 0–1). The VIF was below 2 in all analyses, with a tolerance level from 0.06–0.09, which is quite acceptable. Model fit was investigated with the Hosmer–Lemeshow test to assess the agreement between the observed outcomes and the predicted outcomes of our models. The degree of pseudo-explained variance was reported according to Nagelkerke's R^2.

RESULTS

Representativeness of included patients

A total of 473 patients were included. In the Norwegian region, there were more men in the included

Table II. Participants' characteristics

Pre-stroke demographics	All patients ($n=473$)	Norwegian patients ($n=318$)	Danish patients ($n=155$)	*p*-value
Age, years, mean (95% CI)	71.1 (170.0–72.2)	72.0 (69.4–72.3)	69.3 (67.4–71.3)	0.03
18–64 years, *n* (%)	122 (26)	80 (25)	42 (27)	00.65
65+ years, *n* (%)	351 (74)	238 (75)	113 (73)	
Sex, *n* (%)				
Male	272 (57)	182 (57)	90 (58)	0.86
Female	201 (43)	136 (43)	65 (42)	
Living alone, *n* (%)	175 (39)	131 (42)	44 (28)	0.005
Working, *n* (%)	101 (21)	60 (19)	41 (26)	0.06
Need assistance, *n* (%)	42 (8)	39 (12)	3 (2)	0.001
Stroke characteristics				
Ischaemic stroke, *n* (%)	433 (92)	286 (90)	147 (95)	0.072
Total SSS score, median (IQR 25–75%)	47 (42–54)	47 (41–52)	50 (43–56)	0.001
Very severe SSS score, *n* (%)	9 (2)	8 (2)	1 (1)	0.057[a]
Severe SSS score, *n* (%)	22 (5)	15 (5)	7 (5)	
Moderate SSS score, *n* (%)	144 (30)	108 (34)	36 (23)	
Mild SSS score, *n* (%)	297 (63)	187 (59)	110 (71)	
Stroke unit treatment				
Thrombolysis, *n* (%)	76 (16)	43 (14)	33 (21)	0.032
LOS (days), median (IQR 25%–75%)	4 (2–7)	5 (3–8.25)	2 (1–4)	0.001
Early subacute rehabilitation				
Inpatient rehabilitation, *n* (%)	163 (34)	131 (41)	32 (21)	0.001
Community-based rehabilitation, *n* (%)	118 (25)	52 (17)	66 (42)	0.001
No rehabilitation after discharge from stroke unit, *n* (%)	189 (40)	135 (43)	54 (37)	0.15
Level of functioning at 3 months post stroke				
mRS score 0–1 (no or mild symptoms), *n* (%)	306 (65)	203 (64)	103 (66)	0.28
mRS score 2–3 (moderate symptoms), *n* (%)	129 (27)	85 (27)	44 (28)	
mRS score 4–5 (severe symptoms), *n* (%)	38(8)	30 (9)	8 (5)	

p-values are for comparisons between the Norwegian and Danish patients. [a]Mild SSS score compared with moderate, severe and very severe SSS score.
IQR: interquartile range; SSS: Scandinavian Stroke Scale; LOS: length of stay in stroke unit; mRS: modified Rankin scale.

Table III. Met, unmet and no need for training and help in participants answering these questions in Norway and Denmark

	Norway, *n* = 313	Denmark, *n* = 148	*p*-value
As much training as wanted, *n* = 461			
Met need, *n* (%)	157 (50)	84 (57)	0.144
Unmet need, *n* (%)	47 (15)	20 (14)	
No need, *n* (%)	109 (35)	44 (30)	
As much help as needed, *n* = 466	*n* = 312	*n* = 154	*p*-value
Met need, *n* (%)	189 (61)	84 (55)	0.336
Unmet need, *n* (%)	33 (10)	15 (10)	
No need, *n* (%)	90 (29)	55 (35)	

cohort than among the non-included patients (58% vs 37%, respectively, $p = 0.001$). In the Danish cohort, no statistically significant difference in age, sex or stroke severity was demonstrated when comparing included patients and non-included patients.

Country differences

Norwegian stroke patients were older, more frequently lived alone and were dependent on personal assistance pre-stroke to a higher degree than Danish patients. Norwegian patients also had more severe strokes and longer LOS in stroke units (Table II). The proportion of patients receiving thrombolysis was higher in Denmark. However, the level of functioning measured with the mRS at 3 months post stroke was comparable between the countries.

HADS anxiety and depression data were available for 308 patients. At 3 months, 14% and 16% of Norwegian and Danish participants reported anxiety ($p = 0.59$), and 13% and 14% reported depression ($p = 0.81$), respectively.

The rehabilitation services provided differed markedly; a much larger portion of the Norwegian cohort than the Danish cohort received inpatient rehabilitation, whereas community-based rehabilitation was far more common among the Danish participants (Table II).

As shown in Table III, at 3 months post stroke, 67% of participants reported needs (met/unmet) for training. A total of 69% reported needs (met/unmet) for help. Only 25% of the participants did not perceive any need for help or training. There was no difference between the participants from the two countries regarding perceived need or no need for help or training after stroke (Table III).

Rehabilitation needs (met and unmet) vs no need

Multivariate binary logistic regression revealed that country (Norway), a longer LOS and a lower mRS function score significantly predicted a need for training (either met or unmet) (Table IV). The need for help, whether met or unmet, was predicted by a longer LOS and a lower level of function (Table V). In addition, both inpatient rehabilitation and community-based rehabilitation (Tables IV and V) were associated with a need (met/unmet) for training and help, with the highest OR for inpatient rehabilitation.

Table IV. Predictors of the need for training (met and unmet) vs no need for training.

				Univariate			Multivariate		
Variables	*n* = 461	Met and unmet need for training (*n* = 307)	No need for training (*n* = 154)	OR	95% CI	*p*-value	OR	95% CI	*p*-value
Country, *n* (%)									
Norway	313	204 (65)	109 (71)	1.26	0.82–1.93	0.28	2.23	1.26–3.94	0.006
Denmark	148	104 (34)	44 (29)						
Age, *n* (%)				0.94	0.61–1.47	0.79	0.57	0.32–1.00	0.052
≤ 65 years	121	82 (27)	39 (25)						
> 65 years	340	226 (73)	115 (75)						
Sex, *n* (%)				0.71	0.47–1.05	0.08	1.63	98–2.70	0.060
Male	266	169 (55)	97 (63)						
Female	195	139 (45)	56 (37)						
Living alone pre-stroke, *n* (%)	168	121 (39)	47 (31)	0.71	47–1.07	0.10			
Dependent on help pre-stroke, *n* (%)	40	33 (11)	7 (5)	2.55	1.01–5.92	0.03			
Working pre-stroke, *n* (%)	100	66 (21)	34 (22)	1.04	0.66–1.69	0.82			
SSS median score (25–75% IQR)	461	46 (41–52)	50 (46–56)	1.07	1.07–1.10	0.001			
Stroke subtype, ischaemic, *n* (%)	421	285 (93)	136 (89)	1.54	0.80–2.99	0.19			
Treated with thrombolysis, *n* (%)	73	51 (17)	22 (14)	0.84	0.49–1.45	0.54			
LOS in stroke unit, median days (25–75% IQR)	461	5 (2–8)	2 (2–4.5)	0.81	0.76–0.87	0.001	0.85	0.78–0.94	0.001
mRS score at 3 months				8.30	3.51–19.55	0.001	19	0.07–0.51	0.001
0–2, *n* (%)	375	229 (75)	147 (95)						
3–5, *n* (%)	86	78 (25)	7 (5)						
HADS Anxiety score ≥ 8 at 3 months	45	33 (11)	12 (8)	1.50	0.72–3.11	0.28			
HADS Depression score ≥ 8 at 3 months	40	31(10)	9(6)	1.83	0.84–3.92	0.13			
Inpatient rehabilitation	161	153 (50)	8 (3)	18.1	8.54–37.98	0.001	23.5	10.4–53.2	0.001
Community-based rehabilitation	114	90 (28)	24 (15)	2.20	1.34–3.63	0.002	5.61	3.15– 10.0	0.001
No rehabilitation	186	65 (21)	121 (51)	0.007	0.04–0.11	0.001	Reference		

Nagelkerke's $R^2 = 0.49$. OR: odds ratio; 95% CI: 95% confidence interval; IQR: interquartile range; HADS: Hospital Anxiety and Depression Scale; SSS: Scandinavian Stroke Scale; LOS: length of stay; mRS: modified Rankin scale.

Table V. Predictors of need for help (met and unmet) vs no need for help.

Variables	*n* = 466	Met/unmet need for help (*n* = 321)	No need for help (*n* = 145)	Univariate OR	Univariate 95% CI	Univariate *p*-value	Multivariate OR	Multivariate 95% CI	Multivariate *p*-value
Country, *n* (%)	312	222 (69)	90 (62)	0.73	0.48–1.10	0.13	1.05	0.62–1.77	0.85
Norway	312	222 (69)	90 (62)	0.73	0.48–1.10	0.13	1.05	0.62–1.77	0.85
Denmark	154	99 (31)	55 (38)						
Age, *n* (%)				0.90	0.72–1.40	0.64	0.75	0.45–1.24	0.26
<65 years	122	82 (25)	40 (28)						
≥65 years	344	239 (75)	105 (72)						
Sex, *n* (%)				1.11	0.78–1.73	0.47	1.15	0.72–1.84	0.55
Male	268	181 (57)	87 (60)						
Female	198	140 (43)	58 (40)						
Living alone pre-stroke, *n* (%)	171/464	128 (40)	43 (30)	1.57	1.03–2.39	0.037			
Dependent on help pre-stroke, *n* (%)	38/449	34 (11)	4 (3)	4.31	1.50–12.40	0.007			
Working pre-stroke, *n* (%)	101/466	71 (22)	30 (21)	0.93	0.57–1.50	0.76			
Scandinavian Stroke Scale (SSS), median score (25–75% IQR)	466	46 (41–53)	50 (45–56)	1.05	1.03–1.08	0.001			
Stroke subtype, ischaemic, *n* (%)	426/466	293 (91)	133 (92)	0.95	0.46–1.91	0.87			
Treated with thrombolysis, *n* (%)	76/466	50 (16)	26 (18)	1.18	0.70–1.99	0.53			
LOS in stroke unit, median days (IQR)	466	5 (2–8)	2 (1–5)	0.82	0.76–0.88	0.001	0.89	0.82–0.97	0.010
Modified Rankin scale (mRS) score at 3 months				15.9	4.9–51.3	0.001	11.11	3.30–37.46	0.001
0–2, *n* (%)	382	240 (75)	142 (98)						
3–5, *n* (%)	84	81 (25)	3 (2)						
HADS Anxiety score ≥8 at 3 months	45/297	30 (9)	15 (10)	1.02	0.52–2.00	0.95			
HADS Depression score ≥8 at 3 months	40/304	26 (8)	14 (9)	0.99	0.49–1.97	0.96			
Inpatient rehabilitation	159	148 (46)	11 (7)	10.7	5.56–20.51	0.001	9.8	4.78–20.11	0.001
Community-based rehabilitation	117	84 (26)	33 (23)	0.82	0.52–1.30	0.41	2.84	16.65–4.81	0.001
No rehabilitation	187	86 (27)	101 (69)	0.16	0.10–0.25	0.001	Reference		

Nagelkerke's $R^2 = 0.36$. OR: odds ratio; 95% CI: 95% confidence interval; IQR: interquartile range; HADS: Hospital Anxiety and Depression Scale; SSS: Scandinavian Stroke Scale; LOS: length of stay; mRS: modified Rankin scale.

Met vs unmet need for rehabilitation services

In the subgroup of patients reporting a need (met/unmet) for help (*n*=322) or training (*n*=308), 15% and 22% reported unmet needs for help and training, respectively. Country did not significantly predict unmet needs (Tables V and VI). The LOS in the stroke unit or the type of rehabilitation after discharge was not associated with the perceived level of met or unmet need for training or help during the first 3 months post stroke.

An unmet need for training was associated with a lower mRS function score at 3 months post stroke. The

Table VI. Predictors of met need for training vs unmet need for training.

Variables	*n* = 308	Met need for training (*n* = 241)	Unmet need for training (*n* = 67)	Univariate OR	Univariate 95% CI	Univariate *p*-value	Multivariate OR	Multivariate 95% CI	Multivariate *p*-value
Country, *n* (%)				1.13	0.69–2.26	0.48	1.43	67–3.05	0.36
Norway	204	157 (77)	47 (23)						
Denmark	104	84 (81)	20 (19)						
Age, *n* (%)				0.95	0.52–1.71	0.86	1.15	49–2.70	0.75
≤65 years	82	65 (27)	17 (25)						
>65 years	226	176 (73)	50 (75)						
Sex, *n* (%)				0.92	0.53–1.57	0.73	1,72	0.80–3.70	0.17
Male	169	131 (54)	38 (57)						
Female	139	110 (46)	29 (43)						
Living alone pre-stroke, *n* (%)	121/308	94 (39)	27 (40)	0.85	0.55–164	0.95			
Dependent on help pre-stroke, *n* (%)	33/295	22 (9)	11 (16)	0.51	0.23–1.11	0.09			
Working pre-stroke *n* (%)	66/308	55 (23)	11 (16)	0.67	0.33–1.36	0.26			
SSS, median score (25%–75% IQR)	308	46 (41–53)	44 (37–49)	0.97	0.95–1.00	0.016			
Stroke subtype, ischaemic, *n* (%)	285/308	223 (93)	62 (93)	0.99	0.36–2.80	0.99			
Treated with thrombolysis, *n* (%)	51/307	40 (16)	11 (16)	1.01	0.48–2.08	0.99			
LOS in stroke unit, median days (25%–75% IQR)	308	5 (2–9)	4 (2–8)	0.97	0.93–1.03	0.36			
Modified Rankin scale (mRS) score at 3 months				0.37	0.21–0.65	0.001	0.32	13–0.77	0.011
0–2, *n* (%)	230	191 (79)	39 (58)						
3–5, *n* (%)	78	50 (21)	28 (42)						
Available data on HADS A+D	208								
HADS Anxiety score >8 at 3 months	33/199	21(9)	12 (18)	0.34	0.15–0.77	0.008	0.36	0.15–0.86	0.021
HADS Depression score ≥8 at 3 months	31/202	20 (8)	11 (16)	0.37	0.16–0.86	0.020			
Inpatient rehabilitation	153	118 (49)	35 (52)	1.14	0.66–1.96	0.63			
Community-based rehabilitation	90	75 (31)	15 (22)	1.57	0.83–2.96	0.17			
No rehabilitation	65	48 (20)	17 (25)	1.36	73–2.58	0.33	Reference		

Nagelkerke's $R^2 = 0.15$. OR: odds ratio; 95% CI: 95% confidence interval; IQR: interquartile range; HADS: Hospital Anxiety and Depression Scale; SSS: Scandinavian Stroke Scale; LOS: length of stay; mRS: modified Rankin scale.

percentage was 2-fold higher for unmet needs for training among those with the mRS scores of 3–5 ($p=0.011$) (Table V). A patient with a severe loss of functioning (mRS score 3–5) had a 68% higher probability of reporting unmet needs for training than a patient with an mRS score 0–2. In addition, anxiety ($p=0.021$) was a significant factor, with more anxiety among those who had unmet needs for training (Table VI).

Patients reporting unmet needs for help more often lived alone pre-stroke ($p=0.039$) and were also more depressed at 3 months post stroke ($p=0.028$) (Table VII).

DISCUSSION

This study is, to our knowledge, the first to explore the level of met and unmet post-stroke rehabilitation needs in association with different rehabilitation pathways in participants recruited from 2 countries. Two-thirds of an unselected population of consecutive patients with stroke in Norway and Denmark reported the need for help and training during the first 3 months post stroke, demonstrating the considerable negative impact that stroke has on patients (1).

The 2 cohorts differed, as the Norwegian participants were older, more often dependent on help pre-stroke, more often lived alone, and had more severe strokes than the Danish participants.

The population density and travel distances differed, yet according to data from the national stroke registries, there was no difference in hospital arrival time or acute stroke treatment after stroke in these 2 regions.

The received rehabilitation services differed markedly between the participants in the 2 countries. Nevertheless, the participants from the 2 countries reported similar levels of met and unmet needs for both training and help at 3 months after stroke. The result may imply that a longer stay in a stroke unit and more inpatient rehabilitation during the first 3 months after stroke to a certain extent compensate for the more severe strokes and less use of community-based rehabilitation in Norway. Cultural differences in expectations of help and training may also contribute to the comparable findings of met and unmet needs in the 2 countries.

Living alone and depression were significantly associated with unmet needs for help, whereas a low level of functioning and anxiety at the 3-month follow-up were associated with unmet needs for training.

Unmet need for training and help

We regard it as especially important to investigate predictors that might explain unmet needs for help and training to identify correctable factors to reduce patient-reported unmet rehabilitation needs. At the individual level, unmet rehabilitation needs may reduce functional ability, increase psychological burden, and hence reduce autonomy, post stroke (29). Insufficient professional efforts increase caregivers' burdens (30).

Table VII. Predictors of met need for help vs unmet need for help.

				Univariate			Multivariate		
Variables	*n* = 322	Met need for help (*n* = 274)	Unmet need for help (*n* = 48)	OR	95% CI	*p*-value	OR	95% CI	*p*-value
Country, *n* (%)				1.03	0.50–1.98	0.95	0.70	0.30–1.64	0.41
Norway	223	190 (69)	33 (69)						
Denmark	99	84 (31)	15 (31)						
Age, *n* (%)				1.40	0.72–2.73	0.32	1.46	0.59–3.64	0.42
≤65 years	82	67 (25)	15 (31)						
>65 years	240	207 (75)	33 (69)						
Sex, *n* (%)				0.82	0.44–1.50	0.52	1.89	0.76–4.77	0.17
Male	182	157 (57)	25 (48)						
Female	140	117 (43)	23 (52)						
Living alone, *n* (%)	128/319	103 (38)	25 (52)	0.56	0.30–1.03	0.066	0.40	0.17–0.96	0.039
Dependent on help, *n* (%)	34/306	29 (11)	5 (10)	1.03	0.38–2.81	0.96			
Working, *n* (%)	71/322	62 (23)	9 (19)	0.79	0.36–1.71	0.54			
SSS, median score (IQR)	322	46.5 (41–53.75)	44.5 (38.25–49.75)	0.98	0.96–1.01	0.15			
Stroke subtype, ischaemic, *n* (%)	294/322	249 (91)	45 (94)	0.66	0.19–2.28	0.51			
Treated with thrombolysis, *n* (%)	50/321	40 (15)	10 (21	0.66	0.30–1.42	0.28			
LOS in stroke unit, median days (IQR)	322	5 (2–8.5)	4 (2–7)	0.98	0.92–1.03	0.41			
Modified Rankin scale (mRS) score at 3 months				1.27	0.64–2.51	0.49			
0–2, *n* (%)	241	207 (75)	34 (71)						
3–5, *n* (%)	81	67 (25)	14 (29)						
HADS Anxiety score ≥8 at 3 months	30/197	23 (8)	7 (14)	0.47	0.18–1.23	0.13			
HADS Depression score ≥8 at 3 months	30/199	19 (7)	7 (14)	0.37	0.14–0.99	0.05	0.31	0.11–0.88	0.028
Rehabilitation									
Inpatient rehabilitation	149	125 (46)	24 (50)	0.86	0.46–1.58	0.62			
Community-based	84	76 (28)	8 (17)	1.94	0.88–4.37	0.10			
No rehabilitation	86	70 (26)	16 (33)	0.69	0.36–1.37	0.28		Reference	

Nagelkerke's $R^2=0.011$. OR: odds ratio; 95% CI: 95% confidence interval; IQR: interquartile range; HADS: Hospital Anxiety and Depression Scale; SSS: Scandinavian Stroke Scale; LOS: length of stay; mRS: modified Rankin scale.

On the systemic level, unmet rehabilitation needs may lead to increased use of health services (29), institutionalization and economic costs (31).

