

ICF CORE SETS FOR STROKE

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Objective: To report on the results of the consensus process integrating evidence from preliminary studies to develop the first version of the Comprehensive ICF Core Set and the Brief ICF Core Set for stroke.

Methods: A formal decision-making and consensus process integrating evidence gathered from preliminary studies was followed. Preliminary studies included a Delphi exercise, a systematic review, and an empirical data collection. After training in the ICF and based on these preliminary studies relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds.

Results: The preliminary studies identified a set of 448 ICF categories at the second, third and fourth ICF levels with 193 categories on *body functions*, 26 on *body structures*, 165 on *activities and participation*, and 64 on *environmental factors*. Thirty-nine experts from 12 different countries attended the consensus conference on stroke. Altogether 130 second-level categories were included in the Comprehensive ICF Core Set with 41 categories from the component *body functions*, 5 from *body structures*, 51 from *activities and participation*, and 33 from *environmental factors*. The Brief ICF Core Set included a total of 18 second-level categories (6 on *body functions*, 2 on *body structures*, 7 on *activities and participation*, and 3 on *environmental factors*).

Conclusion: A formal consensus process integrating evidence and expert opinion based on the ICF framework and classification led to the definition of ICF Core Sets for stroke. Both the Comprehensive ICF Core Set and the Brief ICF Core Set were defined.

Key words: stroke, cerebrovascular accident, consensus development conferences, outcome assessment, quality of life, ICF.

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INTRODUCTION

Stroke is a major public health concern, being among the most common causes of death and disability. In 1990, cerebrovascular accident was the second leading cause of mortality, accounting for 4.4 million deaths worldwide (1). About 700 000 people experience a stroke each year in the USA (2). In European and Asian populations average annual stroke attack rates range from 185 to 638 per 100 000 (3). However, 40–77% of patients are alive 1 year after stroke (4) and many survivors are facing long-term disability. In the USA, in 1999 about 1 160 000 non-institutionalized adults suffered from disability due to stroke (5). In the WHO Burden of Disease Study cerebrovascular diseases were found to be the third leading cause of lost “disability-adjusted life years” (DALYs) in the developed countries, worldwide accounting for 38.5×10^6 DALYs in 1990 (6). Stroke also imposes a substantial economic burden with direct and indirect costs of stroke being estimated at \$51.2 billion for 2003 in the USA (2).

Stroke is defined as acute neurological dysfunction of vascular origin with rapid onset of symptoms according to the affected regions of the brain (7). Clinical manifestation of stroke can be described in terms of different arterial syndromes and varies depending on several factors including aetiology, localization and initial stroke severity, but also underlies considerable changes over the course of time (8). Thus, acute symptoms often differ from the later picture of survivors’ disability outcome. As recent epidemiological studies illustrate, disability following stroke appears in form of neurological dysfunctions (e.g. motor, sensory, visual) and limited ability to perform activities of daily living (ADL) (9), as well as neuropsychological deficits (e.g. attention, memory, language) (10, 11). In addition, neuropsychiatric disturbances (e.g. post-stroke depression) are frequently associated with stroke (12, 13).

Several national and international guidelines on stroke management have been published also containing recommendations on interventions and assessment strategies targeted towards the diverse areas of post-stroke disability to be considered beyond the acute phase of the disease. The American Agency for Health Care Policy and Research (AHCPR) has developed recommendations on post-stroke rehabilitation (14),

also including proposals on standardized assessment for a variety of purposes, such as treatment planning and monitoring of rehabilitation progress. With regard to the AHCPR guideline domains to be measured comprise level of consciousness, overall neurological impairment, motor function, balance, cognition, speech and language, ADL, depression, family functioning and quality of life. A pool of 25 preferred instruments to measure these domains is also included in this recommendation.

