

## FORSKNING

# Culturally adapted validated translation of the NIHSS

**The translated NIHSS form and guide remain true to the English version and are harmonised with the non-validated Norwegian version.**

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Abstract

**Background:** The National Institutes of Health Stroke Scale (NIHSS) is an internationally recognised screening tool used by healthcare professionals to record neurological outcomes of patients with a suspected stroke. The scale has been used by nurses and doctors in stroke units in Norway since the 1990s. The Norwegian version of the NIHSS that is currently in use has not been validated.

**Objective:** To give an account of the culturally adapted validated translation of the NIHSS.

**Method:** In collaboration with the University of South-Eastern Norway and a qualified translator, a project group consisting of nurses and doctors from stroke units in Vestre Viken Hospital Trust produced a culturally adapted validated translation of the NIHSS. The translation process followed the steps in the modified translation method of the Regional Competence Centre for Pain (ReKS). We conducted a pilot test with several stroke units.

**Results:** The terminology in the validated NIHSS largely matched that of the non-validated version. The descriptor 'IT' in the validated version corresponds to the original version. Illustrations and text sheets from the original NIHSS were included in the validated version with a few adjustments. Total score and time spent administering the scale were comparable to the non-validated version.

**Conclusion:** Validation of the NIHSS was required to ensure cultural adaptation and that the language was consistent with the original English version. Involving stroke units, conducting a pilot test and putting together a project team of experienced doctors and nurses were important factors in the validation process. The result is a Norwegian validated version of the NIHSS and guide that is true to the original English version and at the same time harmonised with the non-validated existing Norwegian version.

The National Institutes of Health Stroke Scale (NIHSS) is an international stroke scale used by healthcare professionals to record neurological outcomes in suspected strokes and to monitor symptom development (1-5). The NIHSS was developed in 1989 and subsequently revised in 2003 (2).

Nurses and doctors in stroke units in Norway have been using the tool since the 1990s. The eleven different functions that are scored are level of consciousness, LOC questions, LOC commands, best gaze, visual, facial palsy, motor arm and leg, limb ataxia, sensory, best language, dysarthria and neglect.

An NIHSS score provides information on the severity of the stroke and goes from score 0 (no outcome), score 1-4 (minor stroke), score 5-15 (moderate stroke), score 16-20 (moderate to severe stroke) to score 21-42 (severe stroke) (6).

The original English NIHSS form and guide includes illustrations and text sheets. The guide is a detailed description of how the NIHSS should be administered in practice, and how to score (2, 7). Several countries have developed culturally adapted validated translations of the NIHSS in their own language, including illustrations (8, 9).

### ***Background for the translation***

The stroke units in Vestre Viken Hospital Trust have had a common clinical pathway for the treatment of stroke patients since 2002. A long-standing collaboration is in place between the stroke units and the University of South-Eastern Norway (USN) to provide clinical practice placements for nursing students and for students taking postgraduate studies in strokes, where training in the use of NIHSS is an important part.

In connection with this collaboration, discrepancies emerged in the scoring of patients, which led to questions being asked about the standard of the training in the NIHSS. A project group was established, consisting of a doctor, four nurses from the stroke units in Vestre Viken Hospital Trust and a lecturer from USN.

The aim of the project was to develop an e-learning course in Norwegian in order to standardise the training. As part of this work, we found that the Norwegian version of the NIHSS, which has been used in clinical practice for a number of years (1), has not been validated according to the standard method (10).

There is no consensus on how a screening tool should be adapted to another culture, but there is agreement that a mere direct translation is insufficient (11, 12). Because an e-learning course was to be developed, the project group decided to first produce a validated translation of the NIHSS.

### ***Objective***

The objective of the article was to give an account of the culturally adapted validated translation of the NIHSS.

### **Method**

The validated translation process followed the steps in a modified translation method for questionnaires, which was developed at the Regional Competence Centre for Pain (ReKS), Department of Pain Management, Oslo University Hospital (13). The method is supported by the World Health Organization (WHO), which has also developed a method for producing validated translations (10).