The level of unmet rehabilitation needs must be interpreted within the post-stroke time frame and by the definition of the needs used. Most studies report unmet rehabilitation needs in a later phase post stroke and use questionnaires reflecting a much broader definition of rehabilitation needs. In the systematic review (9), only 2 validation articles included participants within the first year.

There are no comparable studies of unmet needs at 3 months post-stroke. Studies at

6 and 12 months post stroke demonstrate great variability in unmet needs, which may stem from large differences in operationalization or use of measures, as well as differing contexts (9).

Unmet needs in the Swedish registry study (13) were assessed using the following single question: Have your needs for rehabilitation after stroke been met? Rehabilitation was defined as activities or training to improve or maintain the ability to cope with daily life. This finding of unmet needs is higher than in the current study, but answering options of partly met needs were included in unmet needs in the Swedish study, whereas the patients in the current study had only yes-or-no answer alternatives. Using dichotomous response options may influence the results, as partial unmet needs may be categorized as both met needs and unmet needs. The recognition of unmet needs may also increase over time, particularly for those facing unfulfilled needs who are hampered in their capability of returning to work (32).

In line with others (33), the current found psychological distress to be correlated with the perception of unmet needs. Anxiety at 3 months was significantly elevated among persons reporting an unmet need for training, while depression was more frequent when the need for help was unfulfilled. Depression was highly significantly associated with unmet needs at 12 months in the Swedish registry study (13).

The estimates of depression and anxiety at 3 months are lower than those observed in other studies (33, 34), but the results must be interpreted with caution because of missing data. In contrast to the Swedish registry study, the higher age and dependency on help pre-stroke among Norwegian participants did not increase the level of unmet needs compared with the level of unmet needs in Danish participants.

The type of rehabilitation offered had no impact on the level of experienced unmet needs. Approximately 50% of persons reporting an unmet need for training or help had completed inpatient rehabilitation. One out of every 7 participants in the current study stated an unmet need for training. Among these patients, 38% had an mRS score of 0–1, indicating no or slight symptoms at 3 months post stroke. This somewhat surprising fact indicates that the mRS might not identify all symptoms patients expect help to solve. Though extensively used, the mRS has a non-linear correlation with cognitive screening tools, as 7.5% of patients with an mRS score of 0–1 have findings of cognitive deficits detected by the Quality of Life in Neurological Disorder (Neuro-QOL) questionnaire (35). Questionnaire screening identifies significantly more needs than clinical evaluation, especially cognitive problems (36). Another possibility is unrealistic expectations for rehabilitation due to symptoms without local available treatment options; for instance, fatigue (37) or minor cognitive deficits (38).

Despite the findings described above, a low level of functioning, as measured with the mRS, at 3 months post stroke was highly significantly associated with unmet needs for training. The Swedish registry study also found a correlation between dependency in activities of daily living and unmet needs at the evaluation time-point at 12 months post stroke (13).

Operationalizing the rehabilitation need concept using questions about help and training

In this study, the questions about training and help were together designed as an expression of the broader concept of rehabilitation. The majority of patients in the study received both training and help, but while training is offered to facilitate functional improvement (39), help may often represent a compensating strategy. Theoretically, the concept of needs is multidimensional. According to Bradshaw (40), felt needs are equated with wants and are limited by the perceptions of the individuals with regard to the health services available. Expressed needs are demands or felt needs turned into action. Expressed needs are commonly used in healthcare services where waiting lists are taken as a measure of unmet needs. Normative needs are those defined by health professionals, administrators or experts in relation to norms or a desirable standard. Finally, comparative needs refer to a measure established by studying the characteristics of those in receipt of a service; in other words, populations in which the evaluated needs are generalized.

We have no possible way of distinguishing between felt needs and expressed needs in patients, as some patients may have had felt needs that were not expressed until their rehabilitation needs were subsequently formulated when asked at 3 months post stroke. In our study, 7/88 patients (8%) with mRS scores of 3–5 expressed no need for training, indicating a mismatch between clinical functioning and patient-reported needs. A plausible interpretation is patients' unawareness of their own needs, due to a lack of insight. Unmet rehabilitation needs may therefore represent a lack of rehabilitation services, unexpressed or unidentified needs, or unrealistic expectations for rehabilitation. Patients and healthcare workers may also have different perspectives on needs (29).

Strengths and limitations

The study included the majority of eligible Norwegian patients with stroke in a given period of time and location. The representativeness of Danish participants is, however, lower. The difference in response rate may be due to different recruitment practices, as the personal contact of the study teams with patients at the stroke units in Norway may have enhanced participation in the study. In addition, some patients in Norway were excluded due to severe medical conditions, resulting in a selection of eligible patients in Norway, which was not possible in Denmark.

When using single questions about help and training, limitations occur because of lack of ability to recognize other unmet needs, as well as partly met or unmet needs.

Data on psychological function must be interpreted with caution because of possible selection bias.

Conclusion

This study is the first to explore unmet needs for rehabilitation within the context of different subacute rehabilitation settings in the regions of Norway and Denmark. The participants from the 2 countries reported similar levels of met and unmet needs for both training (15% unmet needs) and help (10% unmet needs) at 3 months after stroke.

Low levels of functioning and anxiety at 3 months post stroke were associated with perceived unmet needs for training. Living alone pre-stroke and having depression at 3 months enhanced the risk of reporting an unmet need for help. The health services should pay special attention to at-risk patients who are anxious or depressed, live alone, or have more functional deficits after stroke. Variations in service pathways for in-hospital or community-based rehabilitation did not affect the levels of met and unmet rehabilitation needs.

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The authors have no conflicts of interest to declare.

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Appendix

Appendix 1 - Decision Regional Committee for Health Research Ethics

Appendix 2 - Information and consent form

Appendix 3 - Questionnaire package – three months, Danish version

Appendix 4 - Questionnaire package on life quality following apoplexy, Danish version

Appendix 5 - Questionnaire package – three months, Norwegian version

Appendix 6 - Questionnaire package – 12 months, Norwegian version

Appendix 7 - Follow-up registrations adjusted for use in Denmark at three months

Appendix 8 – Follow-up, telephone interview from National Norwegian Stroke Registry

Appendix 9 - Acute phase data from the National Norwegian Stroke Registry

Appendix 10 - Follow-up registrations at three months from the National Norwegian Stroke Registry

Appendix 1

Decision Regional Committee for Health Research Ethics

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			05.03.2014	2013/1472/REK nord
			Deres dato:	**Deres referanse:**
			08.10.2013	

Vår referanse må oppgis ved alle henvendelser

Audny Anke
Rehabiliteringsklinikken, UNN HF

2013/1472 Rehabiliteringsforløp, funksjon og livskvalitet etter hjerneslag i Nord-Norge og Danmark

Forskningsansvarlig: Universitetssykehuset Nord Norge
Prosjektleder: Audny Anke.

Prosjektleders prosjektomtale

Sammenlignende populasjonsbaserte studier etter hjerneslag gir relativt like funn av letalitet, mens det i mindre grad finnes sammenlignende studier av funksjon, livskvalitet og rehabiliteringstiltak etter slagenhet. I Nord-Norge gis rehabilitering på små enheter med lite pasientvolum, mens Danmark har høyere grad av sentralisering. Begge land bruker slagenheter og trombolyse. Norge-Norge har spesielle geografiske utfordringer. Studien er en prospektiv sammenlignende internasjonal multisenterstudie av slagpasienter fra UNN Tromsø/Harstad/Narvik og Århus i Danmark, i samarbeid med Hammel Neurocenter. Basis-informasjon hentes fra hjerneslagregistrene i begge land. Datainnsamling ved 3 og 12 måneder vil gi informasjon om funksjonell status (Modified Rankin Scale), hjelpebehov, bosted, livskvalitet (SSQOL-DK, QOLIBRI, EQ-5D, HADS) og behandlingstilfredshet i de to kohorter. Behandlingskjeden kartlegges med vekt på rehabiliteringstiltak.

Bakgrunn

Prosjektsøknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møte den 26.9.2013. Komiteen hadde merknader til søknaden og fattet utsettelsesvedtak hvor den videre behandling av søknaden vil bli foretatt av en samlet komité.

Prosjektleder har gjennom møte med sekretariatet, samt ved skriftlige tilbakemeldinger gitt tilfredsstillende tilbakemelding på komiteens merknader. Tilbakemeldingen ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møte 20.02.2014.

Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Vedtak:

Med hjemmel i helseforskningsloven § 10 og forskningsetikkloven § 4 godkjennes prosjektet.

Sluttmelding og søknad om prosjektendring

Prosjektleder skal sende sluttmelding til REK nord på eget skjema senest (et halvt år etter prosjektslutt), jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK nord dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang

Prosjektleder kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK nord.

Klagefristen er tre uker fra mottak av dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Kopi til: kari.holthe@unn.no; rek-svar@unn.no

Appendix 2

Information and consent form

Forespørsel om deltakelse i forskningsprosjektet

"Rehabiliteringsforløp, funksjon og livskvalitet etter hjerneslag i Nord-Norge og Danmark"

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie som sammenligner forløpet for pasienter med hjerneslag i Nord-Norge og i en region i Danmark, hvilke behandlings- og rehabiliteringstiltak som gis og hvordan det går det første året etter hjerneslaget. Studien gjennomføres for å få bedre kunnskap om hvordan det går med pasienter med hjerneslag og hvilke behov de har. Studien er et samarbeid mellom rehabiliteringssenteret Hammel Neurocenter i Danmark og Universitetssykehuset Nord-Norge, og kan bidra til at rehabiliteringstilbudet bedres.

Hva innebærer studien?

I forbindelse med innleggelsen og ved telefonisk kontakt 3 måneder etter hjerneslaget registreres opplysninger som inngår i Norsk Hjerneslagregister. Dette er dato for hjerneslaget, tid fra du merket symptomer til innleggelsen, og resultater fra undersøkelser om årsak til hjerneslaget, behandlingstype, eventuelle komplikasjoner, diagnoser, liggetid, utskrivingssted og hjelpetiltak. Det kartlegges også hvilke problemer du har og hvordan du klarer deg i hverdagen. Som del av studien vil det per telefon bli stilt noen tilleggsspørsmål om rehabiliteringstiltak etter utskriving. Du vil få tilsendt et spørreskjema i posten 3 måneder og 12 måneder etter hjerneslaget. I skjemaet spør vi om bakgrunnsdata som familie, utdanning, arbeidssituasjon og bosted. Det er spørsmål om i hvilken grad du opplever problemer med forskjellige daglige aktiviteter, sosiale sammenhenger, følelsesmessige forhold, og om du opplever endringer i din situasjon etter hjerneslaget. I tillegg er det spørsmål om tilfredshet med ulike livsområder og om hvor tilfreds du er med behandlingen og/eller rehabiliteringen.

Mulige fordeler og ulemper

Studien medfører ingen form for risiko eller ubehag annet enn at du besvarer spørsmål ved telefonkontakt og fyller ut de ulike spørreskjemaene. Studien bidrar til bedre kunnskap om problemer etter et hjerneslag, og resultatene i studien vil bli benyttet til å bedre rehabiliteringstilbudet.

Hva skjer med informasjonen om deg

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Informasjon om hjerneslaget og behandlingen du får hentes fra journal på det sykehus som behandler deg og fra Norsk Hjerneslagregister. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Informasjonen som samles vil bli slettet innen utgangen av år 2020. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Audny Anke, prosjektleder, førsteamanuensis dr.med. Universitetssykehuset Nord-Norge, tlf.95936333; eller Guri Heiberg, overlege, UNN Harstad, tlf.95948500; eller Synne Garder Pedersen, fysioterapeut, UNN Tromsø tlf. 91838630.

Rehabilitering, funksjon og livskvalitet etter hjerneslag i Norge og Danmark – 27.08.13

Kapittel A- utdypende forklaring av hva studien innebærer

Pasienter innlagt med hjerneslag ved en av de tre slagenhetene ved UNN Tromsø, UNN Harstad eller UNN Narvik blir forespurt om deltakelse. Pasient og pårørende blir informert om studien ved innleggelsen og samtykke innhentet så raskt pasientens tilstand tillater det. Studien innebærer ikke påvirkning av behandling, men dersom problemer i behandlingsapparatet oppdages vil studieleder kontakte behandlingsansvarlig.

Kapittel B - Personvern, økonomi og forsikring

Personvern

Opplysninger som registreres om deg er i hovedtrekk hentet fra din journal samt spørreskjemaene om problemer og funksjon som du fyller ut. Mange av de opplysninger som registreres i Norsk Hjerneslagregister inngår i studien. Ved 3 måneder vil du bli spurt om behandling og rehabilitering etter utskriving, og vi innhenter opplysninger fra de sykehus eller rehabiliteringsinstitusjoner om hvor lenge du ligger der og hvilken form for medisinsk behandling og rehabilitering du får. All informasjon om deg avidentifiseres og studiens medarbeidere og forskere får kun tilgang til avidentifisert informasjon.

Universitetssykehuset Nord-Norge ved administrerende direktør er databehandlingsansvarlig.

Utlevering av materiale og opplysninger til andre

Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at avidentifiserte opplysninger utleveres til forskere ved Hammel Neurocenter Danmark som deltar i studien.

Rett til innsyn og sletting av opplysninger om deg

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi

Studien er finansiert gjennom forskningsmidler fra Helse Nord RHF.

Forsikring

Deltakerne i studien er omfattet av Pasientskadeerstatningen.

Informasjon om utfallet av studien

Du har som deltaker rett til å få informasjon om studiens resultater.

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Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

----
(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

Appendix 3

Questionnaire package – three months, Danish version

Spørgeskema

Spørgeskema om livskvalitet

- hvordan oplever du din hverdag
3 måneder efter din apopleksi

Regionshospitalet
Hammel Neurocenter

Livskvalitet 3 måneder efter en apopleksi

Introduktion

Svarene i dette spørgeskema giver et overblik over, hvordan du har det, hvor tilfreds du er med forskellige områder af dit liv, og hvor godt du klarer dig 3 måneder efter din apopleksi. Samtidig belyses din tilknytning til arbejdsmarkedet, dit sociale liv, din uddannelse og hvordan du bor.

Såfremt du ***ikke*** selv er i stand til at besvare spørgeskemaet beder vi om, at en pårørende, en ven, en sundhedsfaglig medarbejder eller en anden, der kender dig godt, besvarer spørgsmålene på side 3 til 5 og samtidig angiver den relation vedkommende har til dig, og hvor ofte I ses. De øvrige spørgsmål i spørgeskemaet skal derefter ***ikke*** besvares. Det tager ca. 3 min. at besvare disse spørgsmål.

Du bedes venligst angive dato for udfyldelse af spørgeskemaet nederst på siden.

Vejledning

Spørgeskemaet indeholder flere skemaer, der skal besvares forskelligt. Derfor er der en vejledning til, hvad hvert enkelt skema indeholder, og hvordan det besvares.

I spørgeskemaet finder du fortrykte tal i de fleste svarmuligheder. De har ingen betydning og er ikke et udtryk for høj eller lav værdi på dit svar. Tallene er udelukkende en hjælp, når vi senere skal taste dine svar ind.

Der kan være spørgsmål, som, du måske synes, ligner hinanden. Det skal du blot se bort fra, og besvare spørgsmålene, så godt du kan. **Det er meget vigtigt, at *alle* spørgsmål besvares.**

Det tager ca. 30 minutter at udfylde spørgeskemaet.

Returnering af spørgeskemaerne

Du bedes returnere spørgeskemaet i den vedlagte svarkuvert ***så hurtigt som muligt efter modtagelsen***. Portoen er betalt.

Tak for din hjælp!

ID nr.:	Navn:	Skriv venligst dato for udfyldelse:

Spørgeskema om boligforhold, skolegang, arbejde og samliv før og efter en apopleksi

De følgende spørgsmål handler om dine boligforhold, om du bor alene eller sammen med andre, din uddannelse og din tilknytning til arbejdsmarkedet. Spørgsmålene handler om disse emner ***før*** du fik din apopleksi, og om hvordan det forholder sig ***i dag***. Med ***før*** mener vi, hvordan dine forhold var, **den dag du fik din hjerneskade**. Du kan fx godt have haft flere forskellige jobs med forskellige arbejdstimer før din skade, men du bedes svare på, hvordan din situation var, den dag du fik din skade. Dette gælder alle spørgsmål, hvor der spørges til tiden ***før*** og ***i dag***.

Vejledning: I spørgeskemaet bedes du sætte ***én ring*** om det tal, der passer bedst til dit svar. For nogle spørgsmål gælder det både for perioden ***før*** din apopleksi og for perioden ***i dag***.

1 - Skolegang	***Sæt kun én ring***
Hvor lang tid har du gået i skole?	
• 7 eller færre års skolegang (folkeskole)	1
• 8-10 års skolegang (folkeskole)	2
• 11-14 års skolegang (student, håndværksmæssige, handel og kontoruddannelser, bachelor)	3
• Mere end 14 års skolegang (Universitet, Handelshøjskole)	4
• Ved ikke / uoplyst	9

2 - Tilknytning til arbejdsmarkedet	***Sæt kun én ring for <u>hver</u> af perioderne før din apopleksi og i dag***	
	Før din apopleksi	**I dag**
Hvilken tilknytning til arbejdsmarkedet havde du ***før*** din apopleksi, og hvad er din tilknytning til arbejdsmarkedet ***i dag***?		
• Studerende	1	1
• Ingen tilknytning til arbejdsmarkedet	2	2
• Fuldtidsarbejde	3	3
• Deltidsarbejde • Angiv timer pr. uge: ______________________	4	4
• Efterlønsmodtager eller folkepensionist	5	5
• Førtidspensionist	6	6
• Langtidssygemeldt (sygedagpenge)	7	7
• Arbejdsledig	8	8
• Ved ikke / uoplyst	9	9

3 - Boligforhold	*Sæt kun én ring for hver af perioderne før din apopleksi og i dag*	
	Før din apopleksi	**I dag**
Hvordan boede du ***før*** din apopleksi, og hvordan bor du i ***i dag***?		
• Egen bolig **uden** behov for hjemmehjælp, hjemmesygepleje eller støtte fra andre	1	1
• Egen bolig **med** behov for hjemmehjælp, hjemmesygepleje eller støtte fra andre	2	2
• Ældrebolig, beskyttet bolig eller bolig med mulighed for tilkald af personale døgnet rundt	3	3
• Plejehjem eller institution med døgnvagt	4	4
• Ved ikke / uoplyst	9	9

4 - Samliv	*Sæt kun én ring for hver af perioderne før din apopleksi og i dag*	
	Før din apopleksi	**I dag**
Hvad var din samlivsstatus ***før*** din apopleksi, og hvad er den ***i dag***?		
• Gift eller bor sammen med nogen	1	1
• Enke eller enkemand	2	2
• Bor alene	3	3
• Ved ikke / uoplyst	9	9

Rygning	*Sæt kun én ring for hvert spørgsmål*		
	Ja	**Nej**	**Ved ikke/ uoplyst**
5 - Røg du ***før*** du fik din apopleksi?	1	2	9
6 - Ryger du ***i dag***?	1	2	9
7 - Er du ***tidligere*** ryger (røgfri i over 1 måned)	1	2	9

Vi vil gerne vide, om du mener, at du er kommet dig helt efter din skade i hjernen, og om du i forbindelse med dine daglige gøremål får hjælp fra andre.

	Ja	**Nej**
8 - Mener du, at du er kommet dig helt efter din skade i hjernen?	1	2
9 - Får du hjælp fra andre til nogle af dine daglige gøremål?	1	2

Relationer

Såfremt ovenstående spørgsmål er besvaret af ***en anden end den, der har haft en apopleksi*** bedes du angive din relation til vedkommende, og hvor ofte I ses. Sæt kun én ring for hvert spørgsmål. Du skal ikke besvare resten af spørgsmålene i dette spørgeskema. Tak for din hjælp.