In the UK, 2 more recent guidelines, which also address the issue of post-stroke disability outcome, have been released. The National Clinical Guidelines of the Royal College of Physicians (RCP) (15) summarize evidence on the effectiveness of interventions. These include rehabilitation and address different areas of patient problems that require assessment and professional care. These areas are psychological impairments, communication, motor impairment and spasticity, sensory impairment and pain, gait, ADL and need for equipment and adaptations. The Scottish Intercollegiate Guidelines Network (SIGN) (16) has published an evidence-based clinical guideline on stroke management that also specifies common impairments encountered in an inpatient setting (arm/hand/leg weakness, facial weakness, spinothalamic sensory loss, dysarthria, aphasia, homonymous visual field defect, proprioceptive sensory loss, cognitive impairment, visuospatial dysfunction, balance problems), common physical limitations of activity (stair climbing, bathing, walking, dressing, toileting, transferring between hospitals, feeding, urinary and/or faecal incontinence), as well as medical complications of stroke. Recommendations on instruments to be used for the measurement of these patient problems are included in neither of the UK guidelines but are left to local agreements.

The RCP and the SIGN documents served also as a basis for the development of an evidence-based guideline on stroke management by the New Zealand Guidelines Group (NZGG) (17). The NZGG provides an overview about common issues that arise after stroke and have to be dealt with by skilled health professionals in a rehabilitation team. In addition to the patient problems as covered in the RCP and SIGN guidelines the issue of an appropriate living environment and financial issues and employment are also introduced.

In a recent European recommendation concerning the organization of stroke care of the European Stroke Initiative (EUSI) (18) the careful assessment of the degree of disability in post-stroke patients is regarded most important. According to the EUSI recommendation disability assessment should comprise the domains motor weakness, sensory and proprioceptive deficits, intellectual impairment, and emotional distress and motivational disturbances. No recommendations on specific instruments to be used for the measurement of these areas are given.

Although large degree of consensus exists across the different national and international guidelines regarding stroke patients' problems to be addressed, general agreement on the scope of concepts to be taken into account and on the instruments to be used in stroke disability assessment still seems to be lacking.

Table I. *International Classification of Functioning, Disability and Health (ICF) – categories of the component body functions included in the Comprehensive ICF Core Set for stroke*

ICF code	ICF category title
b110	Consciousness functions
b114	Orientation functions
b117	Intellectual functions
b126	Temperament and personality functions
b130	Energy and drive functions
b134	Sleep functions
b140	Attention functions
b144	Memory functions
b152	Emotional functions
b156	Perceptual functions
b164	Higher-level cognitive functions
b167	Mental functions of language
b172	Calculation functions
b176	Mental function of sequencing complex movements
b180	Experience of self and time functions
b210	Seeing functions
b215	Functions of structures adjoining the eye
b260	Proprioceptive function
b265	Touch function
b270	Sensory functions related to temperature and other stimuli
b280	Sensation of pain
b310	Voice functions
b320	Articulation functions
b330	Fluency and rhythm of speech functions
b410	Heart functions
b415	Blood vessel functions
b420	Blood pressure functions
b455	Exercise tolerance functions
b510	Ingestion functions
b525	Defecation functions
b620	Urination functions
b640	Sexual functions
b710	Mobility of joint functions
b715	Stability of joint functions
b730	Muscle power functions
b735	Muscle tone functions
b740	Muscle endurance functions
b750	Motor reflex functions
b755	Involuntary movement reaction functions
b760	Control of voluntary movement functions
b770	Gait pattern functions

General agreement could however, facilitate the comparability of research findings and in the long run the improvement of stroke care. To achieve this goal, we need a comprehensive framework and classification, which can provide a universal language understood by health professionals, researchers,

Table II. *International Classification of Functioning, Disability and Health (ICF) – categories of the component body structures included in the Comprehensive ICF Core Set for stroke*

ICF code	ICF category title
s110	Structure of brain
s410	Structure of cardiovascular system
s720	Structure of shoulder region
s730	Structure of upper extremity
s750	Structure of lower extremity

policymakers, patients and patient organizations. The new International Classification of Functioning, Disability and Health (ICF) (19) serves this purpose.

