

ICF CORE SETS FOR OBSTRUCTIVE PULMONARY DISEASES

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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 a Brief ICF Core Set for obstructive pulmonary diseases.

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 287 ICF categories at the second, third and fourth ICF levels with 97 categories on *body functions*, 33 on *body structures*, 104 on *activities and participation*, and 53 on *environmental factors*. Seventeen experts from 8 different countries attended the consensus conference on obstructive pulmonary diseases. Altogether 67 second-level and 4 third-level categories were included in the Comprehensive ICF Core Set with 19 categories from the component “body functions”, 5 from “body structures”, 24 from “activities and participation” and 23 from “environmental factors”. The Brief ICF Core Set included a total of 17 second-level categories with 5 on “body functions”, 3 on “body structures”, 5 on “activities and participation” and 4 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 obstructive pulmonary diseases. Both the Comprehensive ICF Core Set and the Brief ICF Core Set were defined.

Key words: chronic obstructive pulmonary diseases, asthma, health status, outcomes research, quality of life, ICF.

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INTRODUCTION

Chronic obstructive pulmonary diseases (OPD) and asthma are the most common conditions associated with chronic airflow limitations. They carry a high burden of disease, and chronic OPD is projected to become the fifth leading cause of years lived with disability (1). Chronic OPD and asthma differ with regard to age, risk factors, course, and treatment (2, 3). However, both conditions share many symptoms and functional limitations.

The recognition of the importance of systematically assessing symptoms and functional limitations to optimize the management of chronic OPD and asthma has led to the development and use of a number of condition-specific health-status measures. A number of organizations, including the American Thoracic Society (4, 5), the American College of Chest Physicians, the American Association of Cardiovascular and Pulmonary Rehabilitation (6, 7), and the National Heart, Lung, and Blood Institute collaborating with WHO (2), have reviewed the use and properties of currently available health-status measures for chronic OPD. However, none of these organizations has made recommendations regarding the use of specific health-status measures or provided a systematic framework that covers the spectrum of symptoms and limitations in functioning of patients with OPD.

With the approval of the new International Classification of Functioning, Disability and Health (ICF, formerly ICIDH-2 <http://www.who.int/classification/icf>) (8), we can now rely on a globally-accepted framework and classification to define the typical spectrum of problems in functioning of patients with OPD. For practical purposes and in line with the concept of condition-specific health-status measures, it would be most helpful to link specific conditions or diseases to salient ICF categories of functioning (9). Such generally-agreed-upon lists of ICF categories can serve as a Brief ICF Core Set to be rated in all patients included in a clinical study with OPD or as a Comprehensive ICF Core Set to guide multidisciplinary assessments in patients with OPD. 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 OPD – the Comprehensive ICF Core Set and the Brief ICF Core Set.

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

ICF code	ICF category title	
2nd level	3rd level	
b130		Energy and drive functions
b134		Sleep functions
b152		Emotional functions
	b1522	Range of emotion
b280		Sensation of pain
	b2801	Pain in body part
b310		Voice functions
b410		Heart functions
b430		Haematological system functions
b435		Immunological system functions
b440		Respiration functions
b445		Respiratory muscle functions
b450		Additional respiratory functions
b455		Exercise tolerance functions
b460		Sensations associated with cardiovascular and respiratory functions
b530		Weight maintenance functions
b730		Muscle power functions
b740		Muscle endurance functions
b780		Sensations related to muscles and movement functions

METHODS

The development of the ICF Core Sets for OPD involved a formal decision-making and consensus process integrating evidence gathered from preliminary studies including a Delphi exercise (10), a systematic review (11) and an empirical data collection using the ICF checklist (12). 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.

The principals followed during the consensus conference regarding the organization, recruitment of the participants, training in the ICF, and the decision-making process has been described elsewhere (13).

RESULTS

The tables on the pre-conference studies presented to the participants included 287 ICF categories at the second, third and fourth levels (97 on *body functions*, 33 on *body structures*, 104 on *activities and participation*, and 53 on *environmental factors*).

Seventeen experts from 8 different countries attended the consensus process for OPD. The professional background of the experts (11 physicians with various sub-specializations; 4 physical therapists, 1 psychologist and 1 nurse) covered the wide spectrum of limitations in functioning that occurs in patients with OPD. The decision-making process for OPD involved 3 working groups, 2 with 6 and 1 with 5 experts, respectively. The process was facilitated by the condition co-ordinator for OPD (TS) and the 3 working-group leaders (AG, AS, DW).

Tables I–IV show the second- and third-level ICF categories included in the Comprehensive ICF Core Set. Table V shows the second-level ICF categories that were selected for the Brief ICF Core Set, as well as the percentage of experts willing to

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

ICF code	ICF category title
s410	Structure of cardiovascular system
s430	Structure of respiratory system
s710	Structure of head and neck region
s720	Structure of shoulder region
s760	Structure of trunk

include the named category in the Brief ICF Core Set. In addition Table VI shows categories that were discussed controversially but not included in both ICF Core Set.