10 - Relation	***Sæt kun én ring***
Ægtefælle eller samlever	1
Søn eller datter	2
Ven	3
Sundhedsfaglig medarbejder	4
Anden relation Skriv hvilken: ____	5

11 - Hvor ofte ser du den person, der har haft en apopleksi	***Sæt kun én ring***
Dagligt	1
Mindst én gang om ugen	2
Sjældnere end én gang om ugen	3

Tilfredshed med dit liv efter en hjerneskade

Vi vil gerne vide, hvor tilfreds du er med forskellige dele af dit liv efter din skade i hjernen. Du bedes for hvert spørgsmål sætte kryds ved det svar, der passer bedst til, hvordan du har det nu (inklusiv den seneste uge). Hvis du har vanskeligheder ved at besvare spørgsmålene, så spørg venligst om hjælp fra andre.

Disse spørgsmål handler om, hvordan du har det nu inklusiv den seneste uge.
Sæt *kun et kryds* for hvert spørgsmål.

	Slet ikke tilfreds	Noget utilfreds	Nogenlunde tilfreds	Godt tilfreds	Meget tilfreds
12 - Alt i alt, hvor tilfreds er du med dit fysiske helbred?	1	2	3	4	5
13 - Alt i alt, hvor tilfreds er du med dine evner til at koncentrere dig, huske og tænke?	1	2	3	4	5
14 - Alt i alt, hvor tilfreds er du med dine følelser, og den sindsstemning du har?	1	2	3	4	5
15 - Alt i alt, hvor tilfreds er du med, hvordan du klarer dine daglige gøremål?	1	2	3	4	5
16 - Alt i alt, hvor tilfreds er du med dig selv og dit sociale liv?	1	2	3	4	5
17 - Alt i alt, hvor tilfreds er du med din nuværende situation og dine fremtidsudsigter?	1	2	3	4	5

Livskvalitet efter en skade i hjernen

Dette spørgeskema indeholder tre grupper af spørgsmål:
Første gruppe handler om, hvordan du, indenfor den sidste uge, har klaret dagligdags aktiviteter.
Anden gruppe handler om, hvordan du, indenfor den sidste uge, har oplevet forskellige forhold i dit liv.
Tredje gruppe handler om, hvordan du synes, du har det **nu** sammenlignet med tiden **før** din skade.

Første gruppe – almindelige dagligdags aktiviteter

(Sæt ring om ét tal for hvert spørgsmål)

	I den sidste uge:	**Kunne slet ikke**	**Meget besvær**	**En del besvær**	**Lidt besvær**	**Intet besvær**
18	Har du haft besvær med at tilberede et måltid?	1	2	3	4	5
19	Har du haft besvær med at spise?	1	2	3	4	5
20	Har du haft besvær med at tage tøj på?	1	2	3	4	5
21	Har du haft besvær med at tage bad?	1	2	3	4	5
22	Har du haft besvær med at gå på toilettet?	1	2	3	4	5
23	Har du haft besvær med at se fjernsyn tydeligt nok?	1	2	3	4	5
24	Har du haft besvær med at række ud efter ting på grund af dårligt syn?	1	2	3	4	5
25	Har du haft besvær med at se ting til den ene side?	1	2	3	4	5
26	Har du haft besvær med at tale?	1	2	3	4	5
27	Har du haft besvær med at tale klart og tydeligt i telefon?	1	2	3	4	5
28	Har andre mennesker haft besvær med at forstå, hvad du sagde?	1	2	3	4	5
29	Har du haft besvær med at finde de ord, du gerne ville sige?	1	2	3	4	5
30	Har du været nødt til at gentage dig selv for at andre kunne forstå, hvad du sagde?	1	2	3	4	5
31	Har du haft besvær med at gå? (Sæt ring omkring 1, hvis du **ikke** kan gå, og fortsæt med spørgsmål **34**)	1	2	3	4	5
32	Har du haft besvær med at holde balancen, når du lænede dig frem eller rakte ud efter noget?	1	2	3	4	5
33	Har du haft besvær med at gå op ad trapper?	1	2	3	4	5
34	Har du haft besvær, fordi du var nødt til at holde en pause, mens du gik eller kørte i kørestol?	1	2	3	4	5
35	Har du haft besvær med at stå oprejst?	1	2	3	4	5

	I den sidste uge:	**Kunne slet ikke**	**Meget besvær**	**En del besvær**	**Lidt besvær**	**Intet besvær**
36	Har du haft besvær med at komme op fra en stol?	1	2	3	4	5
37	Har du haft besvær med at klare de daglige gøremål i hjemmet?	1	2	3	4	5
38	Har du haft besvær med at gøre det færdigt, som du var begyndt på?	1	2	3	4	5
39	Har du haft besvær med at udføre de opgaver, som du plejer?	1	2	3	4	5
40	Har du haft besvær med at skrive i hånden eller på maskine?	1	2	3	4	5
41	Har du haft besvær med at tage strømper på?	1	2	3	4	5
42	Har du haft besvær med at knappe knapper?	1	2	3	4	5
43	Har du haft besvær med at åbne en mælkekarton?	1	2	3	4	5
44	Har du haft besvær med at åbne glas med skruelåg?	1	2	3	4	5

I den næste gruppe spørgsmål bedes du angive, hvorvidt du er enig eller uenig i de forskellige udsagn. Hvert udsagn berører problemer, som nogle oplever efter en skade i hjernen. Sæt én ring omkring tallet i den rubrik, der bedst beskriver, hvor enig eller uenig du er.

Anden gruppe – oplevelser **(Sæt ring om ét tal for hvert spørgsmål)**

	I den sidste uge:	**Helt enig**	**Delvist enig**	**Hverken enig eller uenig**	**Delvist uenig**	**Helt uenig**
45	Jeg har haft svært ved at koncentrere mig	1	2	3	4	5
46	Jeg har haft svært ved at huske ting	1	2	3	4	5
47	Jeg har været nødt til at skrive ting ned for at huske dem	1	2	3	4	5
48	Jeg har været irritabel	1	2	3	4	5
49	Jeg har været utålmodig over for andre	1	2	3	4	5
50	Min personlighed har ændret sig	1	2	3	4	5
51	Jeg har følt mig modløs med hensyn til fremtiden	1	2	3	4	5
52	Jeg har været uinteresseret i andre mennesker eller aktiviteter	1	2	3	4	5
53	Jeg har deltaget mindre i fornøjelser med min familie	1	2	3	4	5

	I den sidste uge:	**Helt enig**	**Delvist enig**	**Hverken enig eller uenig**	**Delvist uenig**	**Helt uenig**
54	Jeg har følt, at jeg var en byrde for min familie	1	2	3	4	5
55	Min fysiske tilstand har påvirket mit familieliv	1	2	3	4	5
56	Jeg er gået mindre i byen, end jeg gerne ville	1	2	3	4	5
57	Jeg har beskæftiget mig med mine fritidsinteresser i kortere perioder, end jeg gerne ville	1	2	3	4	5
58	Jeg har været sammen med færre af mine venner end jeg gerne ville	1	2	3	4	5
59	Jeg har dyrket mindre sex, end jeg gerne ville	1	2	3	4	5
60	Min fysiske tilstand har påvirket mit sociale liv	1	2	3	4	5
61	Jeg har følt mig isoleret fra andre mennesker	1	2	3	4	5
62	Min selvtillid har været lille	1	2	3	4	5
63	Jeg har været uinteresseret i mad	1	2	3	4	5
64	Jeg har følt mig træt det meste af tiden	1	2	3	4	5
65	Jeg har været nødt til at hvile mig ofte i løbet af dagen	1	2	3	4	5
66	Jeg har været for træt til at gøre det, jeg gerne ville	1	2	3	4	5

Svarene på den sidste gruppe spørgsmål handler om, hvordan du synes du har det ***nu*** sammenlignet med tiden ***før*** din skade i hjernen. Sæt én ring om det tal i den rubrik, der bedst beskriver din tilstand nu.

Tredje gruppe - nu sammenlignet med før skaden **(Sæt ring om ét tal for hvert spørgsmål)**

		Meget ændret	**Noget ændret**	**Lidt ændret**	**Uændret**
67	Min personlighed er	1	2	3	4

		Meget dårligere end før	**Noget dårligere end før**	**Lidt dårligere end før**	**Uændret**
68	Mit energiniveau er	1	2	3	4
69	Min taleevne er	1	2	3	4
70	Min gang er	1	2	3	4

		Meget dårligere end før	**Noget dårligere end før**	**Lidt dårligere end før**	**Uændret**
71	Mit syn er	1	2	3	4
72	Mine arme og hænder fungerer	1	2	3	4
73	Min tænkeevne er	1	2	3	4
74	Mit humør er	1	2	3	4
75	Jeg udfører mine opgaver derhjemme eller på mit arbejde	1	2	3	4
76	Jeg klarer mig selv	1	2	3	4
77	Jeg gør noget for min familie	1	2	3	4
78	Jeg gør noget for mine venner	1	2	3	4
79	Alt i alt er min livskvalitet	1	2	3	4

Helbredstilstand

For ***hver*** af de fem spørgsmål bedes du sætte ***én ring*** om det tal, der bedst beskriver din helbredstilstand i dag.

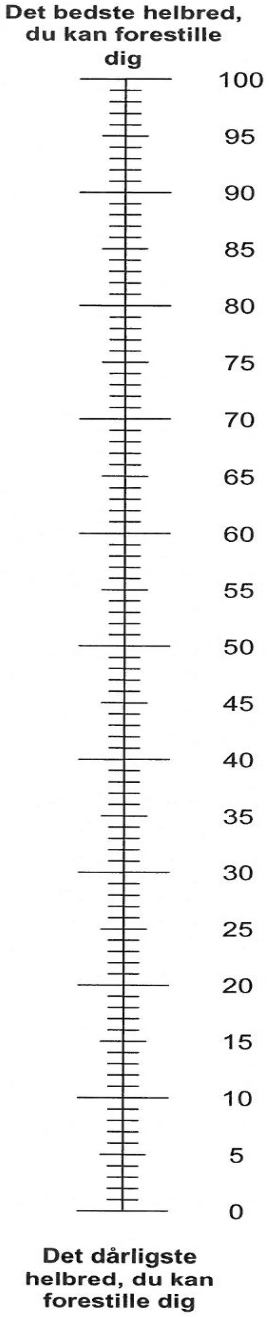
Helbredstilstand	
80 - Bevægelighed	
Jeg har ingen problemer med at gå omkring	1
Jeg har nogle problemer med at gå omkring	2
Jeg er bundet til sengen	3
81 - Personlig pleje	
Jeg har ingen problemer med min personlige pleje	1
Jeg har nogle problemer med min personlige pleje	2
Jeg kan ikke vaske mig eller klæde mig på	3
82 - Sædvanlige aktiviteter (fx arbejde, studie, husarbejde, familie- eller fritidsaktiviteter)	
Jeg har ingen problemer med at udføre mine sædvanlige aktiviteter	1
Jeg har nogen problemer med at udføre mine sædvanlige aktiviteter	2
Jeg kan ikke udføre mine sædvanlige aktiviteter	3
83 - Smerter / ubehag	
Jeg har ingen smerter eller ubehag	1
Jeg har moderate smerter eller ubehag	2
Jeg har ekstreme smerter eller ubehag	3
84 - Angst / depression	
Jeg er ikke ængstelig eller deprimeret	1
Jeg er moderat ængstelig eller deprimeret	2
Jeg er ekstremt ængstelig eller deprimeret	3

Helbredstilstand - fortsat

85 - På nedenstående skala beder vi dig angive, hvor god eller dårlig du mener din helbredstilstand er ***i dag***. Angiv dette ved at tegne en streg fra den sorte kasse til et hvilket som helst punkt på skalaen, der viser, hvor god eller dårlig du mener din helbredstilstand er ***i dag***.

Den bedste helbredstilstand du kan forestille dig er markeret med 100, og den værste helbredstilstand er markeret med 0.

Din
helbredstilstand
i dag



Helbredstilstand - fortsat

Dette skema undersøger, hvordan du har det.
Læs ***hvert*** spørgsmål og sæt ***én ring*** om det tal, der bedst beskriver, hvordan du har haft det følelsesmæssigt inden for ***den sidste uge.***

86: Jeg er anspændt eller stresset		**87: Jeg glæder mig stadig over de ting, jeg plejede at glæde mig over**	
Det meste af tiden	3	Helt bestemt	0
Meget af tiden	2	Ikke helt så meget	1
Engang imellem	1	Kun lidt	2
Overhovedet ikke	0	Næsten ikke	3
88: Jeg får en slags skræmmende fornemmelse, som om noget forfærdeligt skal til at ske		**89: Jeg kan le og se tingene fra den morsomme side**	
Helt bestemt og temmelig slemt	3	Lige så meget som jeg altid har kunnet	0
Ja, men ikke alt for slemt	2	Ikke helt så meget nu	1
En smule, men det bekymrer mig ikke	1	Bestemt ikke så meget nu	2
Overhovedet ikke	0	Overhovedet ikke	3
90: Bekymrende tanker strejfer mig		**91: Jeg er i godt humør**	
En meget stor del af tiden	3	Overhovedet ikke	3
Meget af tiden	2	Ikke ofte	2
Engang imellem, men ikke så tit	1	Nogle gange	1
Kun engang imellem	0	Det meste af tiden	0
92: Jeg kan sidde roligt og føle mig afslappet		**93: Jeg føler det som om, at jeg virker sløv**	
Helt bestemt	0	Næsten hele tiden	3
For det meste	1	Meget ofte	2
Ikke ofte	2	Somme tider	1
Overhovedet ikke	3	Overhovedet ikke	0
94: Jeg får en slags bange fornemmelser, lige som "sommerfugle" i maven		**95: Jeg har mistet interessen for mit udseende**	
Overhovedet ikke	0	Helt bestemt	3
Ikke ofte	1	Jeg er ikke så omhyggelig, som jeg burde	2
Ret ofte	2	Det interesserer mig ikke så meget som før	1
Meget ofte	3	Jeg er lige så omhyggelig som før	0
96: Jeg føler mig rastløs, som om jeg hele tiden skal være i gang		**97: Jeg ser med glæde frem til tingene**	
I udtalt grad	3	Lige så meget, som jeg altid har gjort	0
En hel del	2	En del mindre, end jeg plejer	1
Ikke så ofte	1	Ikke ret tit	2
Overhovedet ikke	0	Overhovedet ikke	3
98: Jeg kan få pludselige fornemmelser af panik		**99: Jeg kan nyde en god bog, et radio- eller TV-program**	
Absolut og meget ofte	3	Ofte	0
Temmelig ofte	2	Nogle gange	1
Ikke ret tit	1	Ikke ofte	2
Overhovedet ikke	0	Meget sjældent	3

Tilfredshed med behandling, træning og rehabilitering

Vi beder dig tage stilling til, hvor tilfreds du har været med den behandling, træning og rehabilitering, du har modtaget i forbindelse med din apopleksi, samt samarbejdet mellem sygehuset og kommunen i forbindelse med udskrivelsen.

For ***hvert*** spørgsmål bedes du sætte ***én ring*** om det tal, der bedst beskriver, hvor tilfreds eller utilfreds du har været med behandlingen, træningen, rehabiliteringen eller samarbejdet.

Tilfredshed med behandling, træning og rehabilitering	
100 - Hvor tilfreds er du med den træning og rehabilitering, du har modtaget *under din indlæggelse* på sygehuset?	
Meget tilfreds	1
Tilfreds	2
Hverken eller	3
Utilfreds	4
Meget utilfreds	5
Jeg fik ingen træning eller rehabilitering under indlæggelsen	6
101 - Hvor tilfreds er du med den træning og rehabilitering, du har modtaget *efter udskrivelsen* fra sygehuset?	
Meget tilfreds	1
Tilfreds	2
Hverken eller	3
Utilfreds	4
Meget utilfreds	5
Jeg har ikke fået træning eller rehabilitering efter udskrivelsen	6
102 - Alt i alt, hvor tilfreds er du med den behandling og rehabilitering, du har modtaget i forbindelse med din apopleksi?	
Meget tilfreds	1
Tilfreds	2
Hverken eller	3
Utilfreds	4
Meget utilfreds	5

Tilfredshed med samarbejdet mellem sygehus og kommune	
103 - Hvor tilfreds er du med samarbejdet mellem sygehuset og kommunen i forbindelse med udskrivelsen fra sygehuset?	
Meget tilfreds	1
Tilfreds	2
Hverken eller	3
Utilfreds	4
Meget utilfreds	5

Hjælp

	Ja	**Nej**
104 - Har du fået hjælp til at udfylde spørgeskemaet?	1	2

Appendix 4

Questionnaire package on life quality following apoplexy, Danish version

midt
regionmidtjylland

Spørgeskema

Spørgeskema om livskvalitet

- hvordan oplever du din hverdag
et år efter din apopleksi

Regionshospitalet
Hammel Neurocenter

Livskvalitet et år efter en apopleksi

Introduktion

Svarene i dette spørgeskema giver et overblik over, hvordan du har det, hvor tilfreds du er med forskellige områder af dit liv, og hvor godt du klarer dig et år efter din apopleksi. Samtidig belyses din tilknytning til arbejdsmarkedet, dit sociale liv, din uddannelse og hvordan du bor.

Såfremt du ***ikke*** selv er i stand til at besvare spørgeskemaet beder vi om, at en pårørende, en ven, en sundhedsfaglig medarbejder eller en anden, der kender dig godt, besvarer spørgsmålene på siderne 3-5 og samtidig angiver den relation vedkommende har til dig, og hvor ofte I ses. De øvrige spørgsmål i spørgeskemaet skal derefter ***ikke*** besvares. Det tager ca. 3 min. at besvare disse spørgsmål.

Du bedes venligst angive dato for udfyldelse af spørgeskemaet nederst på siden.

Vejledning

Spørgeskemaet indeholder flere skemaer, der skal besvares forskelligt. Derfor er der en vejledning til, hvad hvert enkelt skema indeholder, og hvordan det besvares.

I spørgeskemaet finder du, i de fleste svarmuligheder, fortrykte tal. De har ingen betydning og er ikke et udtryk for høj eller lav værdi på dit svar. Tallene er udelukkende en hjælp, når vi senere skal taste dine svar ind.

Der kan være spørgsmål, som, du måske synes, ligner hinanden. Det skal du blot se bort fra, og besvare spørgsmålene, så godt du kan. **Det er meget vigtigt, at *alle* spørgsmål besvares**

Det tager ca. 30 minutter at udfylde spørgeskemaet.

Returnering af spørgeskemaerne

Du bedes returnere spørgeskemaet i den vedlagte svarkuvert ***så hurtigt som muligt efter modtagelsen.*** Portoen er betalt.

***Tak for din hjælp*!**

ID nr.:	Navn:	Skriv venligst dato for udfyldelse:

Spørgeskema om boligforhold, arbejde og samliv
før og efter en apopleksi

De følgende spørgsmål handler om dine boligforhold, om du bor alene eller sammen med andre og din tilknytning til arbejdsmarkedet. Spørgsmålene handler om disse emner ***før*** du fik din apopleksi, og om hvordan det forholder sig ***i dag***. Med ***før*** mener vi, hvordan dine forhold var, **den dag du fik din hjerneskade**. Du kan fx godt have haft flere forskellige jobs med forskellige arbejdstimer før din skade, men du bedes svare på, hvordan din situation var, den dag du fik din skade. Dette gælder alle spørgsmål, hvor der spørges til tiden ***før*** og ***i dag***.

Vejledning: I spørgeskemaet bedes du sætte ***én ring*** om det tal, der passer bedst til dit svar. For nogle spørgsmål gælder det både for perioden ***før*** din apopleksi og for perioden ***i dag***.