With the approval of the ICF we can now rely on a globally agreed framework and classification to define the spectrum of problems in the functioning of stroke patients. For practical purposes and in line with the concept of condition-specific health status measures it would thus seem most helpful to link specific conditions or diseases to salient ICF categories of functioning (20). Such generally agreed-on lists of ICF categories can serve as Brief ICF Core Set to be rated in all patients included in a clinical study with stroke or as Comprehensive ICF Core Set to guide multidisciplinary assessments in patients with stroke. The objective of this paper is to report on the results of the consensus process integrating evidence from preliminary studies to develop the first version of the ICF Core Sets for stroke, the Comprehensive ICF Core Set and the Brief ICF Core Set.

METHODS

The development of the ICF Core Sets for stroke involved a formal decision-making and consensus process integrating evidence gathered from preliminary studies including a Delphi exercise (21), a systematic review (22), and an empirical data collection, using the ICF checklist (23). After training in the ICF and based on these preliminary studies relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds.

Thirty-six experts (25 physicians with various sub-specializations, 7 physical therapists, 2 psychologists, one social worker, and one sociologist) from 12 different countries attended the consensus process on stroke. The decision-making process involved 5 working groups with 7–8 experts each. The process was facilitated by the co-ordinator for stroke (JS) and the 5 working-group leaders (HD, PF, Gunnar Grimby, ZO, HR), and guided by 2 members of the ICF Research Branch (GS, AC).

RESULTS

The tables on the pre-conference studies (21–23) presented to the participants included 448 ICF categories at the second, third, and fourth levels of the classification (193 on *body functions*, 26 on *body structures*, 165 on *activities and participations* and 64 on *environmental factors*).

Tables I–IV show the ICF categories included in the Comprehensive ICF Core Set. Table V shows the ICF categories that were selected for the Brief ICF Core Set, as well as the percentage of experts willing to include the respective category in the Brief ICF Core Set.

Comprehensive ICF Core Set

The total number of categories in the Comprehensive ICF Core Set is 130. No categories at the third and fourth levels were included, but all categories belonged to the second level of the ICF.

The 130 categories of the Comprehensive ICF Core Set are made up of 41 (32%) categories from the component *body functions*, 5 (4%) from the component *body structures*, 51 (39%)

Table III. *International Classification of Functioning, Disability and Health (ICF) – categories of the component activities and participation included in the Comprehensive ICF Core Set for stroke*

ICF code	ICF category title
d115	Listening
d155	Acquiring skills
d160	Focusing attention
d166	Reading
d170	Writing
d172	Calculating
d175	Solving problems
d210	Undertaking a single task
d220	Undertaking multiple tasks
d230	Carrying out daily routine
d240	Handling stress and other psychological demands
d310	Communicating with – receiving – spoken messages
d315	Communicating with – receiving – non-verbal messages
d325	Communicating with – receiving – written messages
d330	Speaking
d335	Producing non-verbal messages
d345	Writing messages
d350	Conversation
d360	Using communication devices and techniques
d410	Changing basic body position
d415	Maintaining a body position
d420	Transferring oneself
d430	Lifting and carrying objects
d440	Fine hand use
d445	Hand and arm use
d450	Walking
d455	Moving around
d460	Moving around in different locations
d465	Moving around using equipment
d470	Using transportation
d475	Driving
d510	Washing oneself
d520	Caring for body parts
d530	Toileting
d540	Dressing
d550	Eating
d570	Looking after one's health
d620	Acquisition of goods and services
d630	Preparing meals
d640	Doing housework
d710	Basic interpersonal interactions
d750	Informal social relationships
d760	Family relationships
d770	Intimate relationships
d845	Acquiring, keeping and terminating a job
d850	Remunerative employment
d855	Non-remunerative employment
d860	Basic economic transactions
d870	Economic self-sufficiency
d910	Community life
d920	Recreation and leisure

from the component *activities and participation*, and 33 (25%) from the component *environmental factors*.