The method starts with a preparation phase, consisting of a forward translation and a back translation. Harmonisation and a pilot test are then performed as part of a cognitive debriefing process. The last step is the finalisation phase. This translation method was chosen as it is in line with the recommendations for validated translation work (10).

ReKS defines the different roles for the professionals involved (13), such as chief consultant, forward translator and project manager. In this project, five professionals formed an expert panel that undertook all of the roles.

The use of an expert panel is recommended for translation work (10). The expert panel consisted of three stroke nurses: two with a postgraduate qualification in neurology and one with a master's degree in nursing. The panel also consisted of a senior consultant neurologist and a senior lecturer in nursing with experience in the treatment of strokes. In addition to the expert panel, four forward translators and a qualified translator undertook defined tasks.

### ***The preparation phase***

In the preparation phase, we contacted the licensee, the National Institute of Neurological Disorders and Stroke (NINDS), to clarify any conditions for the translation from English to Norwegian. The response was that the original version had to be referenced in the final product.

The expert panel reviewed the original version of the NIHSS. The goal was to identify words and terms, both in the form and the guide, that would be challenging to translate.

### ***Forward translation***

According to ReKS, the criteria for forward translators were that their first language was Norwegian, they can write and speak English, and that they preferably have experience with validated translation work (13). There were four forward translators involved in the project: a nurse from a stroke unit, a doctor from a stroke unit, a university lecturer with knowledge of strokes and validated translation work, and a nurse with research experience and experience with validated translation work.

Three of the four had Norwegian as their first language, and one was a native Danish speaker with 30 years of experience with the Norwegian language. All four could write and speak English. The forward translators noted challenges and tried to make the text understandable and adaptable to Norwegian. The forward translators translated the NIHSS and the guide from English to Norwegian without any form of collaboration.

The purpose of the forward translation was to make the text understandable and adaptable to the Norwegian language, culture and discipline as opposed to a literal translation. In line with the translation method, the expert panel discussed with the forward translators whether the illustrations and text sheets used in the original version were recognisable themes in Norwegian culture.

The expert panel reviewed the forward translations without knowing which translator had carried out which translation, and together developed the first Norwegian translation.

### ***Back translation***

A qualified translator was recruited. The criteria for the qualified translator were English as a first language, fluent written and spoken Norwegian, and that they had medical knowledge (10, 13).

The qualified translator should have no knowledge of the text to be translated, and must focus on concepts within a cultural context as opposed to a linguistic framework (10). The qualified translator who back translated the NIHSS form, the guide and the text sheets met the requirements.

### ***Harmonisation***

The expert panel reviewed and discussed the back translation from Norwegian to English. According to ReKS, the original author should participate in this part of the process. The original author did not participate in this project because the text was developed by several authors in collaboration.

The NIHSS was developed by a national institute of neurological conditions and strokes. The main purpose of the work was to compare terms and concepts between the original and the translated version of the NIHSS.

The expert panel had a dialogue with the qualified translator about some concepts that needed to be adjusted in line with the original version of the NIHSS. It was also crucial to ensure that the Norwegian version was culturally and linguistically adapted to Norwegian conditions.

Following the collaboration with the qualified translator, the expert panel prepared a second Norwegian version of the NIHSS. The harmonisation process involved comparing the validated and the non-validated versions of the NIHSS in Norwegian.

The comparison included a discussion on linguistic differences, both in the NIHSS form and the guide. It was also important to ensure that the validated guide was precise and applicable in practice. Following the comparison, the expert panel produced a third Norwegian version of the NIHSS.

### ***Cognitive debriefing***

ReKS describes cognitive debriefing as a test of the finished product (13). The expert panel sent out a preliminary version to nine stroke units. Six stroke units participated in the pilot test, which included 29 stroke patients. WHO points out that it is crucial that the pilot test respondents are representative of the population on which the screening tool will be administered in practice (10).