1 - Tilknytning til arbejdsmarkedet

Sæt kun én ring for <u>hver</u> af perioderne
før din apopleksi og i dag

Hvilken tilknytning til arbejdsmarkedet havde du ***før*** din skade, og hvad er din tilknytning til arbejdsmarkedet ***i dag***?	**Før din apopleksi**	**I dag**
• Studerende	1	2
• Ingen tilknytning til arbejdsmarkedet	2	2
• Fuldtidsarbejde	3	3
• Deltidsarbejde • Angiv timer pr. uge: ______________________	4	4
• Efterlønsmodtager eller folkepensionist	5	5
• Førtidspensionist	6	6
• Langtidssygemeldt (sygedagpenge)	7	7
• Arbejdsledig	8	8
• Ved ikke / uoplyst	9	9

2 - Boligforhold

Sæt kun én ring for <u>hver</u> af perioderne
før din apopleksi og i dag

Hvordan boede du ***før*** din apopleksi, og hvordan bor du i ***i dag***?	**Før din apopleksi**	**I dag**
• Egen bolig **uden** behov for hjemmehjælp, hjemmesygepleje eller støtte fra andre	1	1
• Egen bolig **med** behov for hjemmehjælp, hjemmesygepleje eller støtte fra andre	2	2
• Ældrebolig, beskyttet bolig eller bolig med mulighed for tilkald af personale døgnet rundt	3	3
• Plejehjem eller institution med døgnvagt	4	4
• Ved ikke / uoplyst	9	9

3 - Samliv		*Sæt kun én ring for hver af perioderne før din apopleksi og i dag*
	Før din apopleksi	**I dag**
Hvad var din samlivsstatus ***før*** din apopleksi, og hvad er den ***i dag***?		
• Gift eller bor sammen med nogen	1	1
• Enke eller enkemand	2	2
• Bor alene	3	3
• Ved ikke / uoplyst	9	9

Rygning			*Sæt kun én ring for hvert spørgsmål*
	Ja	**Nej**	**Ved ikke/ uoplyst**
4 - Røg du ***før*** du fik din apopleksi?	1	2	9
5 - Ryger du ***i dag***?	1	2	9
6 - Er du ***tidligere*** ryger (røgfri i over 1 måned)	1	2	9

Vi vil gerne vide, om du mener, at du er kommet dig helt efter din skade i hjernen, og om du i forbindelse med dine daglige gøremål får hjælp fra andre.

	Ja	**Nej**
7 - Mener du, at du er kommet dig helt efter din skade i hjernen?	1	2
8 - Får du hjælp fra andre til nogle af dine daglige gøremål?	1	2

Aktuelle symptomer efter apopleksi

I nedenstående tabel beder vi dig angive, i hvor høj grad du har gener og funktionsnedsættelser efter din apopleksi. ***Sæt én ring*** om det tal du mener bedst beskriver din tilstand ***i dag***.

9 - Status efter apopleksi	
Ingen symptomer overhovedet	0
Ingen synlig funktionsnedsættelse Lette symptomer, men ingen helbredsgener i det daglige, trods symptomer. Udfører de samme gøremål som tidligere	1
Nogen funktionsnedsættelse Mindre handicap. Overkommer mindre end tidligere. Opgivet gøremål pga. helbredet. Klarer sig selv uden hjælp	2
Moderat funktionsnedsættelse Moderat handicap. Behøver let hjælp til daglige gøremål	3
Moderat til svær funktionsnedsættelse Behøver meget hjælp til personlig hygiejne, toiletbesøg og andre daglige gøremål	4
Svær Funktionsnedsættelse Behøver konstant opsyn, er sengeliggende, inkontinent, er afhængig af, at der er nogen næsten hele tiden	5
Ukendt	6

Såfremt ovenstående spørgsmål er besvaret af ***en anden end den, der har haft en apopleksi*** bedes du angive din relation til vedkommende, og hvor ofte I ses. Sæt kun én ring ved hvert spørgsmål. Du skal ikke besvare flere spørgsmål i dette spørgeskema. Tak for din hjælp.

10 - Relation	***Sæt kun én ring***
Ægtefælle eller samlever	1
Søn eller datter	2
Ven	3
Sundhedsfaglig medarbejder	4
Anden relation Skriv hvilken: ______________________________	5

11 - Hvor ofte ser du den person, der har haft en apopleksi	***Sæt kun én ring***
Dagligt	1
Mindst én gang om ugen	2
Sjældnere end én gang om ugen	3

Tilfredshed med dit liv efter en hjerneskade

Vi vil gerne vide, hvor tilfreds du er med forskellige dele af dit liv efter din skade i hjernen. Du bedes for hvert spørgsmål sætte kryds ved det svar, der passer bedst til, hvordan du har det nu (inklusiv den seneste uge). Hvis du har vanskeligheder ved at besvare spørgsmålene, så spørg venligst om hjælp fra andre.

Disse spørgsmål handler om, hvordan du har det nu inklusiv den seneste uge.
Sæt *<u>kun et kryds</u>* for hvert spørgsmål.

	Slet ikke tilfreds	Noget utilfreds	Nogenlunde tilfreds	Godt tilfreds	Meget tilfreds
12 - Alt i alt, hvor tilfreds er du med dit fysiske helbred?	1	2	3	4	5
13 - Alt i alt, hvor tilfreds er du med dine evner til at koncentrere dig, huske og tænke?	1	2	3	4	5
14 - Alt i alt, hvor tilfreds er du med dine følelser, og den sindsstemning du har?	1	2	3	4	5
15 - Alt i alt, hvor tilfreds er du med, hvordan du klarer dine daglige gøremål?	1	2	3	4	5
16 - Alt i alt, hvor tilfreds er du med dig selv og dit sociale liv?	1	2	3	4	5
17 - Alt i alt, hvor tilfreds er du med din nuværende situation og dine fremtidsudsigter?	1	2	3	4	5

Livskvalitet efter en skade i hjernen

Dette spørgeskema indeholder tre grupper af spørgsmål:
Første gruppe handler om, hvordan du, indenfor den sidste uge, har klaret dagligdags aktiviteter.
Anden gruppe handler om, hvordan du, indenfor den sidste uge, har oplevet forskellige forhold i dit liv.
Tredje gruppe handler om, hvordan du synes, du har det **nu** sammenlignet med tiden **før** din skade.

Første gruppe – almindelige dagligdags aktiviteter **(Sæt ring om ét tal for hvert spørgsmål)**

	I den sidste uge:	**Kunne slet ikke**	**Meget besvær**	**En del besvær**	**Lidt besvær**	**Intet besvær**
18	Har du haft besvær med at tilberede et måltid?	1	2	3	4	5
19	Har du haft besvær med at spise?	1	2	3	4	5
20	Har du haft besvær med at tage tøj på?	1	2	3	4	5
21	Har du haft besvær med at tage bad?	1	2	3	4	5
22	Har du haft besvær med at gå på toilettet?	1	2	3	4	5
23	Har du haft besvær med at se fjernsyn tydeligt nok?	1	2	3	4	5
24	Har du haft besvær med at række ud efter ting på grund af dårligt syn?	1	2	3	4	5
25	Har du haft besvær med at se ting til den ene side?	1	2	3	4	5
26	Har du haft besvær med at tale?	1	2	3	4	5
27	Har du haft besvær med at tale klart og tydeligt i telefon?	1	2	3	4	5
28	Har andre mennesker haft besvær med at forstå, hvad du sagde?	1	2	3	4	5
29	Har du haft besvær med at finde de ord, du gerne ville sige?	1	2	3	4	5
30	Har du været nødt til at gentage dig selv for at andre kunne forstå, hvad du sagde?	1	2	3	4	5
31	Har du haft besvær med at gå? (Sæt ring omkring 1, hvis du **ikke** kan gå, og fortsæt med spørgsmål **34**)	1	2	3	4	5
32	Har du haft besvær med at holde balancen, når du lænede dig frem eller rakte ud efter noget?	1	2	3	4	5
33	Har du haft besvær med at gå op ad trapper?	1	2	3	4	5
34	Har du haft besvær, fordi du var nødt til at holde en pause, mens du gik eller kørte i kørestol?	1	2	3	4	5
35	Har du haft besvær med at stå oprejst?	1	2	3	4	5

	I den sidste uge:	Kunne slet ikke	Meget besvær	En del besvær	Lidt besvær	Intet besvær
36	Har du haft besvær med at komme op fra en stol?	1	2	3	4	5
37	Har du haft besvær med at klare de daglige gøremål i hjemmet?	1	2	3	4	5
38	Har du haft besvær med at gøre det færdigt, som du var begyndt på?	1	2	3	4	5
39	Har du haft besvær med at udføre de opgaver, som du plejer?	1	2	3	4	5
40	Har du haft besvær med at skrive i hånden eller på maskine?	1	2	3	4	5
41	Har du haft besvær med at tage strømper på?	1	2	3	4	5
42	Har du haft besvær med at knappe knapper?	1	2	3	4	5
43	Har du haft besvær med at åbne en mælkekarton?	1	2	3	4	5
44	Har du haft besvær med at åbne glas med skruelåg?	1	2	3	4	5

I den næste gruppe spørgsmål bedes du angive, hvorvidt du er enig eller uenig i de forskellige udsagn. Hvert udsagn berører problemer, som nogle oplever efter en skade i hjernen. Sæt én ring omkring tallet i den rubrik, der bedst beskriver, hvor enig eller uenig du er.

Anden gruppe – oplevelser **(Sæt ring om ét tal for hvert spørgsmål)**

	I den sidste uge:	Helt enig	Delvist enig	Hverken enig eller uenig	Delvist uenig	Helt uenig
45	Jeg har haft svært ved at koncentrere mig	1	2	3	4	5
46	Jeg har haft svært ved at huske ting	1	2	3	4	5
47	Jeg har været nødt til at skrive ting ned for at huske dem	1	2	3	4	5
48	Jeg har været irritabel	1	2	3	4	5
49	Jeg har været utålmodig over for andre	1	2	3	4	5
50	Min personlighed har ændret sig	1	2	3	4	5
51	Jeg har følt mig modløs med hensyn til fremtiden	1	2	3	4	5
52	Jeg har været uinteresseret i andre mennesker eller aktiviteter	1	2	3	4	5
53	Jeg har deltaget mindre i fornøjelser med min familie	1	2	3	4	5

	I den sidste uge:	Helt enig	Delvist enig	Hverken enig eller uenig	Delvist uenig	Helt uenig
54	Jeg har følt, at jeg var en byrde for min familie	1	2	3	4	5
55	Min fysiske tilstand har påvirket mit familieliv	1	2	3	4	5
56	Jeg er gået mindre i byen, end jeg gerne ville	1	2	3	4	5
57	Jeg har beskæftiget mig med mine fritidsinteresser i kortere perioder, end jeg gerne ville	1	2	3	4	5
58	Jeg har været sammen med færre af mine venner end jeg gerne ville	1	2	3	4	5
59	Jeg har dyrket mindre sex, end jeg gerne ville	1	2	3	4	5
60	Min fysiske tilstand har påvirket mit sociale liv	1	2	3	4	5
61	Jeg har følt mig isoleret fra andre mennesker	1	2	3	4	5
62	Min selvtillid har været lille	1	2	3	4	5
63	Jeg har været uinteresseret i mad	1	2	3	4	5
64	Jeg har følt mig træt det meste af tiden	1	2	3	4	5
65	Jeg har været nødt til at hvile mig ofte i løbet af dagen	1	2	3	4	5
66	Jeg har været for træt til at gøre det, jeg gerne ville	1	2	3	4	5

Svarene på den sidste gruppe spørgsmål handler om, hvordan du synes du har det ***nu*** sammenlignet med tiden ***før*** din skade i hjernen. Sæt én ring om det tal i den rubrik, der bedst beskriver din tilstand nu.

Tredje gruppe - nu sammenlignet med før skaden **(Sæt ring om ét tal for hvert spørgsmål)**

		Meget ændret	Noget ændret	Lidt ændret	Uændret
67	Min personlighed er	1	2	3	4

		Meget dårligere end før	Noget dårligere end før	Lidt dårligere end før	Uændret
68	Mit energiniveau er	1	2	3	4
69	Min taleevne er	1	2	3	4
70	Min gang er	1	2	3	4

		Meget dårligere end før	**Noget dårligere end før**	**Lidt dårligere end før**	**Uændret**
71	Mit syn er	1	2	3	4
72	Mine arme og hænder fungerer	1	2	3	4
73	Min tænkeevne er	1	2	3	4
74	Mit humør er	1	2	3	4
75	Jeg udfører mine opgaver derhjemme eller på mit arbejde	1	2	3	4
76	Jeg klarer mig selv	1	2	3	4
77	Jeg gør noget for min familie	1	2	3	4
78	Jeg gør noget for mine venner	1	2	3	4
79	Alt i alt er min livskvalitet	1	2	3	4

Helbredstilstand

For ***hver*** af de fem spørgsmål bedes du sætte ***én ring*** om det tal, der bedst beskriver din helbredstilstand i dag.

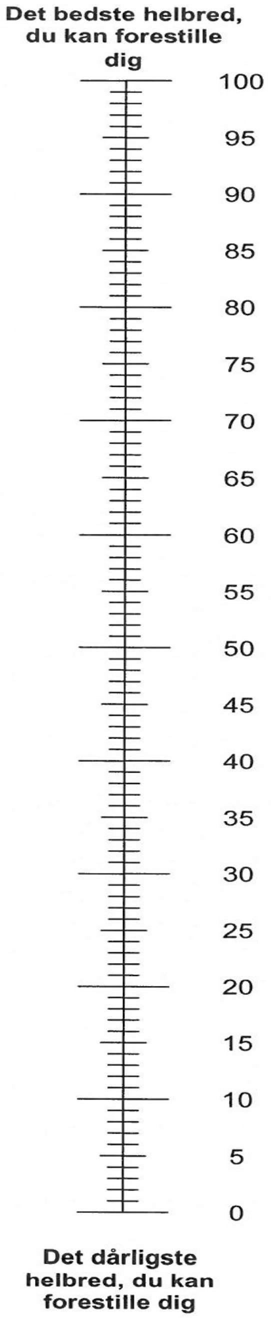
Helbredstilstand	
80 - Bevægelighed	
Jeg har ingen problemer med at gå omkring	1
Jeg har nogle problemer med at gå omkring	2
Jeg er bundet til sengen	3
81 - Personlig pleje	
Jeg har ingen problemer med min personlige pleje	1
Jeg har nogle problemer med min personlige pleje	2
Jeg kan ikke vaske mig eller klæde mig på	3
82 - Sædvanlige aktiviteter (fx arbejde, studie, husarbejde, familie- eller fritidsaktiviteter)	
Jeg har ingen problemer med at udføre mine sædvanlige aktiviteter	1
Jeg har nogle problemer med at udføre mine sædvanlige aktiviteter	2
Jeg kan ikke udføre mine sædvanlige aktiviteter	3
83 - Smerter / ubehag	
Jeg har ingen smerter eller ubehag	1
Jeg har moderate smerter eller ubehag	2
Jeg har ekstreme smerter eller ubehag	3
84 - Angst / depression	
Jeg er ikke ængstelig eller deprimeret	1
Jeg er moderat ængstelig eller deprimeret	2
Jeg er ekstremt ængstelig eller deprimeret	3

Helbredstilstand - fortsat

85 - På nedenstående skala beder vi dig angive, hvor god eller dårlig du mener din helbredstilstand er ***i dag***. Angiv dette ved at tegne en streg fra den sorte kasse til et hvilket som helst punkt på skalaen, der viser, hvor god eller dårlig du mener din helbredstilstand er ***i dag***.

Den bedste helbredstilstand du kan forestille dig er markeret med 100, og den værste helbredstilstand er markeret med 0.

Din
helbredstilstand
i dag



Helbredstilstand - fortsat

Dette skema undersøger, hvordan du har det.
Læs ***hvert*** spørgsmål og sæt ***én ring*** om det tal, der bedst beskriver, hvordan du har haft det følelsesmæssigt inden for ***den sidste uge.***

86: Jeg er anspændt eller stresset		**87: Jeg glæder mig stadig over de ting, jeg plejede at glæde mig over**	
Det meste af tiden	3	Helt bestemt	0
Meget af tiden	2	Ikke helt så meget	1
Engang imellem	1	Kun lidt	2
Overhovedet ikke	0	Næsten ikke	3
88: Jeg får en slags skræmmende fornemmelse, som om noget forfærdeligt skal til at ske		**89: Jeg kan le og se tingene fra den morsomme side**	
Helt bestemt og temmelig slemt	3	Lige så meget som jeg altid har kunnet	0
Ja, men ikke alt for slemt	2	Ikke helt så meget nu	1
En smule, men det bekymrer mig ikke	1	Bestemt ikke så meget nu	2
Overhovedet ikke	0	Overhovedet ikke	3
90: Bekymrende tanker strejfer mig		**91: Jeg er i godt humør**	
En meget stor del af tiden	3	Overhovedet ikke	3
Meget af tiden	2	Ikke ofte	2
Engang imellem, men ikke så tit	1	Nogle gange	1
Kun engang imellem	0	Det meste af tiden	0
92: Jeg kan sidde roligt og føle mig afslappet		**93: Jeg føler det som om, at jeg virker sløv**	
Helt bestemt	0	Næsten hele tiden	3
For det meste	1	Meget ofte	2
Ikke ofte	2	Somme tider	1
Overhovedet ikke	3	Overhovedet ikke	0
94: Jeg får en slags bange fornemmelser, lige som "sommerfugle" i maven		**95: Jeg har mistet interessen for mit udseende**	
Overhovedet ikke	0	Helt bestemt	3
Ikke ofte	1	Jeg er ikke så omhyggelig, som jeg burde	2
Ret ofte	2	Det interesserer mig ikke så meget som før	1
Meget ofte	3	Jeg er lige så omhyggelig som før	0
96: Jeg føler mig rastløs, som om jeg hele tiden skal være i gang		**97: Jeg ser med glæde frem til tingene**	
I udtalt grad	3	Lige så meget, som jeg altid har gjort	0
En hel del	2	En del mindre, end jeg plejer	1
Ikke så ofte	1	Ikke ret tit	2
Overhovedet ikke	0	Overhovedet ikke	3
98: Jeg kan få pludselige fornemmelser af panik		**99: Jeg kan nyde en god bog, et radio- eller TV-program**	
Absolut og meget ofte	3	Ofte	0
Temmelig ofte	2	Nogle gange	1
Ikke ret tit	1	Ikke ofte	2
Overhovedet ikke	0	Meget sjældent	3

Tilfredshed med behandling, træning og rehabilitering

Vi beder dig tage stilling til, hvor tilfreds du har været med den behandling, træning og rehabilitering, du har modtaget i forbindelse med din apopleksi.

For ***hvert*** spørgsmål bedes du sætte ***én ring*** om det tal, der bedst beskriver, hvor tilfreds eller utilfreds du har været med behandlingen, træningen eller rehabiliteringen.

Tilfredshed med træning og rehabilitering	
100 - Hvor tilfreds er du med den træning og rehabilitering, du har modtaget *under din indlæggelse* på sygehuset?	
Meget tilfreds	1
Tilfreds	2
Hverken eller	3
Utilfreds	4
Meget utilfreds	5
Jeg fik ingen træning eller rehabilitering under indlæggelsen	6
101 - Hvor tilfreds er du med den træning og rehabilitering, du har modtaget *efter udskrivelsen* fra sygehuset?	
Meget tilfreds	1
Tilfreds	2
Hverken eller	3
Utilfreds	4
Meget utilfreds	5
Jeg har ikke fået træning eller rehabilitering efter udskrivelsen	6
102 - Alt i alt, hvor tilfreds er du med den behandling og rehabilitering, du har modtaget i forbindelse med din apopleksi?	
Meget tilfreds	1
Tilfreds	2
Hverken eller	3
Utilfreds	4
Meget utilfreds	5
103 - Har du modtaget træning eller rehabilitering i perioden fra 3 måneder efter din apopleksi?	
Ja	1
Nej	2
104 - hvis ja, modtager du så træning eller rehabilitering nu?	
Ja	1
Nej	2

Hjælp

	Ja	**Nej**
105 - Har du fået hjælp til at udfylde spørgeskemaet?	1	2

Appendix 5

Questionnaire package – three months, Norwegian version

Livet etter hjerneslag

Rehabiliteringsforløp, funksjon og livskvalitet 3 måneder etter hjerneslag.