The 41 categories of the component “body functions” represent 36% of the total number of ICF categories at the second level in this component. Most of the *body functions* categories belong to chapter 1 *mental functions* (15 categories), chapter 7 *neuromusculoskeletal and movement-related functions* (9 categories), and chapter 2 *sensory functions and pain* (6

Table IV. *International Classification of Functioning, Disability and Health (ICF) – categories of the component environmental factors included in the Comprehensive ICF Core Set for stroke*

ICF code	ICF category title
e110	Products or substances for personal consumption
e115	Products and technology for personal use in daily living
e120	Products and technology for personal indoor and outdoor mobility and transportation
e125	Products and technology for communication
e135	Products and technology for employment
e150	Design, construction and building products and technology of buildings for public use
e155	Design, construction and building products and technology of buildings for private use
e165	Assets
e210	Physical geography
e310	Immediate family
e315	Extended family
e320	Friends
e325	Acquaintances, peers, colleagues, neighbours and community members
e340	Personal care providers and personal assistants
e355	Health professionals
e360	Health-related professionals
e410	Individual attitudes of immediate family members
e420	Individual attitudes of friends
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members
e440	Individual attitudes of personal care providers and personal assistants
e450	Individual attitudes of health professionals
e455	Individual attitudes of health-related professionals
e460	Societal attitudes
e515	Architecture and construction services, systems and policies
e525	Housing services, systems and policies
e535	Communication services, systems and policies
e540	Transportation services, systems and policies
e550	Legal services, systems and policies
e555	Associations and organizational services, systems and policies
e570	Social security services, systems and policies
e575	General social support services, systems and policies
e580	Health services, systems and policies
e590	Labour and employment services, systems and policies

categories). Chapter 3 *voice and speech functions* is represented by 3 categories, chapter 4 *functions of the cardiovascular, haematological, immunological and respiratory systems* by 4 categories, and chapter 5 *functions of the digestive, metabolic and endocrine systems*, and chapter 6 *genitourinary and reproductive functions* by 2 categories, respectively.

The 5 categories of the component *body structures* represent 9% of the total number of ICF categories at the second level in this component. They belong to chapter 7 *structures related to movement* (3 categories), chapter one *structures of the nervous system* (one category), and chapter 4 *structures of the cardiovascular, immunological and respiratory systems* (one category).

The 51 categories of the component *activities and participation* represent 43% of the total number of ICF categories at the second level in this component. All 9 chapters of this component

are represented in the *Comprehensive ICF Core Set*. Most of the *activities and participation* categories belong to chapter 4 *mobility* (12 categories), chapter 3 *communication* (8 categories), chapter 1 *learning and applying knowledge* (7 categories), and chapter 5 *self-care* (6 categories). Chapter 2 *general tasks and demands* is represented by 4 categories, chapter 6 *domestic life* by 3, chapter 7 *interpersonal interactions and relationships* by 4, chapter 8 *major life areas* by 5, and chapter 9 *community, social and civic life* by 2 categories.

The 33 categories of the component *environmental factors* represent 45% of the total number of ICF categories at the second level in this component. All 5 chapters of this component are represented in the *Comprehensive ICF Core Set*. Most of the *environmental factors* selected belong to chapter 5 *services, systems and policies* (10 categories). Chapter 1 *products and technology* is included with 8 categories, chapter 3 *support and relationships* and chapter 4 *attitudes* are both included with 7 categories, and chapter 2 *natural environment and human-made changes to the environment* with 1 category.

Brief ICF Core Set

The Brief ICF Core Set comprises a total of 18 categories, which represent 14% of the categories chosen in the *Comprehensive ICF Core Set*. The Brief ICF Core Set includes 6 categories from the *Comprehensive ICF Core Set* in the component *body functions* (15%), 2 categories (40%) from *body structures*, 7 (14%) from *activities and participation* and 3 (9%) from *environmental factors*. The 6 *body functions* categories represent 10% of the total number of second-level ICF categories in this component, the 2 categories from *body structures* 4%, the 7 categories from *activities and participations* 6%, and the 3 categories from *environmental factors* 4%.