Pilot testing is useful for ensuring the content validity, face validity and reliability of the validated version of the NIHSS and attachments (14). Two healthcare professionals (herein referred to as test subjects) - either two nurses or one nurse and one doctor from each of the six stroke units - tested the same patient using the non-validated version.

Both tested the same patient at the same time to ensure they had the same understanding of the tool, and thus consistent approaches to scoring. One test subject then used the validated version and the other used the non-validated version on the same patient at the same time, and subsequently compared scores.



	IT = Ikke testbar. Beskriv:																		
8	<b>Sensibilitet</b> (for stikk) 0 = Normal 1 = Mild til moderat utfall (kjenne stikk som mindre skarpt) 2 = Alvorlig til total utfall (også ved coma, kvadriplegisk)																		
9	<b>Språk</b> (tale, taleforståelse, leseforståelse, benevning) 0 = Ingen afasi 1 = Mild til moderat afasi, samtale mulig 2 = Alvorlig afasi, samtale svært vanskelig eller umulig 3 = Ikke språk (også ved coma)																		
10	<b>Dysartri</b> (spontan tale) 0 = Ingen dysartri 1 = Mild - moderat dysartri (lett snøvling) 2 = Nær uforståelig tale eller stum/global afasi (også coma) IT = Ikke testbar. Beskriv:																		
11	<b>Neglekt</b> (bilateral simultan stimulering av syn og hudfølelse) 0 = Ingen neglekt (også ved hemianopsi med normal sensibilitet) 1 = Neglekt i en sansemodalitet 2 = Neglekt i begge sansemodaliteter																		
<b>Total NIHSS-Score</b>																			
eHåndbok dok-id: 16277 Nov. 2018		Undersøkerens signatur																	

Norsk validert oversettelse 2018, Vestre Viken HF og Universitetet i Sør-Øst Norge: <https://www.ninds.nih.gov/sites/default/files/NIHStrokeScaleBooklet.pdf>

### Concepts that were recognisable in practice

We identified terms in both the NIHSS form and the guide that were interpreted in different ways. One forward translator deliberately used as general language as possible in the translation, in order to make it easy for the clinician to understand the meaning. Terms in the English NIHSS form that were challenging to translate into Norwegian are shown in Table 1.

**Table 1.** Terms in the NIHSS form that were a challenge to translate from English to Norwegian

Original English NIHSS	Forward translation to Norwegian, version 1	Back translation to English	Harmonisation with the non-validated Norwegian NIHSS, version 3	Validated Norwegian NIHSS, version 4
Alert	Våken og adekvat	Awake and adequate	Våken	Våken og adekvat
Best gaze	Øyebevegelser	Eye movement	Blikkbevegelse	Blikkbevegelse
Visual field	Synsfelt	Field of vision	Synsfelt	Synsfelt
UN Amputation or joint fusion / intubated or other physical barrier, explain:	IT Amputasjon eller leddprotese / intubert eller annen fysisk barriere, beskriv:	IT Amputation or joint prosthesis / intubated or with another physical barrier, describe:	Skår = 0 Ikke testbar	IT Ikke testbar, beskriv:
Extinction and inattention (formerly neglect)	Redusert oppmerk- somhet / neglekt	Reduced attention / neglect	Neglect	Neglekt

All forward translators found it difficult to translate the term 'alert', which is used in the original version to describe the level of consciousness. It was not only the level of alertness that was difficult to define, but also what type of response could be expected for the different levels of alertness.

The four forward translators each suggested a different Norwegian translation (*våken og klar*, *målrettet respons*, *våken og oppmerksom*, and *våken og adekvat*). The expert panel discussed the Norwegian term *adekvat*. In the original version, score 0 is described as 'Alert; keenly responsive'. The expert panel decided that the Norwegian term *adekvat* was the most suitable as it covered both *våken* and *adekvat*.