En studie i Norge og Danmark

Pasientidentifikasjon:

Introduksjon og formål med undersøkelsen

Dette er en spørreundersøkelse for å vurdere funksjon og livskvalitet tre måneder etter hjerneslag. Spørreskjemaet sendes til personer som har gjennomgått hjerneslag i utvalgte kommuner i Nord-Norge og i Midt-Jylland i Danmark.

Svarene i dette spørreskjema gir et overblikk over hvor fornøyd du er med livet ditt og hvor godt du klarer daglige gjøremål tre måneder etter hjerneslaget. Vi ønsker også informasjon om ditt sosiale liv, arbeid, utdannelse, bosituasjon og hvor tilfreds du er med behandlings- og rehabiliteringstilbudet. Alle personlige opplysninger vil bli anonymisert.

Dersom du ***ikke*** selv klarer å besvare spørreskjemaet, ber vi om at en pårørende, en venn eller en fagperson som kjenner deg godt, svarer på spørsmålene på side 2-4. Vi ber også om at den som fyller ut opplyser om hvilken relasjon vedkommende har til deg, og hvor ofte dere møtes. Øvrige spørsmål i spørreskjemaet skal da ***ikke*** besvares. Det tar ca. 3 minutter å besvare disse spørsmålene.

Veiledning

Spørreskjemaet inneholder flere typer spørsmål som skal besvares ulikt. Vennligst les instruksjonen for hvert skjema nøye.

Det kan være spørsmål som ligner hverandre. Det skal du se bort fra, og besvare alle spørsmålene etter beste evne. ***Det er viktig at alle spørsmål besvares.***

Det tar ca. 30 min å fylle ut spørreskjemaet.

Returnering av spørreskjemaet

Du bes om å returnere spørreskjemaet i den vedlagte svarkonvolutten, senest . . . .
Porto er forhåndsbetalt.

Takk for hjelpen!

Dato for utfylling:

Spørsmål om utdanning, arbeid, bolig og sivilstatus

I spørreskjemaet ber vi deg om å sette et kryss for det svaret som passer best for deg. For noen spørsmål gjelder det både for perioden ***før*** hjerneslaget og perioden ***i dag***. Med ***før*** mener vi hvordan situasjonen var ***den dagen du fikk hjerneslag***. For eksempel skal du opplyse om hvilken arbeidssituasjon du var i den dagen du fikk slaget, og ikke ta med opplysninger om tidligere arbeid. Dette gjelder alle spørsmål der vi spør etter ***før*** og ***i dag***.

UTDANNING

- ☐ Mindre enn 7 år
- ☐ 8-10 år (grunnskole)
- ☐ 11-14 år (videregående, yrkesutdanning)
- ☐ Over 14 år (høgskole eller universitetsutdanning)

ARBEID ELLER TRYGDEYTELSER

Før hjerneslaget	I dag	
☐	☐	Student
☐	☐	Hjemmeværende
☐	☐	I full jobb
☐	☐	I deltidsjobb, vennligst oppgi timeantall pr. uke:
☐	☐	Alderspensjonist
☐	☐	Uførepensjonist
☐	☐	Sykemeldt
☐	☐	Arbeidsledig

BOLIG

Før hjerneslaget	I dag	
☐	☐	Egen bolig ***uten*** behov for hjemmehjelp, hjemmesykepleie eller støtte fra andre
☐	☐	Egen bolig ***med*** behov for hjemmehjelp, hjemmesykepleie eller støtte fra andre
☐	☐	Eldrebolig, omsorgsbolig eller bolig med mulighet for å tilkalle personale
☐	☐	Sykehjem eller institusjon med fast personale

SIVILSTATUS

Før hjerneslaget	I dag	
☐	☐	Gift eller samboer
☐	☐	Enke eller enkemann
☐	☐	Bor alene

RØYKING

Ja	Nei	
☐	☐	Røkte du før du fikk hjerneslag?
☐	☐	Røyker du i dag?
☐	☐	Er du tidligere røyker (røykfri i mer enn 1 måned)?

Vi vil gjerne vite om du synes du har kommet deg helt etter hjerneslaget, og om du får hjelp av andre til daglige gjøremål.

Ja	Nei	
☐	☐	Synes du at du har kommet deg helt etter hjerneslaget?
☐	☐	Får du hjelp av andre til noen av dine daglige gjøremål?

Relasjoner

Dersom spørsmålene ovenfor er besvart ***av en annen enn den som har hatt hjerneslag,*** ber vi om at du opplyser om din relasjon til vedkommende, og hvor hyppig dere møtes. Sett bare ***et*** kryss for hvert spørsmål. Du skal ikke besvare resten av spørsmålene i dette spørreskjemaet. Takk for hjelpen.

RELASJON

- ☐ Ektefelle eller samboer
- ☐ Sønn eller datter
- ☐ Venn
- ☐ Helsearbeider
- ☐ Annen relasjon. Angi hvilken:

KONTAKTHYPPIGHET

Hvor ofte treffer du den som har hatt et hjerneslag?

- ☐ Daglig
- ☐ Minst 1 gang i uken
- ☐ Sjeldnere enn 1 gang i uken

Tilfredshet med livet etter hjerneslag

Vi ønsker å vite hvor fornøyd du er med forskjellige deler av livet ditt etter hjerneslaget

Du bes om for hvert spørsmål å sette kryss ved det svaret som passer best til hvordan du har det nå (den siste uken). Sett bare ett kryss for hvert spørsmål.

	Ikke i det hele tatt	Litt fornøyd	Moderat fornøyd	Ganske fornøyd	Meget fornøyd
Alt i alt, hvor fornøyd er du med din fysiske helse?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med dine evner til å konsentrere deg, huske og tenke?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med dine følelser og den sinnsstemning du har?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med hvordan du klarer dine daglige gjøremål?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med ditt personlige og sosiale liv?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med din nåværende situasjon og dine framtidsutsikter?	☐	☐	☐	☐	☐

Referanse: von Steinbüechel N. et al. QOLIBRI- OS (2012)

Livskvalitet etter hjerneslag

Dette skjema handler om daglige aktiviteter, erfaringer og om hvordan du har det ***nå*** sammenlignet med ***før*** hjerneslaget. Alle spørsmål gjelder opplevelsene du har hatt den siste uken.

Vanlige daglige aktiviteter

Sett ***ett*** kryss for hvert spørsmål om hvordan du har klart daglige aktiviteter den siste uken.

	Den siste uken:	Kunne overhodet ikke	Store problem	Noe problem	Lette problem	Ingen problem
1	Hadde du problemer med å tilberede et måltid?	☐	☐	☐	☐	☐
2	Hadde du problemer med å spise?	☐	☐	☐	☐	☐
3	Hadde du problemer med påkledning?	☐	☐	☐	☐	☐
4	Hadde du problemer med å ta et bad eller en dusj?	☐	☐	☐	☐	☐
5	Hadde du problemer med å gå på toalettet?	☐	☐	☐	☐	☐
6	Hadde du problemer med å se tydelig nok på tv?	☐	☐	☐	☐	☐

	Den siste uken:	Kunne overhodet ikke	Store problem	Noe problem	Lette problem	Ingen problem
7	Hadde du problemer med å strekke deg etter ting på grunn av dårlig syn?	☐	☐	☐	☐	☐
8	Hadde du problemer med å se ting på den ene siden av synsfeltet?	☐	☐	☐	☐	☐
9	Hadde du problemer med å snakke?	☐	☐	☐	☐	☐
10	Hadde du problemer med å snakke klart og tydelig i telefon?	☐	☐	☐	☐	☐
11	Hadde andre mennesker problemer med å forstå hva du sa?	☐	☐	☐	☐	☐
12	Hadde du problemer med å finne ord som du ville si?	☐	☐	☐	☐	☐
13	Måtte du gjenta deg selv slik at andre kunne forstå deg?	☐	☐	☐	☐	☐
14	Hadde du problemer med å gå? (Sett kryss i “Kunne overhodet ikke” hvis du ikke kan gå, og fortsett på spørsmål 17.)	☐	☐	☐	☐	☐
15	Hadde du problemer med å holde balansen når du lente deg frem eller strakk deg etter noe?	☐	☐	☐	☐	☐
16	Hadde du problemer med å gå opp trapper?	☐	☐	☐	☐	☐
17	Hadde du behov for å ta pause mens du gikk eller brukte rullestol?	☐	☐	☐	☐	☐
18	Hadde du problemer med å stå?	☐	☐	☐	☐	☐
19	Hadde du problemer med å reise deg fra en stol?	☐	☐	☐	☐	☐
20	Hadde du problemer med å klare de daglige gjøremål i hjemmet?	☐	☐	☐	☐	☐
21	Hadde du problemer med å gjøre ferdig oppgaver du hadde begynt på?	☐	☐	☐	☐	☐
22	Hadde du problemer med å utføre de oppgaver som du pleier?	☐	☐	☐	☐	☐
23	Hadde du problemer med å skrive for hånd eller bruke tastatur?	☐	☐	☐	☐	☐
24	Hadde du problemer med å ta på sokker?	☐	☐	☐	☐	☐
25	Hadde du problemer med å kneppe knapper?	☐	☐	☐	☐	☐
26	Hadde du problemer med å bruke glidelås?	☐	☐	☐	☐	☐
27	Hadde du problemer med å åpne et glass med skrulokk?	☐	☐	☐	☐	☐

Erfaringer den siste uken

Hvert utsagn berører problemer som man kan oppleve etter hjerneslag. Her skal du angi hvorvidt du er enig eller uenig i utsagnene nedenfor. Alle utsagn gjelder den siste uken.

Sett ***ett*** kryss for hvert spørsmål

	Den siste uken:	Helt enig	Delvis enig	Verken enig eller uenig	Delvis uenig	Helt uenig
28	Jeg hadde problemer med å konsentrere meg.	☐	☐	☐	☐	☐
29	Jeg hadde problemer med å huske ting	☐	☐	☐	☐	☐
30	Jeg måtte skrive ned ting for å huske dem	☐	☐	☐	☐	☐
31	Jeg var irritabel	☐	☐	☐	☐	☐
32	Jeg var utålmodig med andre	☐	☐	☐	☐	☐
33	Personligheten min har endret seg	☐	☐	☐	☐	☐
34	Jeg følte meg motløs med tanke på fremtiden	☐	☐	☐	☐	☐
35	Jeg var ikke interessert i andre mennesker eller aktiviteter	☐	☐	☐	☐	☐
36	Jeg deltok mindre i lystbetonte aktiviteter med min familie	☐	☐	☐	☐	☐
37	Jeg følte at jeg var en byrde for min familie	☐	☐	☐	☐	☐
38	Min fysiske tilstand påvirket mitt familieliv	☐	☐	☐	☐	☐
39	Jeg gikk ikke ut så ofte som jeg ønsket	☐	☐	☐	☐	☐
40	Jeg brukte mindre tid på fritidsinteresser enn jeg ville	☐	☐	☐	☐	☐
41	Jeg traff ikke så mange av mine venner som jeg ville	☐	☐	☐	☐	☐
42	Jeg hadde sex mer sjelden enn jeg ønsket	☐	☐	☐	☐	☐
43	Min fysiske tilstand påvirket mitt sosiale liv	☐	☐	☐	☐	☐
44	Jeg følte meg isolert fra andre mennesker	☐	☐	☐	☐	☐
45	Jeg hadde lite selvtillit	☐	☐	☐	☐	☐
46	Jeg hadde liten matlyst	☐	☐	☐	☐	☐
47	Jeg følte meg trøtt mesteparten av tiden	☐	☐	☐	☐	☐
48	Jeg måtte ofte hvile meg i løpet av dagen	☐	☐	☐	☐	☐
49	Jeg var for trøtt til å gjøre det jeg ville	☐	☐	☐	☐	☐

Endringer etter hjerneslaget

Her skal du svare på hvordan du har det nå, sammenlignet med tiden før hjerneslaget.

Sett ***ett*** kryss på det svaret som best beskriver din tilstand nå.

		Betydelig endret	Noe endret	Litt endret	Uendret
50	Min personlighet er	☐	☐	☐	☐

		Mye dårligere enn før	Noe dårligere enn før	Litt dårligere enn før	Uendret
51	Energinivået mitt er	☐	☐	☐	☐
52	Språkevnen min er	☐	☐	☐	☐
53	Gangfunksjonen min er	☐	☐	☐	☐
54	Synet mitt er	☐	☐	☐	☐
55	Armene og hendene mine fungerer	☐	☐	☐	☐
56	Min evne til å tenke er	☐	☐	☐	☐
57	Humøret mitt er	☐	☐	☐	☐
58	Jeg utfører oppgavene mine i hjemmet eller på arbeid	☐	☐	☐	☐
59	Jeg klarer meg selv	☐	☐	☐	☐
60	Jeg gjør noe for familien min	☐	☐	☐	☐
61	Jeg gjør noe for vennene mine	☐	☐	☐	☐
62	Alt i alt er min livskvalitet	☐	☐	☐	☐

Stroke Specific Quality of Life Scale - DK (Muus I. et al. 2005)

Sinnsstemning/følelser

Dette skjemaet undersøker hvordan du har hatt det den siste uken. Sett ***ett*** kryss ved det svaret som best beskriver dine følelser. Ikke tenk for lenge på svaralternativene – de spontane svarene er best.

1. Jeg føler meg nervøs og urolig

- ☐ Mesteparten av tiden
- ☐ Mye av tiden
- ☐ Fra tid til annen
- ☐ Ikke i det hele tatt

2. Jeg gleder meg fortsatt over tingene slik jeg pleide før

- ☐ Avgjort like mye
- ☐ Ikke fullt så mye
- ☐ Bare lite grann
- ☐ Ikke i det hele tatt

3. Jeg har en urofølelse som om noe forferdelig vil skje

- ☐ Ja, og noe svært ille
- ☐ Ja, ikke så veldig ille
- ☐ Litt, bekymrer meg lite
- ☐ Ikke i det hele tatt

5. Jeg har hodet fullt av bekymringer

- ☐ Veldig ofte
- ☐ Ganske ofte
- ☐ Av og til
- ☐ En gang i blant

7. Jeg kan sitte i fred og ro og kjenne meg avslappet

- ☐ Ja, helt klart
- ☐ Vanligvis
- ☐ Ikke så ofte
- ☐ Ikke i det hele tatt

9. Jeg føler meg urolig som om jeg har sommerfugler i magen

- ☐ Ikke i det hele tatt
- ☐ Fra tid til annen
- ☐ Ganske ofte
- ☐ Svært ofte

11. Jeg er rastløs som om jeg stadig må være aktiv

- ☐ Uten tvil svært mye
- ☐ Ganske mye
- ☐ Ikke så veldig mye
- ☐ Ikke i det hele tatt

13. Jeg kan plutselig få en følelse av panikk

- ☐ Uten tvil svært ofte
- ☐ Ganske ofte
- ☐ Ikke så veldig ofte
- ☐ Ikke i det hele tatt

4. Jeg kan le og se det morsomme i situasjoner

- ☐ Like mye nå som før
- ☐ Ikke like mye nå som før
- ☐ Avgjort ikke som før
- ☐ Ikke i det hele tatt

6. Jeg er i godt humør

- ☐ Aldri
- ☐ Noen ganger
- ☐ Ganske ofte
- ☐ For det meste

8. Jeg føler meg som om alt går langsommere

- ☐ Nesten hele tiden
- ☐ Svært ofte
- ☐ Fra tid til annen
- ☐ Ikke i det hele tatt

10. Jeg bryr meg ikke lengre om hvordan jeg ser ut

- ☐ Ja, jeg har sluttet å bry meg
- ☐ Ikke som jeg burde
- ☐ Kan hende ikke nok
- ☐ Bryr meg som før

12. Jeg ser med glede frem til hendelser og ting

- ☐ Like mye som før
- ☐ Heller mindre enn før
- ☐ Avgjort mindre enn før
- ☐ Nesten ikke i det hele tatt

14. Jeg kan glede meg over gode bøker, radio og tv

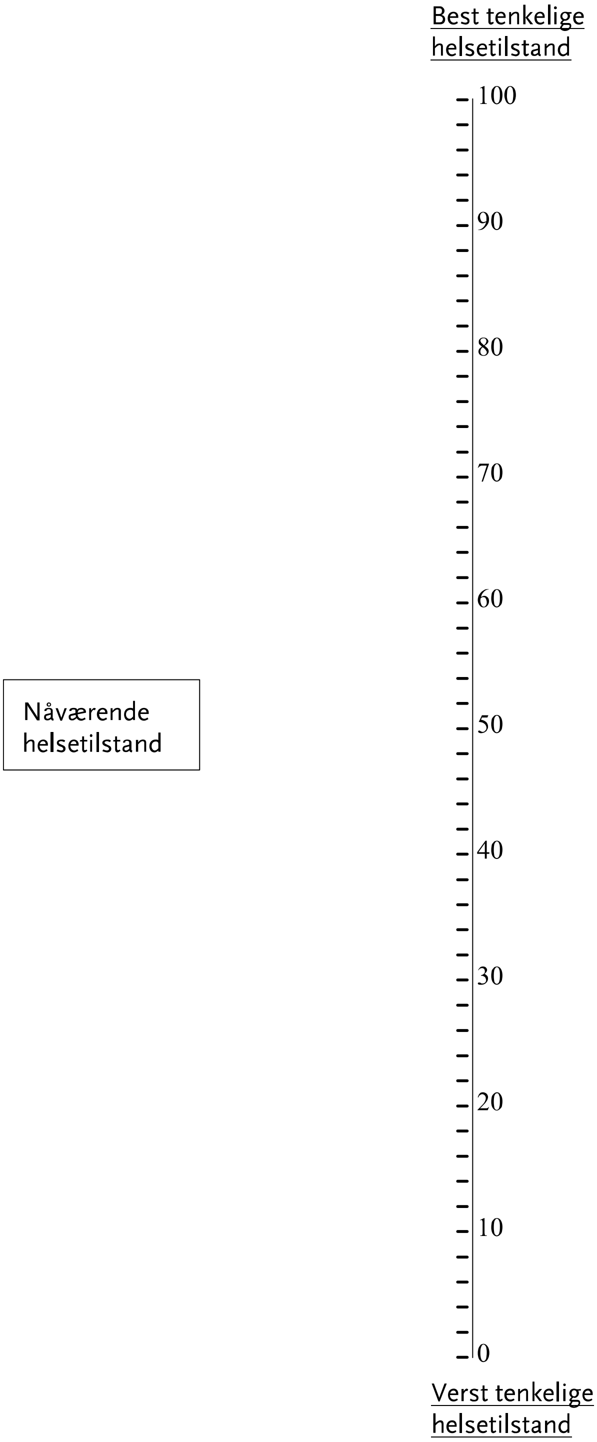
- ☐ Ofte
- ☐ Fra tid til annen
- ☐ Ikke så ofte
- ☐ Svært sjelden

HAD (Zigmond og Snaith 1983)

HELSETILSTAND

På skalaen nedenfor ber vi deg om å markere hvor god eller dårlig din helsetilstand er i dag. Du angir dette, ved å tegne en strek fra boksen til det punkt på skalaen.

Den beste helsetilstanden du kan forestille deg er markert med “100”, og den verst tenkelige helsetilstanden er markert med “0”



Beskrivelse av helsetilstand

Her finner du fem ulike tema med tre ulike svaralternativer. Sett ***ett*** kryss for det svaralternativet som best beskriver din helsetilstand i dag.