All ICF categories taken into account in the final decision process are presented in Table V. However, a preliminary cut-off was established at 50% to reflect majority opinion.

DISCUSSION

The formal consensus process integrating results from preliminary studies and expert knowledge at the 2nd ICF Core Sets Conference led to the definition of a Brief ICF Core Set and a *Comprehensive ICF Core Set* for multidisciplinary assessment.

The main challenge to the expert panel during the conference was to select a sufficiently small number of categories for feasible ICF Core Sets in a condition with such a great variability and complexity as stroke. Experts were also confronted with the difficult task during the conference to overcome the disease perspective on acute stroke and to emphasize in contrast the functioning perspective in the long-term disabling condition stroke.

As stroke can affect any part of the brain, the large number of *body functions* areas considered relevant is not surprising. Among the *body functions* included in the *Comprehensive ICF Core Set* for stroke *mental functions, neuromusculoskeletal and*

Table V. *International Classification of Functioning, Disability and Health (ICF) – categories included in the Brief ICF Core Set for stroke and percentage of experts willing to include the named category in the Brief ICF Core Set. 50% represent a preliminary cut-off. >50% is bold*

ICF component	%	ICF code	ICF category title
Body functions	100	b110	Consciousness functions
	86	b114	Orientation functions
	82	b730	Muscle power functions
	75	b167	Mental functions of language
	50	b140	Attention functions
	25	b144	Memory functions
Body structures	100	s110	Structure of brain
	7	s730	Structure of upper extremity
Activities and participation	100	d450	Walking
	100	d330	Speaking
	93	d530	Toileting
	68	d550	Eating
	50	d510	Washing oneself
	43	d540	Dressing
	4	d310	Communicating with – receiving – spoken messages
Environmental factors	93	e310	Immediate family
	43	e355	Health professionals
	29	e580	Health services, systems and policies

movement-related functions and *sensory functions and pain* are covered in great depth. Overall, the selected categories are largely consistent with the well-known manifestations of the underlying pathology (7). Categories from the above-mentioned chapters are also included in the Brief ICF Core Set. However, the Comprehensive ICF Core Set for stroke contains some further categories. *Functions of the cardiovascular system (heart functions, blood vessel, and blood pressure functions)* and *exercise tolerance functions* were regarded as important features of patients' functioning to be recorded in comprehensive, multidisciplinary assessment for providing information on crucial prerequisites for rehabilitation intervention management and secondary prevention. Also *sexual functions* were selected for the *Comprehensive ICF Core Set* marking an important aspect in patients' disability experience (24, 25) that according to experts' opinion should not be neglected.

In contrast, *body structures* affected by stroke can be described with comparatively few categories. Consistent with the main organ systems involved, the selected categories include the *structures of the brain* and of the *cardiovascular system*. In addition, also changes in *structures related to movement (shoulder, upper and lower extremities)* were considered relevant. These categories point to the long-term effects of typical motor and sensory impairments on muscular, joint and other movement related body structures, as it can be seen for example in shoulder-hand syndrome in hemiplegia.

Limitations and restrictions in *activities and participation* may indeed be most relevant to patients with stroke. This is reflected by the fact that most categories included in the Comprehensive ICF Core Set belong to this ICF component. All aspects of patients' everyday activities and involvement in life situations are represented showing that stroke inserts an overall effect on patients' lives. The areas that are covered represent key issues for patients with stroke, including *mobility, self-care, communication, and learning*.