In the non-validated Norwegian NIHSS version, the Norwegian term *våken* is used for score 0. Here, the term *adekvat* was used for score 1, which is a lower level of consciousness. In the pilot test, several informants reported that the guide in the validated version of the NIHSS was clearer on the scoring of consciousness.

The original version uses the term 'non-paretic hand' when testing responses to commands. The forward translators used various translations in Norwegian, such as *ikke-paretisk hånd*, *ikke-paretiske hånden*, *neve på ikke-affisert side* and *hånden uten parese*.

**«We placed a large emphasis on harmonisation with the non-validated version.»**

The forward translation sent to the qualified translator included the Norwegian term *den friske hånden*. This term is known from the non-validated Norwegian version and was therefore chosen as a validated translation. We placed a large emphasis on harmonisation with the non-validated version.

The patient's horizontal eye movements are scored in the NIHSS. The original version uses the term 'best gaze'. The forward translators suggested various Norwegian translations (*blikk*, *blikkbevegelser*, *øyebevegelser* and *blikkøvelser*). The term *blikk* refers more to the direction the patient is looking, and the expert group therefore considered it most correct to use *blikkbevegelse* as a validated translation.

In the original version, several terms, such as 'oculocephalic' and 'caloric testing', are used to test reflexive movements of the eyes. These are known concepts in neurology, but require specialist knowledge or training to be able to understand what they mean.

In the original version, the term 'visual field' is used when scoring the patient's vision. All four forward translators used the Norwegian term *synsfelt*, which is a well-known medical term and was therefore chosen for the validated translation.

In the original version, the score for 'motor arm' and 'motor leg' is recorded as untestable (UN) in the case of amputation. In the non-validated Norwegian version, the corresponding condition is scored with the value 0. In order to remain true to the English original version, we included the Norwegian term for 'untestable' in the validated version. The change did not have any consequences for the overall NIHSS score.

***Language adapted to Norwegian culture***

In the original English version of the NIHSS, the patient's language and motor speech are tested using standardised illustrations and text sheets. For language comprehension, pictures of a glove, key, cactus, chair, feather and hammock are used, as well as a scene from a kitchen in a home.

**«The expert panel agreed to keep all the English illustrations as they are recognisable in Norwegian culture.»**

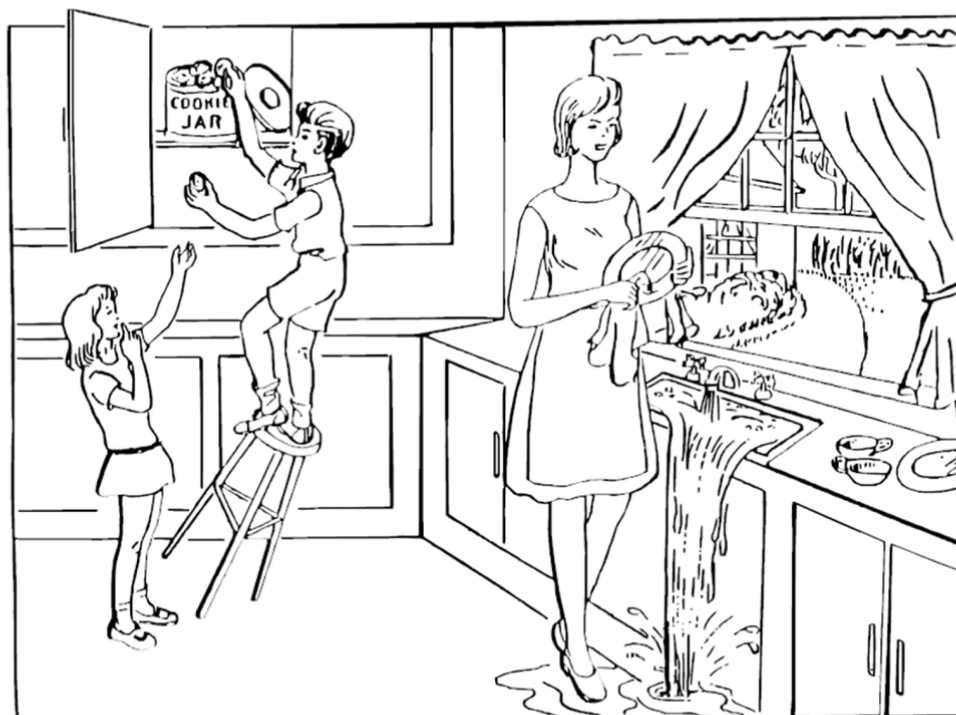
The expert panel agreed to keep all the English illustrations as they are recognisable in Norwegian culture. The picture of a glove could be interpreted as a hand, and this was accepted as a correct answer in the original version (7). Figures 2 and 3 show the illustrations from the original English version of the NIHSS, all of which were retained in the validated Norwegian version.