1. Gange

- ☐ Jeg har ingen problemer med å gå omkring
- ☐ Jeg har litt problemer med å gå omkring
- ☐ Jeg er sengeliggende

2. Personlig stell

- ☐ Jeg har ingen problemer med personlig stell
- ☐ Jeg har litt problemer med å vaske meg eller kle på meg
- ☐ Jeg er ute av stand til å vaske meg eller kle på meg

3. Vanlige gjøremål

- ☐ Jeg har ingen problemer med å utføre mine vanlige gjøremål
- ☐ Jeg har litt problemer med å utføre mine vanlige gjøremål
- ☐ Jeg er ute av stand til å utføre mine vanlige gjøremål

4. Smerte og ubehag

- ☐ Jeg har verken smerte eller ubehag
- ☐ Jeg har moderate smerter eller ubehag
- ☐ Jeg har sterke smerter eller ubehag

5. Angst og depresjon

- ☐ Jeg er verken engstelig eller deprimert
- ☐ Jeg er noe engstelig eller deprimert
- ☐ Jeg er svært engstelig eller deprimert

EQ 5D the EuroQol Group 1990

Tilfredshet med behandling og rehabilitering

I dette skjemaet skal du svare på hvor tilfreds du er med behandlingen, treningen og rehabiliteringstilbudet som du har fått i forbindelse med hjerneslaget.

Sett ***ett*** kryss for hvert av de tre spørsmålene.

Hvor tilfreds er du med treningen og rehabiliteringen du fikk *under innleggelse* på sykehuset?

- ☐ Meget fornøyd
- ☐ Fornøyd
- ☐ Verken fornøyd eller misfornøyd
- ☐ Misfornøyd
- ☐ Meget misfornøyd
- ☐ Jeg fikk ikke trening eller rehabilitering under innleggelse

Hvor tilfreds er du med treningen og rehabiliteringen du fikk *etter utskrivelse* fra sykehuset?

- ☐ Meget fornøyd
- ☐ Fornøyd
- ☐ Verken fornøyd eller misfornøyd
- ☐ Misfornøyd
- ☐ Meget misfornøyd
- ☐ Jeg fikk ikke trening eller rehabilitering etter utskrivelse

Hvor tilfreds er du med samarbeidet mellom sykehus og kommune i forbindelse med utskrivelse fra sykehuset?

- ☐ Meget fornøyd
- ☐ Fornøyd
- ☐ Verken fornøyd eller misfornøyd
- ☐ Misfornøyd
- ☐ Meget misfornøyd

Alt i alt, hvor fornøyd er du med behandlingen og rehabiliteringen etter hjerneslaget?

- ☐ Meget fornøyd
- ☐ Fornøyd
- ☐ Verken fornøyd eller misfornøyd
- ☐ Misfornøyd
- ☐ Meget misfornøyd

Hjelp til utfylling

Ja	Nei	
☐	☐	Har du fått hjelp til utfylling av spørreskjemaet

Takk for hjelpen!

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Appendix 6

Questionnaire package – 12 months, Norwegian version

Livet etter hjerneslag

Rehabiliteringsforløp, funksjon og livskvalitet 12 måneder etter hjerneslag.

En studie i Norge og Danmark

Pasientidentifikasjon:

Introduksjon og formål med undersøkelsen

Dette er en spørreundersøkelse for å vurdere funksjon og livskvalitet tolv måneder etter hjerneslag. Spørreskjemaet sendes til personer som har gjennomgått hjerneslag i utvalgte kommuner i Nord-Norge og i Midt-Jylland i Danmark.

Svarene i dette spørreskjema gir et overblikk over hvor fornøyd du er med livet ditt og hvor godt du klarer daglige gjøremål tolv måneder etter hjerneslaget. Vi ønsker også informasjon om ditt sosiale liv, arbeid, utdannelse, bosituasjon og hvor tilfreds du er med behandlings- og rehabiliteringstilbudet. Alle personlige opplysninger vil bli anonymisert.

Dersom du ***ikke*** selv klarer å besvare spørreskjemaet, ber vi om at en pårørende, en venn eller en fagperson som kjenner deg godt, svarer på spørsmålene på side 3-4. Vi ber også om at den som fyller ut opplyser om hvilken relasjon vedkommende har til deg, og hvor ofte dere møtes. Øvrige spørsmål i spørreskjemaet skal da ***ikke*** besvares. Det tar ca. 3 minutter å besvare disse spørsmålene.

Veiledning

Spørreskjemaet inneholder flere typer spørsmål som skal besvares ulikt. Vennligst les instruksjonen for hvert skjema nøye.

Det kan være spørsmål som ligner hverandre. Det skal du se bort fra, og besvare alle spørsmålene etter beste evne. ***Det er viktig at alle spørsmål besvares.***

Det tar ca. 30 min å fylle ut spørreskjemaet.

Returnering av spørreskjemaet

Du bes om å returnere spørreskjemaet i den vedlagte svarkonvolutten, senest . . . .
Porto er forhåndsbetalt.

Takk for hjelpen!

Dato for utfylling:

Spørsmål om utdanning, arbeid, bolig og sivilstatus

I spørreskjemaet ber vi deg om å sette et kryss for det svaret som passer best for deg. For noen spørsmål gjelder det både for perioden ***før*** hjerneslaget og perioden ***i dag***. Med ***før*** mener vi hvordan situasjonen var ***dagen før du fikk hjerneslag***. For eksempel skal du opplyse om hvilken arbeidssituasjon du var i dagen før du fikk slaget, og ikke ta med opplysninger om tidligere arbeid. Dette gjelder alle spørsmål der vi spør etter ***før*** og ***i dag***.

ARBEID ELLER TRYGDEYTELSER

Før hjerneslaget	I dag	
☐	☐	Student
☐	☐	Hjemmeværende
☐	☐	I full jobb
☐	☐	I deltidsjobb, vennligst oppgi timeantall pr. uke:
☐	☐	Alderspensjonist
☐	☐	Uførepensjonist
☐	☐	Sykemeldt
☐	☐	Arbeidsledig

BOLIG (Angi hvilken type bolig du bodde i før hjerneslaget, og hvilken type bolig du bor i nå)

Før hjerneslaget	I dag	
☐	☐	Egen bolig ***uten*** behov for hjemmehjelp, hjemmesykepleie eller støtte fra andre
☐	☐	Egen bolig ***med*** behov for hjemmehjelp, hjemmesykepleie eller støtte fra andre
☐	☐	Eldrebolig, omsorgsbolig eller bolig med mulighet for å tilkalle personale
☐	☐	Sykehjem eller institusjon med fast personale

SIVILSTATUS

Før hjerneslaget	I dag	
☐	☐	Gift eller samboer
☐	☐	Enke eller enkemann
☐	☐	Bor alene

RØYKING

Ja	Nei	
☐	☐	Røkte du før du fikk hjerneslag?
☐	☐	Røyker du i dag?
☐	☐	Er du tidligere røyker (røykfri i mer enn 1 måned)?

Vi vil gjerne vite om du synes du har kommet deg helt etter hjerneslaget, og om du får hjelp av andre til daglige gjøremål.

Ja	Nei	
☐	☐	Synes du at du har kommet deg helt etter hjerneslaget?
☐	☐	Får du hjelp av andre til noen av dine daglige gjøremål?

Aktuelle problemer etter et hjerneslag

I tabellen nedenfor ber vi om at du angir i hvor stor grad du har problemer og redusert funksjon etter hjerneslaget. Tabellen kan fylles ut av pasient, pårørende eller helsepersonell:

Sett én ring rundt det tallet som best beskriver din situasjon ***i dag***.

STATUS ETTER HJERNESLAG	
0	***Ingen symptomer i det hele tatt***
1	***Ingen betydningsfull/synlig funksjonssvikt*** Lette symptomer, men ingen problemer i det daglige, og klarer å utføre alle vanlige aktiviteter som før.
2	***Lett funksjonssvikt*** Klarer ikke å utføre alle aktiviteter som før, men klarer de fleste daglig gjøremål. Klarer seg selv uten hjelp.
3	***Moderat funksjonssvikt*** Trenger noe hjelp til daglige gjøremål. Kan gå uten hjelp.
4	***Alvorlig funksjonssvikt*** Trenger mye hjelp til personlig hygiene, toalettbesøk, og andre daglige gjøremål. Kan ikke gå uten hjelp.
5	***Svært alvorlig funksjonssvikt*** Trenger konstant tilsyn og hjelp. Er sengeliggende og avhengig av at det er der noen der nesten hele tiden.
6	***Ukjent***

Referanse: Modified Rankin Scale. Rankin 1957

Relasjoner

Dersom spørsmålene ovenfor er besvart ***av en annen enn den som har hatt hjerneslag,*** ber vi om at du opplyser om din relasjon til vedkommende, og hvor hyppig dere møtes. Sett bare ***et*** kryss for hvert spørsmål. Du skal ikke besvare resten av spørsmålene i dette spørreskjemaet. Takk for hjelpen.

RELASJON

- ☐ Ektefelle eller samboer
- ☐ Sønn eller datter
- ☐ Venn
- ☐ Helsearbeider
- ☐ Annen relasjon. Angi hvilken:

KONTAKTHYPPIGHET

Hvor ofte treffer du den som har hatt et hjerneslag?

- ☐ Daglig
- ☐ Minst 1 gang i uken
- ☐ Sjeldnere enn 1 gang i uken

Tilfredshet med livet etter hjerneslag

Vi ønsker å vite hvor fornøyd du er med forskjellige deler av livet ditt etter hjerneslaget

Du bes om for hvert spørsmål å sette kryss ved det svaret som passer best til hvordan du har det nå (den siste uken). Sett bare ett kryss for hvert spørsmål.

	Ikke i det hele tatt	Litt fornøyd	Moderat fornøyd	Ganske fornøyd	Meget fornøyd
Alt i alt, hvor fornøyd er du med din fysiske helse?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med dine evner til å konsentrere deg, huske og tenke?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med dine følelser og den sinnsstemning du har?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med hvordan du klarer dine daglige gjøremål?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med ditt personlige og sosiale liv?	☐	☐	☐	☐	☐
Alt i alt, hvor fornøyd er du med din nåværende situasjon og dine framtidsutsikter?	☐	☐	☐	☐	☐

Referanse: von Steinbüechel N. et al. QOLIBRI- OS (2012)

Livskvalitet etter hjerneslag

Dette skjema handler om daglige aktiviteter, erfaringer og om hvordan du har det ***nå*** sammenlignet med ***før*** hjerneslaget. Alle spørsmål gjelder opplevelsene du har hatt den siste uken.

Vanlige daglige aktiviteter

Sett ***ett*** kryss for hvert spørsmål om hvordan du har klart daglige aktiviteter den siste uken.

	Den siste uken:	Kunne overhodet ikke	Store problem	Noe problem	Lette problem	Ingen problem
1	Hadde du problemer med å tilberede et måltid?	☐	☐	☐	☐	☐
2	Hadde du problemer med å spise?	☐	☐	☐	☐	☐
3	Hadde du problemer med påkledning?	☐	☐	☐	☐	☐
4	Hadde du problemer med å ta et bad eller en dusj?	☐	☐	☐	☐	☐
5	Hadde du problemer med å gå på toalettet?	☐	☐	☐	☐	☐
6	Hadde du problemer med å se tydelig nok på tv?	☐	☐	☐	☐	☐

	Den siste uken:	Kunne overhodet ikke	Store problem	Noe problem	Lette problem	Ingen problem
7	Hadde du problemer med å strekke deg etter ting på grunn av dårlig syn?	☐	☐	☐	☐	☐
8	Hadde du problemer med å se ting på den ene siden av synsfeltet?	☐	☐	☐	☐	☐
9	Hadde du problemer med å snakke?	☐	☐	☐	☐	☐
10	Hadde du problemer med å snakke klart og tydelig i telefon?	☐	☐	☐	☐	☐
11	Hadde andre mennesker problemer med å forstå hva du sa?	☐	☐	☐	☐	☐
12	Hadde du problemer med å finne ord som du ville si?	☐	☐	☐	☐	☐
13	Måtte du gjenta deg selv slik at andre kunne forstå deg?	☐	☐	☐	☐	☐
14	Hadde du problemer med å gå? (Sett kryss i “Kunne overhodet ikke” hvis du ikke kan gå, og fortsett på spørsmål 17.)	☐	☐	☐	☐	☐
15	Hadde du problemer med å holde balansen når du lente deg frem eller strakk deg etter noe?	☐	☐	☐	☐	☐
16	Hadde du problemer med å gå opp trapper?	☐	☐	☐	☐	☐
17	Hadde du behov for å ta pause mens du gikk eller brukte rullestol?	☐	☐	☐	☐	☐
18	Hadde du problemer med å stå?	☐	☐	☐	☐	☐
19	Hadde du problemer med å reise deg fra en stol?	☐	☐	☐	☐	☐
20	Hadde du problemer med å klare de daglige gjøremål i hjemmet?	☐	☐	☐	☐	☐
21	Hadde du problemer med å gjøre ferdig oppgaver du hadde begynt på?	☐	☐	☐	☐	☐
22	Hadde du problemer med å utføre de oppgaver som du pleier?	☐	☐	☐	☐	☐
23	Hadde du problemer med å skrive for hånd eller bruke tastatur?	☐	☐	☐	☐	☐
24	Hadde du problemer med å ta på sokker?	☐	☐	☐	☐	☐
25	Hadde du problemer med å kneppe knapper?	☐	☐	☐	☐	☐
26	Hadde du problemer med å bruke glidelås?	☐	☐	☐	☐	☐
27	Hadde du problemer med å åpne et glass med skrulokk?	☐	☐	☐	☐	☐

Erfaringer den siste uken

Hvert utsagn berører problemer som man kan oppleve etter hjerneslag. Her skal du angi hvorvidt du er enig eller uenig i utsagnene nedenfor. Alle utsagn gjelder den siste uken.

Sett ***ett*** kryss for hvert spørsmål

	Den siste uken:	Helt enig	Delvis enig	Verken enig eller uenig	Delvis uenig	Helt uenig
28	Jeg hadde problemer med å konsentrere meg.	☐	☐	☐	☐	☐
29	Jeg hadde problemer med å huske ting	☐	☐	☐	☐	☐
30	Jeg måtte skrive ned ting for å huske dem	☐	☐	☐	☐	☐
31	Jeg var irritabel	☐	☐	☐	☐	☐
32	Jeg var utålmodig med andre	☐	☐	☐	☐	☐
33	Personligheten min har endret seg	☐	☐	☐	☐	☐
34	Jeg følte meg motløs med tanke på fremtiden	☐	☐	☐	☐	☐
35	Jeg var ikke interessert i andre mennesker eller aktiviteter	☐	☐	☐	☐	☐
36	Jeg deltok mindre i lystbetonte aktiviteter med min familie	☐	☐	☐	☐	☐
37	Jeg følte at jeg var en byrde for min familie	☐	☐	☐	☐	☐
38	Min fysiske tilstand påvirket mitt familieliv	☐	☐	☐	☐	☐
39	Jeg gikk ikke ut så ofte som jeg ønsket	☐	☐	☐	☐	☐
40	Jeg brukte mindre tid på fritidsinteresser enn jeg ville	☐	☐	☐	☐	☐
41	Jeg traff ikke så mange av mine venner som jeg ville	☐	☐	☐	☐	☐
42	Jeg hadde sex mer sjelden enn jeg ønsket	☐	☐	☐	☐	☐
43	Min fysiske tilstand påvirket mitt sosiale liv	☐	☐	☐	☐	☐
44	Jeg følte meg isolert fra andre mennesker	☐	☐	☐	☐	☐
45	Jeg hadde lite selvtillit	☐	☐	☐	☐	☐
46	Jeg hadde liten matlyst	☐	☐	☐	☐	☐
47	Jeg følte meg trøtt mesteparten av tiden	☐	☐	☐	☐	☐
48	Jeg måtte ofte hvile meg i løpet av dagen	☐	☐	☐	☐	☐
49	Jeg var for trøtt til å gjøre det jeg ville	☐	☐	☐	☐	☐

Endringer etter hjerneslaget

Her skal du svare på hvordan du har det nå, sammenlignet med tiden før hjerneslaget.

Sett ***ett*** kryss på det svaret som best beskriver din tilstand nå.

		Betydelig endret	Noe endret	Litt endret	Uendret
50	Min personlighet er	☐	☐	☐	☐

		Mye dårligere enn før	Noe dårligere enn før	Litt dårligere enn før	Uendret
51	Energinivået mitt er	☐	☐	☐	☐
52	Språkevnen min er	☐	☐	☐	☐
53	Gangfunksjonen min er	☐	☐	☐	☐
54	Synet mitt er	☐	☐	☐	☐
55	Armene og hendene mine fungerer	☐	☐	☐	☐
56	Min evne til å tenke er	☐	☐	☐	☐
57	Humøret mitt er	☐	☐	☐	☐
58	Jeg utfører oppgavene mine i hjemmet eller på arbeid	☐	☐	☐	☐
59	Jeg klarer meg selv	☐	☐	☐	☐
60	Jeg gjør noe for familien min	☐	☐	☐	☐
61	Jeg gjør noe for vennene mine	☐	☐	☐	☐
62	Alt i alt er min livskvalitet	☐	☐	☐	☐

Stroke Specific Quality of Life Scale (Williams et al. 1999)

Sinnsstemning/følelser

Dette skjemaet undersøker hvordan du har hatt det den siste uken. Sett ***ett*** kryss ved det svaret som best beskriver dine følelser. Ikke tenk for lenge på svaralternativene – de spontane svarene er best.

1. Jeg føler meg nervøs og urolig

☐ Mesteparten av tiden

☐ Mye av tiden

☐ Fra tid til annen

☐ Ikke i det hele tatt

2. Jeg gleder meg fortsatt over tingene slik jeg pleide før

☐ Avgjort like mye

☐ Ikke fullt så mye

☐ Bare lite grann

☐ Ikke i det hele tatt

3. Jeg har en urofølelse som om noe forferdelig vil skje

☐ Ja, og noe svært ille
☐ Ja, ikke så veldig ille
☐ Litt, bekymrer meg lite
☐ Ikke i det hele tatt

4. Jeg kan le og se det morsomme i situasjoner

☐ Like mye nå som før
☐ Ikke like mye nå som før
☐ Avgjort ikke som før
☐ Ikke i det hele tatt

5. Jeg har hodet fullt av bekymringer

☐ Veldig ofte
☐ Ganske ofte
☐ Av og til
☐ En gang i blant

6. Jeg er i godt humør

☐ Aldri
☐ Noen ganger
☐ Ganske ofte
☐ For det meste

7. Jeg kan sitte i fred og ro og kjenne meg avslappet

☐ Ja, helt klart
☐ Vanligvis
☐ Ikke så ofte
☐ Ikke i det hele tatt

8. Jeg føler meg som om alt går langsommere

☐ Nesten hele tiden
☐ Svært ofte
☐ Fra tid til annen
☐ Ikke i det hele tatt

9. Jeg føler meg urolig som om jeg har sommerfugler i magen

☐ Ikke i det hele tatt
☐ Fra tid til annen
☐ Ganske ofte
☐ Svært ofte

10. Jeg bryr meg ikke lengre om hvordan jeg ser ut

☐ Ja, jeg har sluttet å bry meg
☐ Ikke som jeg burde
☐ Kan hende ikke nok
☐ Bryr meg som før

11. Jeg er rastløs som om jeg stadig må være aktiv

☐ Uten tvil svært mye
☐ Ganske mye
☐ Ikke så veldig mye
☐ Ikke i det hele tatt

12. Jeg ser med glede frem til hendelser og ting

☐ Like mye som før
☐ Heller mindre enn før
☐ Avgjort mindre enn før
☐ Nesten ikke i det hele tatt

13. Jeg kan plutselig få en følelse av panikk

☐ Uten tvil svært ofte
☐ Ganske ofte
☐ Ikke så veldig ofte
☐ Ikke i det hele tatt

14. Jeg kan glede meg over gode bøker, radio og tv

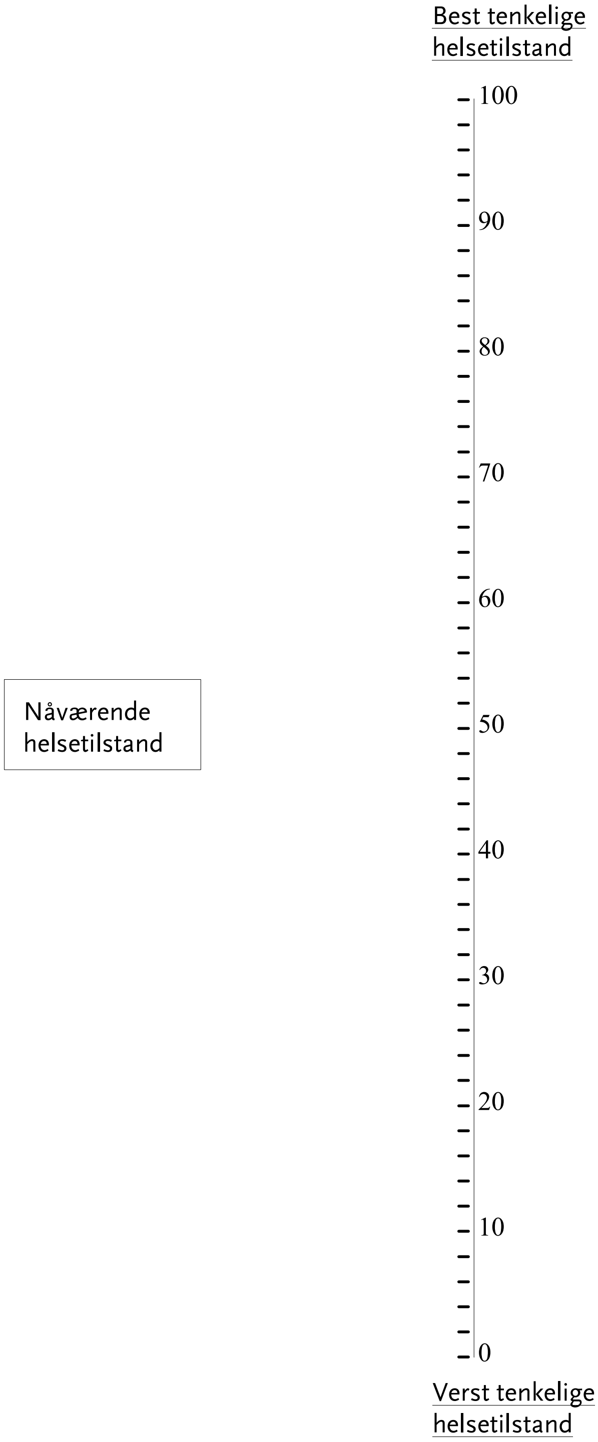
☐ Ofte
☐ Fra tid til annen
☐ Ikke så ofte
☐ Svært sjelden

HAD (Zigmond og Snaith 1983)

HELSETILSTAND

På skalaen nedenfor ber vi deg om å markere hvor god eller dårlig din helsetilstand er i dag. Du angir dette, ved å tegne en strek fra boksen til det punkt på skalaen.