About two-thirds of the *activities and participation* categories, that were pre-selected by means of the preliminary studies and entered the decision process were considered being relevant for stroke patients. Only one-third of the pre-selected ICF categories was excluded by the expert panel, some of them being not specifically related to stroke (e.g. *producing messages in formal sign language*), or being by definition rarely an issue in the targeted adult population (e.g. *school education, learning to read*). Several categories of the ICF component *activities and participation* were subject to controversial discussion. In a number of cases, ICF categories of the *activities and participation* component were considered being highly related to specific impairments of *body functions*, and decision was difficult because experts disagreed whether to include the corresponding categories from both components or to make a selection to accomplish more feasible *ICF Core Sets* without redundancy of categories. For example the *activities and participation* category d110 *watching* was excluded because experts regarded the typical aspects of patients' disability in this area being sufficiently and more adequately represented by the *body functions* category b210 *seeing functions* that was therefore included in the Comprehensive ICF Core Set. In other cases, experts considered ICF categories of the *activities and participation* component being related to each other in a way that may display a hierarchy of burden to the patient (e.g. d760 *family relationships* and d730 *relating with strangers*), thus it was discussed and decided to select out of this related categories the more burdensome one (e.g. d760 *family relationships*), even though patients' functioning may also be limited in the area described by the dismissed categories.

The component *environmental factors* is represented by a large number of 33 categories from the full scope of ICF chapters, which demonstrates the awareness of the important influence of patients' surroundings and life situations on their health and also on the course of rehabilitation. *Products*

and technology, as well as services, systems and policies, support and relationships, and attitudes are highly important to patients with stroke because they can serve as either a barrier or a facilitator and may therefore influence stroke outcome.

The chapter *products and technology* includes matters like assistive devices, means of transportation or the features of buildings. These *environmental factors* obviously play a significant role for patients' functioning, despite limited evidence on associations between barriers in the physical environment, accessibility, and technology on the one hand and functioning on the other hand (26). But also medication (e110 *products or substances for personal consumption*) is included in this chapter, which is important not only in acute stroke care but also in rehabilitation and secondary prevention. Medication may influence stroke patients' functioning being a barrier, e.g. due to adverse events, while for example antidepressant medication (27, 28) or botulinum toxin treatment (29, 30) may improve functioning following stroke.

With regard to the influence of *services, systems and policies* on functioning after stroke, in general, there is little research. While experience clearly indicates a considerable impact of these *environmental factors*, the influence of different types of health services (e.g. stroke unit care and rehabilitation interventions) on stroke outcome is the only well documented field (31–33). Thus, it is not surprising that the expert panel regarded the category e580 *health services, systems and policies* among the most important *environmental factors* and also included it into the Brief ICF Core Set for stroke.

The importance of the social environment (social support and attitudes) for patients' functioning is a widely accepted but also a rarely investigated issue. The experts acknowledged support by the family as the most important environmental factor for stroke patients and included it also in the Brief ICF Core Set. Findings from several studies confirm the influence of the family on stroke outcome (34).

The Comprehensive ICF Core Set for stroke is the largest of the ICF Core Sets developed for the 12 most burdensome chronic conditions. The large scope of categories included in the Comprehensive ICF Core Set reflects the important and complex impairments, limitations, and restrictions of *activities and participation* involved, as well as the numerous interactions with *environmental factors*. The selected categories for the Brief ICF Core Set account for the fundamental and most striking aspects of stroke-related functioning. However, the importance of the extensive validation of this first version of the ICF Core Sets from the perspective of different professions and in different countries has to be pointed out. The first version of the ICF Core Sets will also be tested in the view of patients and in different clinical settings. It is important to stress that this first version of the ICF Core Sets is only recommended for validation or pilot studies.

Regarding the comprehensiveness of the ICF, it is most interesting to note that the panel of experts did not identify problems of patients' functional health not contained in the ICF. This emphasizes the validity of the ICF classification,

which was based on a painstaking international development process. Nevertheless, the expert panel expressed the strong conviction that "personal factors" that are not classified yet by the ICF play a very important role in patients' functioning and health, and should therefore be considered in future.

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