**Figure 2.** Illustrations from the original NIHSS form

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**Figure 3.** Illustration from the original NIHSS form



With regard to the text sheets, we changed two of the terms to make them a better fit with Norwegian culture. One term was 'baseball player', which was changed to the Norwegian term for a basketball player, as Norwegians are more familiar with basketball than baseball.

The second term, 'huckleberry', was changed to the Norwegian word for gooseberry for two reasons. One reason is that the huckleberry is not found in Norway, but gooseberries are. The second reason is that the Norwegian word for gooseberry (*stikkelsbær*) contains two s-sounds, which is helpful when testing for dysarthria. Table 2 shows the text words in both the English and the validated translated version, adapted to Norwegian culture.

**Table 2.** English text and validated translation of text adapted to Norwegian culture

Text in English version of NIHSS	Translated and culturally adapted text in validated version of NIHSS
MAMA	MAMMA
TIP - TOP	TIPP-TOPP
FIFTY - FIFTY	FEMTI-FEMTI
THANKS	TUSEN TAKK
HUCKLEBERRY	STIKKELSBÆR
BASEBALL PLAYER	BASKETBALLSPILLER
YOU KNOW HOW	DU VET HVORDAN
DOWN TO EARTH	JORDNÆR
I CAME HOME FROM WORK	JEG KOM HJEM FRA JOBB
CLOSE TO THE TABLE IN THE DINING ROOM	I NÆRHETEN AV BORDET I SPISESTUEN
THEY HEARD HIM SPEAK ON THE RADIO LAST NIGHT	DE HØRTE AT HAN SNAKKET PÅ RADIOEN I GÅR KVELD



In the pilot test, the test subjects tested out the illustrations and text sheets in the validated version and were positive about using them. Two test subjects commented that the text sheets could not be used, but it turned out that the patients who were tested scored 2 on language function. This indicates severe aphasia, where speech is difficult or impossible. It was therefore not possible to test the use of the text words in these patients.

'Extinction' is the term used in the original version where the patient's attention is assessed. The forward translators suggested four different terms in Norwegian: *extinction og uoppmerksomhet*, *neglekt*, *redusert oppmerksomhet/neglekt* and *ekstinksjon og uoppmerksomhet*.

In the non-validated Norwegian version, the terms 'neglect/extinction' are used. The expert panel chose *redusert oppmerksomhet/neglekt* in the forward translation. *Neglekt* is a term used in neurology, and one that medical personnel are familiar with.

On some of the sub-scale exams in the NIHSS, the original version provides an opportunity to describe the reason for 'untestable', while the non-validated Norwegian version uses score = 0 instead. The expert panel's experience from practice shows that clinicians prefer to describe the reason for untestability in the form. The expert panel therefore decided to follow the original version.

In the original version, the title 'the investigator' is used for the person administering the NIHSS. The person administering the NIHSS was given at the top of the form. In the first Norwegian validated version, which was sent to the translator, the Norwegian term *testleder* was chosen for 'the investigator'.

The translator back translated this to 'testing leader'. The expert panel was not satisfied with this term and considered the Norwegian term for clinician (*kliniker*) instead. After harmonisation with the non-validated Norwegian version, the group decided not to give a title.