Den beste helsetilstanden du kan forestille deg er markert med “100”, og den verst tenkelige helsetilstanden er markert med “0”



Beskrivelse av helsetilstand

Her finner du fem ulike tema med tre ulike svaralternativer. Sett ***ett*** kryss for det svaralternativet som best beskriver din helsetilstand i dag.

1. Gange

- ☐ Jeg har ingen problemer med å gå omkring
- ☐ Jeg har litt problemer med å gå omkring
- ☐ Jeg er sengeliggende

2. Personlig stell

- ☐ Jeg har ingen problemer med personlig stell
- ☐ Jeg har litt problemer med å vaske meg eller kle på meg
- ☐ Jeg er ute av stand til å vaske meg eller kle på meg

3. Vanlige gjøremål

- ☐ Jeg har ingen problemer med å utføre mine vanlige gjøremål
- ☐ Jeg har litt problemer med å utføre mine vanlige gjøremål
- ☐ Jeg er ute av stand til å utføre mine vanlige gjøremål

4. Smerte og ubehag

- ☐ Jeg har verken smerte eller ubehag
- ☐ Jeg har moderate smerter eller ubehag
- ☐ Jeg har sterke smerter eller ubehag

5. Angst og depresjon

- ☐ Jeg er verken engstelig eller deprimert
- ☐ Jeg er noe engstelig eller deprimert
- ☐ Jeg er svært engstelig eller deprimert

EQ 5D the EuroQol Group 1990

Tilfredshet med behandling og rehabilitering

I dette skjemaet skal du svare på hvor tilfreds du er med behandlingen, treningen og rehabiliteringstilbudet som du har fått i forbindelse med hjerneslaget.

Sett ***ett*** kryss for hvert av de tre spørsmålene.

Hvor tilfreds er du med treningen og rehabiliteringen du fikk *under innleggelse* på sykehuset?

☐ Meget fornøyd

☐ Fornøyd

☐ Verken fornøyd eller misfornøyd

☐ Misfornøyd

☐ Meget misfornøyd

☐ Jeg fikk ikke trening eller rehabilitering under innleggelse

Hvor tilfreds er du med treningen og rehabiliteringen du fikk *etter utskrivelse* fra sykehuset?

☐ Meget fornøyd

☐ Fornøyd

☐ Verken fornøyd eller misfornøyd

☐ Misfornøyd

☐ Meget misfornøyd

☐ Jeg fikk ikke trening eller rehabilitering etter utskrivelse

Alt i alt, hvor fornøyd er du med behandlingen og rehabiliteringen etter hjerneslaget?

☐ Meget fornøyd

☐ Fornøyd

☐ Verken fornøyd eller misfornøyd

☐ Misfornøyd

☐ Meget misfornøyd

Har du blitt mottatt trening eller rehabilitering i perioden fra 3 måneder etter hjerneslaget?

☐ Ja

☐ Nei

Hvis ja, mottar du trening eller rehabilitering nå?

☐ Ja

☐ Nei

Hjelp til utfylling

Ja	Nei	
☐	☐	Har du fått hjelp til utfylling av spørreskjemaet

Takk for hjelpen!

Tromsprodukt · 40 00 72 02

Appendix 7

Follow-up registrations adjusted for use in Denmark at three months

telefoninterview 3 mdr. efter apopleksi

Samarbejdsprojekter mellem Norge og Danmark

ID nr.:

Patientoplysninger

1 - Køn	Mand	1	Kvinde	2
2 - CPR nr.				
3 - Navn				
4 - Telefon				
5 - Telefon, pårørende				

Patientstatus

6 - Er opfølgningen udført	Ja	1	Nej	2
7 - Dato for opfølgning (dd.mm.åå.)				

8 - Årsag:	
Kan ikke træffes Antal henvendelser **mindst 20** _____	1
Ønsker ikke at svare	2
Afgået ved døden	3
Andet Skriv årsag: ______________________	4
Hemmeligt telefon nr.	5

9 - Boligforhold

Egen bolig uden hjemmehjælp eller hjemmesygepleje	1	
Egen bolig med hjemmehjælp eller hjemmesygepleje	2	Hvis borgeren har nødkaldeanlæg scores 3.
Ældre- eller handicapvenlig bolig med mulighed for tilkald af personale hele døgnet	3	Der scores 3 uanset om borgeren gør brug af muligheden for tilkald eller ej.
Plejehjem eller institution	4	Der scores kun 4 såfremt borgeren har ***fast*** bopæl på plejehjem eller institution. Ved aflastning scores de boligforhold borgeren ellers bor i.
Ukendt	9	

10 - Samlivsstatus

Gift eller samlevende	1
Enke eller enkemand	2
Enlig	3
Ukendt	9

11 - Boligsituation

Bor alene	1	
Samboende (fx ægtefælle, samlever, søskende, barn)	2	
Bor på institution eller plejehjem	3	Der scores kun 3 såfremt borgeren har ***fast*** bopæl på plejehjem eller institution. Ved aflastning scores de boligforhold borgeren ellers bor i.
Ukendt	9	

Udarbejdet juli 2013 af Guri Heiberg, Audny Anke og Henriette Holm Stabel med baggrund i Norsk Hjerneslagsregister version 3.0.

12 - Genindlæggelse

Har været indlagt hele tiden	1
Genindlagt for ny apopleksi	2
Genindlagt af anden årsag	3
Ikke genindlagt	4

13 - Specificer:	
Blodprop	1
Blødning	2
Ukendt	9

14 - Rehabilitering efter udskrivelse

Døgnrehabilitering på specialiseret afd. med tværfaglige medarbejdere (Sygehuse, Vejlefjord, RHN, Skive og lign.)	1
Specialiseret dagrehabilitering med tværfaglige medarbejdere (Hjerneskadecentrene, Voksen Special tilbud, Kommunal jobafklaring og lign.)	2
Kommunalt dagcenterehabilitering	3
Hjemmerehabilitering /hverdagsrehabilitering ved hjemmehjælp efter introduktion fra ergo- og/eller fysioterapeut	4
Hjemmerehabilitering /hverdagsrehabilitering ved ergo- og/eller fysioterapeut	5
Behandling og/eller træning ved privat praktiserende fysioterapeut	6
Andet Skriv hvad: ________________________________	7
Ingen rehabilitering efter udskrivelse	8
Ukendt	9

15 - Navn på rehabiliteringssted	**16** - Dato for indlæg.	**17** - Dato for udskriv.	**18** – Udskrevet til	**15a** – antal uger
a:				
b:				
c:				
d:				

19 - Blev du overflyttet fra apopleksiafd. og direkte til videre døgn-rehabilitering	
Ja	1
Nej – ***hvis nej besvares også nedenstående***	2

20 - Hvor lang tid gik der fra, at du blev udskrevet fra sygehuset, til du påbegyndte videre specialiseret døgnrehabilitering?	
Indenfor 1 uge	1
Indenfor 2 uger	2
Indenfor 3 uger	3
Indenfor 4 uger	4
Mere end 4 uger	5

Såfremt borgeren har modtaget anden rehabilitering end døgnrehabilitering markeres rehabiliteringstilbudet ***i ét af de grønne felter***. De grønne pile følges herefter, så hvert rehabiliteringstilbud registreres.

21 - Hvor lang tid gik der fra, at du blev udskrevet fra sygehuset, til du påbegyndte videre rehabilitering?	
Indenfor 1 uge	1
Indenfor 2 uger	2
Indenfor 3 uger	3
Indenfor 4 uger	4
Mere end 4 uger	5

Specificering af behandlings- eller rehabiliteringstiltag i kommunalt regi som patienten har modtaget efter udskrivelsen

Har du modtaget behandling eller rehabilitering fra......

22 - Fagperson	**Ja**	**Nej**	**23 - Rehabiliteringstilbud (skriv tal fra boks med rehabiliterings ovenfor)**	**24 – Dato start**	**25 – Dato slut**	**Antal uger**	**26 - Fortsat tilbud? (Ja/Nej)**	**27 - Timer pr. uge**	**28 - Dage pr. uge**
Sygeplejerske									
Fysioterapeut									
Ergoterapeut									
Logopæd									
Andre faggrupper (fx psykolog)									
29 - Har du trænet hjemme alene? (ingen fagpersoner har været involveret)									
Hjemmetræning alene									

Udvalgte funktioner

30 - Hjælp i dagligdagen (mulighed for at markere flere svar)	
Ingen hjælp	1
Hjælp fra familie	2
Hjemmehjælp	3
Hjemmesygepleje	4
Institution / plejehjem	5
Andre	6
31 - Forflytning	
Jeg kan forflytte mig selv alene og uden opsyn både ude og inde	1
Jeg kan forflytte mig selv alene og uden opsyn inde, men ikke ude	2
Jeg behøver hjælp fra andre til forflytninger	3
Ved ikke / ukendt	9
32 - Toiletbesøg	
Jeg klarer toiletbesøg selv	1
Jeg kan ikke klare toiletbesøg selv; behov for hjælp, bruger bækken / bleer	2
Ved ikke / ukendt	9
33 - Af- og påklædning	
Jeg klarer selv af- og påklædning, herunder overtøj, sko og strømper	1
Jeg har behov for hjælp til af- og påklædning	2
Ved ikke / ukendt	9

Opfølgning på din rehabilitering og livskvalitet

34 - Har du sprog og/eller taleproblemer efter din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
35 - Har du problemer med synet efter din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
36 - Er du kommet dig helt efter din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
37 - Har du modtaget tilstrækkelig hjælp i det daglige efter din apopleksi?	
Ja	1
Nej	2
Har ikke behov for hjælp	3
Ved ikke / ukendt	9
38 - Har du modtaget så meget træning, som du har ønsket efter din apopleksi?	
Ja	1
Nej	2
Har ikke behov for hjælp	3
Ved ikke / ukendt	9
39 - Har du været til lægekontrol efter din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
40 - Er du lige så tilfreds med tilværelsen, som du var før din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
41 - Tager du medicin mod for højt blodtryk?	
Ja	1
Nej	2
Ved ikke / ukendt	9
42 - Tager du blodfortyndende medicin?	
Ja	1
Nej	2
Ved ikke / ukendt	9

43 - Tager du medicin mod for højt kolesterol?	
Ja	1
Nej	2
Ved ikke / ukendt	9
44 - Tager du medicin mod grådlabilitet, depression eller nedsat humør (SSRI præparater)	
Ja	1
Nej	2
Ved ikke / ukendt	9
45 - Ryger du eller har du røget tidligere?	
Nej - har aldrig røget	1
Ja - ryger	2
Ja - er eks-ryger (røgfri > 1 mdr.)	3
Ukendt	9
46 - Var du aktiv på arbejdsmarkedet før du fik din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
47 - Er du aktiv på arbejdsmarkedet nu?	
Ja	1
Nej	2
Ved ikke / ukendt	9
48 - Kørte du bil før du fik din apopleksi?	
Ja	1
Nej	2
Ved ikke / ukendt	9
49 - Kører du bil nu?	
Ja	1
Nej	2
Ved ikke / ukendt	9

50 - Besvarelse

Interview er foretaget med: (mulighed for at markere flere svar)	
Patient	1
Familie	2
Sundhedsfagligt personale	3
Andre Skriv hvem:____	4

51 - Status for funktionsniveau – Modified Rankin Scale

Status efter apopleksi	
Ingen symptomer overhovedet	0
Ingen synlig funktionsnedsættelse Lette symptomer, men ingen helbredsgener i det daglige, trods symptomer. Udfører de samme gøremål som tidligere	1
Nogen funktionsnedsættelse Mindre handicap. Overkommer mindre end tidligere. Opgivet gøremål pga. helbredet. Klarer sig selv uden hjælp	2
Moderat funktionsnedsættelse Moderat handicap. Behøver let hjælp til daglige gøremål	3
Moderat til svær funktionsnedsættelse Behøver meget hjælp til personlig hygiejne, toiletbesøg og andre daglige gøremål	4
Svær Funktionsnedsættelse Behøver konstant opsyn, er sengeliggende, inkontinent, er afhængig af, at der er nogen næsten hele tiden	5
Ukendt	6

Appendix 8

Follow-up, telephone interview from National Norwegian Stroke Registry

Telefonintervju. Tillegg til Norsk Hjerneslagregisters oppfølgingsskjema 3. 0.

Pasientidentifikasjon	**Dato**

Hvis utskrevet fra slagenhet/ akuttavdeling til heldøgnsrehabilitering:

Navn på rehabiliteringsavdeling i sykehus, opptreningssenter eller Rehabiliteringsenhet i sykehjem	Dato innlagt	Dato utskrevet	Utskrevet til: (sykehus, sykehjem, hjemmet, annet)
1.			
2.			

Ble du direkte overført fra slagenhet til videre rehabilitering ?	
JA	**NEI**

Hvor lang ventetid var det fra utskriving slagenhet til innleggelse rehabilitering	
Innen 1 uke	
Innen 2 uker	
Innen 3 uker	
Innen 4 uker	
Mer enn 4 uker	

Spesifiser type behandling/ rehabilitering pasienten har fått etter utskriving fra sykehus:
Spørsmålet omfatter ikke døgnbaserte tjenester som sykehjem eller opptreningsinstitusjon.

Fagperson	Ja	Nei	Dato start	Dato slutt	Fortsatt tilbud?	Timer pr. uke	Dager pr. uke
Sykepleier							
Fysioterapeut							
Ergoterapeut							
Logoped							
Andre faggrupper (psykolog, synspedagog, treningssenter)							
Dagrehabilitering							
Ambulant oppfølging							
Trent alene hjemme							

Spørsmålet stilles samtidig med de øvrige medikament spørsmål i oppfølgingsskjema

Bruker du medisin mot gråtelabilitet, depresjon eller nedsatt humør	JA	Nei	Vet ikke
(for eksempel Cipramil , , Citalopram, Cipralex, Escitalopram Fluoxetin, Fontex, Paroxetin, Seroxat, Sertralin, Zoloft			

Appendix 9

Acute phase data from the National Norwegian Stroke Registry

Norsk hjerneslagregister

Akuttskjema 2015

Anvendes ved registrering av alle pasienter innlagt med akutt hjerneslag fra og med 01.01.2015

Personnummer ☐☐☐☐☐☐☐☐☐☐☐

Navn ☐

Adresse ☐

Telefon ☐

Inklusjonskontroll. Pasienten har hjerneslagdiagnose i henhold til ett av følgende kriterier:

☐ 1 Akutte fokale utfall + positiv bildediagnostikk. Innlagt i sykehus innen 28 døgn fra symptomdebut.

☐ 2 Akutte fokale utfall ÷ positiv bildediagnostikk. Innlagt i sykehus innen 28 døgn fra symptomdebut.

☐ 3 Ingen av ovennevte, pasienten skal ikke registreres

Slagdiagnose

☐ I 61 Hjerneblødning (CT/MR eller obduksjon har vist blødning)

☐ I 63 Hjerneinfarkt (CT/MR obduksjon er uten aktuell patologi eller har vist et aktuelt infarkt)

☐ I 64 Hjerneslag ikke spesifisert som blødning eller infarkt (CT/MR ikke tatt)

☐ Hjerneslag som hoveddiagnose

☐ Hjerneslag som bidiagnose

For pasienter med primær hjerneblødning:
Er det gitt blødningsstoppende behandling?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, hvilken?

☐ 1 Faktorkonsentrat (Octaplex)

☐ 2 Ferskt frosset plasma (Octaplas)

☐ 3 K-vitamin

☐ 4 Faktorkonsentrat + 2 eller 3

☐ 5 Annet

Tilstand før det aktuelle hjerneslaget

Boligforhold

☐ 1 Egen bolig uten hjemmesykepleie/hjemmehjelp

☐ 2 Egen bolig med hjemmesykepleie/hjemmehjelp

☐ 3 Omsorgsbolig med døgnkontinuerlige tjenester og personale

☐ 4 Sykehjem

☐ 9 Ukjent

Sivilstatus

☐ 1 Gift/samboende

☐ 2 Enke/enkemann

☐ 3 Enslig

☐ 9 Ukjent

Bosituasjon

☐ 1 Pasienten bodde alene

☐ 2 Pasienten bodde sammen med noen (f.eks. ektefelle/samboer, søsken, barn)

☐ 3 Pasienten bodde i institusjon/sykehjem

☐ 9 Ukjent

Forflytning

☐ 1 Pasienten kunne forflytte seg alene/uten tilsyn, både inne og ute (bruk av hjelpemiddel tillatt)

☐ 2 Pasienten kunne forflytte seg alene/uten tilsyn inne, men ikke ute

☐ 3 Pasienten fikk hjelp av en annen person ved forflytning

☐ 9 Ukjent

Toalettbesøk

☐ 1 Pasienten klarte toalettbesøk alene

☐ 2 Pasienten klarte ikke toalettbesøk alene. Trengte hjelp til bruk av bekken eller bleie, eller trengte hjelp under toalettbesøket

☐ 9 Ukjent

Påkledning

☐ 1 Pasienten klarte av- og påkledning selv, også ytterklær, sko og strømper

☐ 2 Pasienten trengte hjelp med av- og påkledning

☐ 9 Ukjent

Funksjonsstatus

Modified Rankin Scale (Se egen veiledning) ☐ 0-6

Risikofaktorer før hjerneslaget

Tidligere hjerneslag?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, anfør type hjerneslag

☐ 1 Infarkt
☐ 2 Blødning
☐ 9 Ukjent
☐ 3 Uspesifisert
☐ 4 Både infarkt og blødning

Tidligere TIA? (Opplysninger om sikre tegn på TIA i form av klare forbigående fokale utfall)

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, når var siste TIA?