Comprehensive ICF Core Set

The number of second- and third-level categories in the Comprehensive ICF Core Set is 71, with 67 categories on the second level and 4 categories on the third level. The 71 categories of the Comprehensive ICF Core Set are made up of 19 (27%) categories from the component *body functions*, 5 (7%) from the component *body structures*, 24 (34%) from the component *activities and participation*, and 23 (32%) from the component *environmental factors*.

Body functions. Seventeen of the 19 categories of the component *body functions* are at the second level of the classification and 2 at the third level of the classification. The 17 categories at

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 obstructive pulmonary diseases*

ICF code	ICF category title	
2nd	3rd	
d230		Carrying out daily routine
d240		Handling stress and other psychological demands
d330		Speaking
d410		Changing basic body position
d430		Lifting and carrying objects
d450		Walking
d455		Moving around
d460		Moving around in different locations
d465		Moving around using equipment
d470		Using transportation
d475		Driving
	d4750	Driving human-powered transportation
d510		Washing oneself
d540		Dressing
d570		Looking after ones health
d620		Acquisition of goods and services
d640		Doing housework
d650		Caring for household objects
d660		Assisting others
d770		Intimate relationships
d845		Acquiring, keeping and terminating a job
d850		Remunerative employment
d910		Community life
d920		Recreation and leisure

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

ICF code	ICF category title
2nd 3rd	
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
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
e225	Climate
e245	Time-related changes
e2450	Day/night cycles
e260	Air quality
e310	Immediate family
e320	Friends
e340	Personal care providers and personal assistants
e355	Health professionals
e410	Individual attitudes of immediate family members
e420	Individual attitudes of friends
e450	Individual attitudes of health professionals
e460	Societal attitudes
e540	Transportation services, systems and policies
e555	Associations and organizational services, systems and policies
e575	General social support services, systems and policies
e580	Health services, systems and policies
e585	Education and training services, systems and policies
e590	Labour and employment services, systems and policies

the second level represent 12% of the total number of ICF categories at the second level in this component. With exception of chapter b6 *genitourinary and reproductive functions* and chapter b8 *functions of the skin and related structures*, all *body-*

functions chapters are represented in the Comprehensive ICF Core Set.

Most of the *body-functions* categories belong to the *additional functions and sensations of the cardiovascular and respiratory systems* (6 categories). Also *immunological and haematological system functions*, part of chapter 4, are covered by 1 category each.

Chapter 1 *mental functions* is represented by 3 categories at the second level and the category b1522 *range of emotion* at the third level. The asthma associated mood disorders depression and anxiety were emphasized in particular (14, 15), whereas for COPD the situation is less clear (16, 17). There was great consensus about the potential deleterious sleep disturbances in asthma (18, 19) and COPD (20, 21) patients.

Chapter 7 *neuromusculoskeletal and movement-related functions* is represented by 3 categories at the second level, and chapter 5 *functions of the digestive, metabolic and endocrine systems* as well as chapter 3 *voice and speech functions* by 1 category, respectively. Four categories of these chapters were discussed controversially but not included in the ICF Core Sets. For example, b5105 *swallowing* was considered important by some group members, as supported by the literature (22–24). More details are given in Table VI.

Chapter 2 *sensory functions and pain* is represented by the third level category b2801 *pain in body part* and by its corresponding second level category b280 *sensation of pain* of which it is a member.

Body structures. The 5 categories of the component *body structures* represent 9% of the total number of ICF categories at the second level in this component. Two categories belong to the *structure of respiratory and cardiovascular system* (chapter 4). Alterations in the *structure of cardiovascular system* were considered by some experts to represent either a comorbidity or a complication, e.g. pulmonale. However, the category was included taking into account the well-known

Table V. *Brief ICF Core Set for OPD* and the percentage of experts willing to include the named category in the Brief ICF Core Set. 50% represent a preliminary cut-off. >50% is in bold typeface*

ICF component	%	ICF code	ICF category title	
Body functions	100	b440	Respiration functions	
	100	b455	Exercise tolerance functions	
	92	b460	Sensations associated with cardiovascular and respiratory functions	
	75	b450	Additional respiratory functions	
	50	b740	Muscle endurance functions	
	100	s430	Structure of respiratory system	
Body structures	83	s410	Structure of cardiovascular system	
	50	s760	Structure of trunk	
	100	d450	Walking	
Activities and participation	100	d455	Moving around	
	58	d230	Carrying out daily routine	
	58	d640	Doing housework	
	50	d540	Dressing	
	Environmental factors	100	e260	Air quality
		100	e110	Products or substances for personal consumption
75		e115	Products and technology for personal use in daily living	
67		e225	Climate	

* OPD = obstructive pulmonary diseases.