Through contact with the stroke units that were asked to pilot test the validated version, nurses and doctors were concerned that the validated version might take longer to administer than the non-validated one, and that the overall score might change. The pilot test showed that these concerns were unfounded.

## Discussion

In the translation work, the project group chose an expert panel who mostly had extensive experience in administering the NIHSS. This expertise helped to ensure satisfactory validity of content where the language was culturally adapted to practice (15, 16). One weakness of the translation process was that it was not possible to contact the original authors. Using the original author is an important part of validation work (10, 11, 13, 17).

**«This expertise helped to ensure satisfactory validity of content where the language was culturally adapted to practice.»**

There is no standard method for translation validation and cultural adaptation, but the existing methods are largely in agreement (10, 13). Several researchers discuss the importance of regularly revising validation and cultural adaptation, as language and culture change over time (11, 18, 19).

### ***Practitioners and researchers were together on the validation***

The expert panel placed an emphasis on harmonising the validated version with the non-validated one, since it had already been translated into Norwegian and used in practice for a number of years. As such, the hope was that it could be perceived as valid and thereby support the validated version.

In pilot testing, face validity is tested, where healthcare professionals provide concrete feedback on terms and wording that may be difficult to understand (14). The face validity reveals whether formulations and terms are understandable to the target group (14).

In this way, a pilot test will ensure that a validated translation is adapted to the culture in which it is to be used (20). A pilot test can be carried out as a focus group interview with several clinicians together. Researchers stress that inaccuracies are easier to detect through conversation (16).

In our project group, conducting a focus group interview was considered to be resource-intensive because it would involve interviews with nurses and doctors from several stroke units in Norway.

Six of the nine stroke units invited to participate in the pilot test agreed to take part. Those that did not participate said that their unit was too busy, and that the testing could not be prioritised. Nevertheless, the result provided an impression of what worked well and what should be changed.

### ***We respected both the original version and the existing translated version***

Throughout the project work, attention was focused on bias as a result of the existing translated version having been used in Norway for a number of years. It was therefore particularly important to compare the non-validated and the validated versions in the pilot test.

The pilot test revealed that two test subjects had different scores for the patient's outcome. It would have been easier to have a conversation about the reason for the different scoring, which could have led to suggestions for more comprehensible formulations. Other studies support the use of such a method (18, 19).

### ***Elements of our version differ from the non-validated version***

Most countries that have validated the NIHSS in their own language and culture have included the same illustrations and text sheets as the original version. Some countries have adapted them to their own culture (9, 21, 22).

In our project, the expert panel decided to retain the same illustrations and text sheets with a few adaptations. This means that the validated Norwegian version of the NIHSS is significantly different from the non-validated one, which does not use illustrations or text sheets. The pilot test showed that the scale did not take longer to administer when illustrations and text sheets were used.

### **«The pilot test showed that the scale did not take longer to administer when illustrations and text sheets were used.»**

Nevertheless, this change in practice is difficult to implement without guidance in a transitional phase. Another significant difference between the validated and non-validated versions is the scoring of 'untestable'. In the non-validated version, 'untestable' is given a score of 0, while the validated version describes 'untestable' using the descriptor 'IT' (which stands for untestable in Norwegian) as the score. None of the test subjects in the pilot test commented on this difference in scoring.

The project group's starting point was a desire to develop standardised training in the use of the NIHSS. The Norwegian validated version is the basis for an e-learning course that Norwegian health trusts can now use. The e-learning course will facilitate quality assurance in the use of the NIHSS in practice.

### **Conclusion**

Validation of the NIHSS was required to ensure culturally appropriate language. In the validation process, it was important to involve stroke units in pilot testing the form and guide and to use an expert panel with experienced doctors and nurses.

The result is a Norwegian validated version of the NIHSS form and guide that is true to the original English version, and also harmonised with the non-validated Norwegian version.

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