☐ 1 Innen siste uke
☐ 2 1-4 uker før slaget
☐ 3 4-12 uker før slaget
☐ 4 Over 12 uker før slaget

Tidligere hjerteinfarkt?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Gjennomgått store hjerte-/karintervensjoner?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, når?

☐ 1 Innen siste uke
☐ 2 1-4 uker før slaget
☐ 3 4-12 uker før slaget
☐ 4 Over 12 uker før slaget

Atrieflimmer bekreftet med EKG tidligere eller i løpet av innleggelsen (gjelder også paroxystisk atrieflimmer/flutter)**?**

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Diabetes, tidligere diagnostisert eller nyoppdaget?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Røykestatus

☐ 0 Aldri
☐ 1 Røyker
☐ 2 Eks-røyker (røykfri > 1 mnd)
☐ 9 Ukjent

Status i akuttfasen

Bevissthetsgrad ved innleggelsen

☐ 0 Våken
☐ 1 Døsig, reagerer adekvat ved lett stimulering
☐ 2 Døsig, reagerer først ved kraftig/gjentatt stimulering
☐ 3 Reagerer ikke, eller bare med ikke-målrettet bevegelse
☐ 9 Ukjent

Fokale utfall

Facialisparese

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

Beinparese

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

Andre nye fokale slagsymptomer

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

Hvilke fokale symptomer?

☐ Ataksi
☐ Sensibilitetsutfall
☐ Neglekt
☐ Dobbeltsyn
☐ Synsfeltutfall
☐ Vertigo

Armparese

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

Språk- eller taleproblemer

☐ 1 Ja
☐ 2 Nei
☐ 9 Ukjent

NIHSS (National Institutes of Health Stroke Scale)

Angi totalscore ved innkomst (innen 24 timer) ☐ ☐ Ikke utført

Cerebral CT eller MR ved innkomst (innen 12 t)?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Sidelokalisasjon av symptomer

☐ 1 Høyre ☐ 2 Venstre ☐ 3 Bilateralt ☐ 4 Ikke relevant ☐ 9 Ukjent

Medikamentell behandling før debut av hjerneslaget og ved utreise

Dersom det er dokumentert i journal/epikrise at pasienten starter med antikoagulasjon innen to uker etter symptomdebut av hjerneslaget kan det krysses av for antikoagulasjon ved utreise

Ved mors registreres alle medikamenter ved utreise som **Nei**

	Før debut av hjerneslaget			**Ved utreise**		
Medikament (Eksempler)	Ja 1	Nei 2	Ukjent 9	Ja 1	Nei 2	Ukjent 9
Acetylsalisylsyre (ASA) (Asasantin Retard, Acetylsalisylsyre, Albyl E, Aspirin, Axanum, Dispril, Globoid)	☐	☐	☐	☐	☐	☐
ADP-reseptorblokker (Brilique, Clopidogrel, Efient, Plavix)	☐	☐	☐	☐	☐	☐
Dipyridamol (Asasantin Retard, Persantin (Retard)):	☐	☐	☐	☐	☐	☐
Warfarin (Marevan)	☐	☐	☐	☐	☐	☐
Andre perorale antikoagulasjonsmidler enn Warfarin (Angiox, Arixtra, Eliquis, Novastan, Pradaxa, Xarelto)	☐	☐	☐	☐	☐	☐

Medikamentell behandling før debut av hjerneslaget og ved utreise, fortsettelse

	Før debut av hjerneslaget Ja 1	 Nei 2	 Ukjent 9	Ved utreise Ja 1	 Nei 2	 Ukjent 9
Diuretika (Aldactone, Atacand Plus, Benetor Comp, Burinex, Candemox Comp, Candesartan/ Hydrochlorothiazide, Centyl, CoAprovel, Corixil, Cozaar Comp, Diovan Comp, Diural, Enalapril Comp, Esidrex, Furix, Furosemid, Inspra, Irbesartan/Hydroklortiazid, Lasix Retard, Lisinopril/ Hydroklortiazid, Lodoz, Losartan/ Hydrochlorotiazide, Micardis Plus, Moduretic mite, Normorix mite, Olmetec Comp, Renitec Comp, Samsca, Spirix, Teveten Comp, Valsartan/ Hydrochlorotiazide, Zestoretic mite)	☐	☐	☐	☐	☐	☐
ACE-hemmer (Captopril, Enalapril, Enalapril Comp, Gopten, Lisinopril, Lisinopril/ Hydroklortiazid, Perindoprilarginin servier, Ramipril, Renitec, Renitec Comp, Triatec, Zanipress, Zestoretic, Zestoretic mite, Zestril, Zofenil, Zofenil Comp)	☐	☐	☐	☐	☐	☐
A2-antagonist (Alea. Amias, Aprovel, Atacand, Atacand Plus, Benetor, Benetor Comp, Candemox Comp, Candesartan, Candesartan/ Hydrochlorotiazide, CoAprovel, Corixil, Cozaar, Cozaar Comp, Diovan, Diovan Comp, Exforge, Irbesartan, Irbesartan/ Hydroklortiazid, Losartan, Losartan/Hydrochlorotiazide, Micardis, MicardisPlus, Olmetec, Olmetec Comp, Sevikar, Teveten, Teveten Comp, Valsartan, Valsartan/ Hydrochlorotiazide)	☐	☐	☐	☐	☐	☐
Betablokker (Atenolol, Bisoprolol, Brevibloc, Carvedilol, Emconcor, Hypoloc, Inderal Retard, Lodoz, Metoprolol, Pranolol, Seloken, Selo-zok, Sotalol, Tenormin, Trandate, Uniloc.)	☐	☐	☐	☐	☐	☐
Kalsiumantagonist (Adalat, Alea, Amlodipin, Cardizem, Exforge, Felodipin, Isoptin, Lerkandipin, Lomir, Nimotop, Norvasc, Plendil, Sevikar, Verakard, Zanidip.)	☐	☐	☐	☐	☐	☐
Statin og andre lipidsenkende (Atorvastatin, Cholestagel, Crestor, Ezetrol, Inegy, Lescol. Lestid, Lipitor, Lovastatin, Omacor, Pravachol, Pravastatin, Questran, Simvastatin, Sortis, Zocor)	☐	☐	☐	☐	☐	☐
Medikamentell behandling for høyt blodtrykk	☐	☐	☐	☐	☐	☐

Antikoagulasjonsbehandling under innleggelsen

	Ja 1	Nei 2	Ukjent 9
Antikoagulasjon med Heparin/lavmolekylært Heparin i.v. eller s.c. gitt som behandling av det akutte hjerneslaget (Atenativ, Enoksaparin, Fragmin, Hepaflex, Heparin, Innohep, Klexane)	☐	☐	☐
Antikoagulasjon med Heparin/lavmolekylært Heparin i.v. eller s.c gitt som profylakse og/eller behandling mot DVT og eventuell lungeemboli (Atenativ, Enoksaparin, Fragmin, Hepaflex, Heparin, Innohep, Klexane)	☐	☐	☐

Trombolytisk behandling

Trombolyse ☐ 1 Ja ☐ 2 Nei ☐ 3 Inkl. i studie ☐ 9 Ukjent

Hvilket sykehus? ______

Starttidspunkt for trombolyse

Dato	Måned	År	Timer	Min
☐☐	☐☐	☐☐	☐☐	☐☐

NIHSS (Totalscore) *Før* trombolyse ______ ☐ Ikke utført

NIHSS (Totalscore) 24 t *etter* trombolyse ______ ☐ Ikke utført

Hjerneblødning med klinisk forverring innen 36 timer etter behandlingsstart tilsvarende 4 poeng eller mer på NIHSS (skal være verifisert med CT/MR eller obduksjon ☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Trombektomi

Er trombektomi eller annen endovaskulær behandling gjennomført? ☐ 1 Ja ☐ 2 Nei ☐ 3 Inkl. i studie ☐ 9 Ukjent

Hvilket sykehus? ______

Starttidspunkt for trombektomi

Dato	Måned	År	Timer	Min
☐☐	☐☐	☐☐	☐☐	☐☐

NIHSS (Totalscore) *Før* trombolyse ______ ☐ Ikke utført

NIHSS (Totalscore) 24 t *etter* trombektomi ______ ☐ Ikke utført

Hemikraniektomi

Er hemikraniektomi gjennomført? ☐ 1 Ja ☐ 2 Nei ☐ 3 Inkl. i studie ☐ 9 Ukjent

Hvilket sykehus? ______

Starttidspunkt for hemikraniektomi

Dato	Måned	År	Timer	Min
☐☐	☐☐	☐☐	☐☐	☐☐

Behandlingskjeden

Symptomdebut

Angi tidspunkt for symptomdebut. Dersom pasienten vaknet med symptom angis siste tidspunkt uten sypmtom, for eksempel ved leggetid

☐☐ ☐☐ ☐☐ ☐☐ ☐☐
Dato Måned År Timer Min

Våknet pasienten med symptom på hjerneslag?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Innleggelsestidsunkt

☐☐ ☐☐ ☐☐ ☐☐ ☐☐
Dato Måned År Timer Min

Hvor oppsto hjerneslaget?

- ☐ 1 Utenfor sykehus
- ☐ 2 I sykehus, ikke prosedyrerelatert
- ☐ 3 I sykehus, prosedyrerelatert

Avdeling/enhet først innlagt?

- ☐ 1 Slagenhet (se veiledning)
- ☐ 2 Annen sengeavdeling

Overflyttet fra sykehus

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvilket sykehus?

☐

Dato overflyttet fra sykehus

☐☐ ☐☐ ☐☐
Dato Måned År

Ble AMK/ambulanse varslet?

- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 3 Ukj.

Transportmetode

- ☐ 1 Ambulanse
- ☐ 2 Luftambulanse
- ☐ 3 Kombinasjon av ambulanse og luftambul.
- ☐ 4 Annet

Hvilken avdeling?

- ☐ 1 Medisinsk
- ☐ 2 Nevro
- ☐ 3 Nevrokirurgi
- ☐ 4 Intensiv/ annen overvåkingsavd.
- ☐ 5 Observasjon
- ☐ 6 Annen

Hvilke undersøkelser og tiltak er utført under oppholdet?

Bildediagnostikk av hjerneslaget

- ☐ 1 Ingen
- ☐ 2 CT
- ☐ 3 MRI
- ☐ 4 CT + MRI
- ☐ 5 Annen
- ☐ 9 Ukjent

Bildediagnostikk av ekstrakranielle kar

- ☐ 1 Ingen
- ☐ 2 Ultralyd
- ☐ 3 CT-angio
- ☐ 4 MR-angio
- ☐ 5 Kombinasjon
- ☐ 9 Ukjent

Bildediagnostikk av intrakranielle kar

- ☐ 1 Ingen
- ☐ 2 Ultralyd
- ☐ 3 CT-angio
- ☐ 4 MR-angio
- ☐ 5 Kombinasjon
- ☐ 9 Ukjent

Bildediagnostikk av hjerte

- ☐ 1 Ingen
- ☐ 2 Transthorakal ultralyd. Ecco cor
- ☐ 3 Transøsofageal ultralyd. Ecco cor
- ☐ 4 MRI
- ☐ 5 Kombinasjon av flere
- ☐ 6 Annen
- ☐ 9 Ukjent

Registrering av hjerterytme

- ☐ 1 Ingen
- ☐ 2 EKG
- ☐ 3 Telemetri/kontinuerlig EKG monitorering
- ☐ 4 Holtermonitorering
- ☐ 5 Kombinasjon av flere
- ☐ 9 Ukjent

Er fysiologisk homeostase kontrollert og behandlet i henhold til sjekkliste for pasientsikkerhetsprogrammet?

- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 3 Ikke relevant
- ☐ 9 Ukjent

Er svelgfunksjonen vurdert/testet?

- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 3 Ikke relevant
- ☐ 9 Ukjent

Er pasienten mobilisert ut av seng i løpet av de første 24 timer etter innleggelsen?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Har pasienten fått en tverrfaglig vurdering?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Utskriving

Utskrivingsdato

☐☐ ☐☐ ☐☐
Dato Måned År

Avdeling/enhet utskrevet fra?

- ☐ 1 Slagenhet (se veiledning)
- ☐ 2 Annen sengeavdeling

Hvilken avdeling?

- ☐ 1 Medisinsk
- ☐ 2 Nevrologisk
- ☐ 3 Nevrokirurgisk
- ☐ 4 Intensiv / annen overvåkingsavdeling
- ☐ 5 Observasjonsavdeling
- ☐ 6 Annen avdeling

Utskrives til

- ☐ 1 Egen bolig uten hjemmesykepleie/ hjemmehjelp
- ☐ 2 Egen bolig med hjemmesykepleie/ hjemmehjelp
- ☐ 3 Omsorgsbolig med døgnkontinuerlige tjenester og personale
- ☐ 4 Sykehjem
- ☐ 5 Annen avdeling for videre behandling
- ☐ 6 Annen avd. i påvente av sykehjem/rehab.
- ☐ 7 Rehabiliteringsavdeling/-institusjon - inkludert rehabilitering i sykehjem
- ☐ 8 Opptreningssenter
- ☐ 9 Ukjent
- ☐ 10 Død i løpet av oppholdet
- ☐ 11 Annet - spesifiser

Mors

Morsdato

☐☐ ☐☐ ☐☐
Dato Måned År

Obdusert?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Er pasienten fulgt opp av et tverrfaglig team i forbindelse med utskriving fra sykehus?

☐ 1 Ja ☐ 2 Nei ☐ 9 Ukjent

Hvis ja, sett ett kryss

- ☐ 1 Team organisatorisk tilknyttet sykehus
- ☐ 2 Team organisatorisk tilknyttet kommune

Appendix 10

Follow-up registrations at three months from the National Norwegian Stroke Registry

Norsk hjerneslagregister

Oppfølgingsskjema 2015

Anvendes ved 3 måneders registrering av akutte hjerneslag innlagt fra og med 01.01.2015

Personnummer ☐☐☐☐☐☐☐☐☐☐☐ **Telefon** ______

Navn ______

Pasientstatus

Oppfølgingsdato

☐☐ Dato ☐☐ Måned ☐☐ År

Boligforhold

- ☐ 1 Egen bolig uten hjemmesykepleie/hjemmehjelp
- ☐ 2 Egen bolig med hjemmesykepleie/hjemmehjelp
- ☐ 3 Omsorgsbolig med døgn døgnkontinuerlige tjenester og personale
- ☐ 4 Sykehjem
- ☐ 9 Ukjent

Sivilstatus

- ☐ 1 Gift/samboende
- ☐ 2 Enke/enkemann
- ☐ 3 Enslig
- ☐ 9 Ukjent

Bosituasjon

- ☐ 1 Bor alene
- ☐ 2 Bor sammen med noen (f.eks. ektefelle/samboer, søsken, barn)
- ☐ 3 Bor i institusjon/sykehjem
- ☐ 9 Ukjent

Innlagt sykehus etter utskriving (flere alternativer mulig)

- ☐ 1 Hele tiden innlagt
- ☐ 2 Reinnlagt for nytt slag
- ☐ 3 Reinnlagt annen årsak
- ☐ 4 Ikke reinnlagt

Spesifiser

- ☐ 1 Infarkt
- ☐ 2 Blødning
- ☐ 9 Ukjent

Er du operert i halspulsåre?

- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Ukjent

Rehabiliteringstiltak etter utskriving (flere alternativer mulig)

- ☐ 1 Døgnopphold i rehab.avd.
- ☐ 2 Opptreningssenter
- ☐ 3 Døgnrehabilitering i sykehjem
- ☐ 4 Dagrehabilitering
- ☐ 5 Hjemmerehabilitering
- ☐ 6 Rehabilitering i fysikalsk institutt
- ☐ 7 Behandling hod logoped
- ☐ 8 Annet (spesifiser) ______
- ☐ 9 Ukjent

Spesielle funksjoner

Hjelp i daglige gjøremål (ADL) (flere alternativer mulig)

- ☐ 1 Ingen
- ☐ 2 Familie
- ☐ 3 Hjemmehjelp
- ☐ 4 Hjemmesykepleie
- ☐ 5 Institusjon
- ☐ 6 Andre

Forflytning

- ☐ 1 Jeg kan forflytte meg alene/uten tilsyn både ute og inne.
- ☐ 2 Jeg kan forflytte meg alene/uten tilsyn inne, men ikke ute.
- ☐ 3 Jeg trenger hjelp av en annen person ved forflytning
- ☐ 9 Vet ikke / ukjent

Toalettbesøk

- ☐ 1 Jeg klarer toalettbesøk selv
- ☐ 2 Jeg klarer ikke toalettbesøk alene. Trenger hjelp til bruk av bekken eller bleie, eller trenger hjelp under toalettbesøk
- ☐ 9 Vet ikke / ukjent

Av-/påkledning

- ☐ 1 Jeg klarer av-/påkledning selv, også ytterklær, sko og strømper
- ☐ 2 Jeg trenger hjelp med av-/påkledning
- ☐ 9 Vet ikke / ukjent

Skjema fortsetter på andre siden

Oppfølging og livskvalitet

Har du problemer med å lese og skrive (som ikke var tilstede før hjerneslaget)?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Har du problemer med å svelge (som ikke var tilstede før hjerneslaget)?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Har du problemer med å snakke (som ikke var tilstede før hjerneslaget)?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Har du synsproblemer (som ikke var tilstede før hjerneslaget)?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Har du kommet deg helt etter hjerneslaget?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Har du fått tilstrekkelig hjelp etter hjerneslaget?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 3 Har ikke behov
- ☐ 9 Vet ikke / ukjent

Har du fått så mye trening som du ønsker etter hjerneslaget?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 3 Har ikke behov
- ☐ 9 Vet ikke / ukjent

Har du vært til legekontroll etter hjerneslaget?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Er du like fornøyd med tilværelsen etter hjerneslaget som før hjerneslaget?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Tar du medisin mot høyt blodtrykk?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Tar du blodfortynnende medisin mot blodpropp?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Tar du medisin mot høyt kolesterol?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Røykestatus
- ☐ 0 Aldri
- ☐ 1 Røyker
- ☐ 2 Eks-røyker (røykfri > 1 mnd)
- ☐ 9 Ukjent

Var du yrkesaktiv da du fikk hjerneslag?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Er du yrkesaktiv nå?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Kjørte du bil før du fikk hjerneslag?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Kjører du bil nå?
- ☐ 1 Ja
- ☐ 2 Nei
- ☐ 9 Vet ikke / ukjent

Funksjonsstatus (Modified Rankin Scale)

Sett kun ett kryss ved svaralternativet som best beskriver ditt funksjonsnivå

- ☐ 0 Ingen symtomer
- ☐ 1 Ingen betydningsfull funksjonssvikt til tross for symptomer, klarer å utføre alle oppgaver og aktiviteter som før
- ☐ 2 Lett funksjonssvikt; klarer ikke å utføre alle aktiviteter som før, men klarer sine daglige gjøremål
- ☐ 3 Moderat funksjonssvikt: trenger noe hjelp, men går uten hjelp
- ☐ 4 Alvorlig funksjonssvikt; klarer ikke å gå uten hjelp og klarer ikke å ivareta sine grunnleggende behov uten hjelp
- ☐ 5 Svært alvorlig funksjonssvikt; sengeliggende og trenger konstant tilsyn og hjelp
- ☐ 6 Død

Besvart av (flere alternativer mulig)
- ☐ 1 Pasient
- ☐ 2 Familie
- ☐ 3 Helsepersonell
- ☐ 4 Andre

Spesifiser ☐

Hvordan ble oppfølgingsskjema etter 3 måneder registrert?
- ☐ 1 Per telefon
- ☐ 2 Per brev
- ☐ 3 Ved besøk på poliklinikk