Table VI. *International Classification of Functioning, Disability and Health (ICF) – categories that were discussed controversially but not included in the ICF Core Sets*

ICF component	ICF code	ICF category title	Arguments that were discussed
Body functions	b510	Ingestion functions	Swallowing is critical in severe OPD patients, as supported in the literature (22), but was not considered primarily being affected by OPD.
	b535	Sensations associated with the digestive system	Specially feeling bloated (b5351) was considered by some members, others focused on disturbance of the thoracoabdominal motion (40, 41). The prevalence of those symptoms is considered to be low.
	b620	Urination functions	Incontinence might be increased by dyspnoea and cough (42). Considered as a separate condition.
	b710	Mobility of joint functions	Same arguments as for b735.
	b735	Muscle tone functions	Hypertonus of the muscles of the shoulder girdle and of the intercostal muscles may influence a wrong breathing technique. Considered to be related rather to muscle weakness of the upper limb muscles (43, 44).
Activities and participation	d350	Conversation	These categories were considered relevant only in very severe OPD patients and not representing all the OPD patients.
	d355	Discussion	
	d530	Toileting	
	d550	Eating	
	d720	Complex interpersonal interactions	
Environmental factors	d760	Family relationships	Not chosen because wording of chapter 3 indicates only facilitators.
	e350	Domesticated animals	

alterations in the pulmonary vascular system in patients with OPD (25).

Three additional categories belong to *structures related to movement* (chapter 7). Regarding *structure of trunk* (s760), structural changes in inspiratory muscles were mentioned (26). The inclusion of *structure of head and neck* (s710) as well as *structure of shoulder region* (s720) was discussed controversially. The physical therapists mentioned that the frequent shoulder and neck problems in OPD patients might be due to structural changes, others pointed out a lack of literature supporting this point of view.

Activities and participation. The 24 categories of the component *activities and participation* represent 20% of the total number of ICF categories at the second level in this component. Most of the *activities and participation* categories belong to chapter 4 *mobility* (9 categories). However, with exception of chapter 1 *learning and applying knowledge* all 9 chapters of this component are represented in the Comprehensive ICF Core Set. Chapter 6 *domestic life* is represented by 4 categories, chapter 5 *self care* by 3 categories, chapter 2 *general tasks and demands*, chapter 8 *major life areas* and chapter 9 *community, social and civic life* by 2 categories, respectively. Chapter 3 *communication* as well as chapter 7 *interpersonal interactions and relationships* are represented by 1 category.

The importance of many various categories was highlighted by the different occupational groups, e.g. the psychologists pointed out that *handling stress and other psychological demands* (d240) may be strongly affected by the impaired breathing illustrated by the association between stressful events and subjects asthma (27, 28) and vice versa.

In contrast, some categories in this component were con-

sidered relevant in a minor number of patients only and therefore not included in the ICF Core Sets. A summary of the details is given in Table IV.

Environmental factors. The 23 categories of the component *environmental factors* represent 31% of the total number of ICF categories at the second level in this component. Most of the *environmental-factors* categories belong to chapter 5 covering in much detail, e.g. *general social support, health, education and training services, systems and policies* (6 categories). The positive relationship between social support and chronic illness self-management in asthma (29) as well as in chronic OPD (30, 31) was emphasized. However, all 5 chapters of this component are represented in the Comprehensive ICF Core Set. Chapter 1 *products and technology* including, for instance, inhaler devices is represented by 5 categories. Chapter 2 *natural environment and human-made changes to environment*, e.g. *air quality and climate*, as well as chapter 3 *support and relationships* and chapter 4 *attitudes* are represented by 4 categories.

Regarding the category *domesticated animals* (e350) the situation was less clear. Since the wording of chapter 3 seems to be only indicating “facilitators”, the condition group did not include this category.

Brief ICF Core Set

The Brief ICF Core Set comprises 17 categories. Five categories (29%) were chosen from the component *body functions*, 3 (28%) from *body structures*, 5 (29%) from *activities and participation*, and 4 (24%) from *environmental factors*. Exclusively categories at the second level were included.

The 5 categories of the component *body functions* represent 3%, the 3 categories of the component *body structures* 5%, the 5

categories of the component *activities and participation* 4% and the 4 categories of the component *environmental factors* 5% of the total number of ICF categories at the second level in their respective components.

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.

Within the component *body functions*, the category b445 *respiratory muscle functions* and the category b410 *heart functions* were considered relevant according to a ranking exercise performed before the final vote, but were not selected to be included in Brief ICF Core Set. The same is true for the categories within the component *activities and participation*: d510 *washing oneself*, d920 *recreation and leisure*, and d845 *acquiring, keeping and terminating a job* and the categories within the component *environmental factors*: e355 *health professionals* and e310 *immediate family*.

DISCUSSION

The formal consensus process integrating evidence from preliminary studies and expert knowledge at the third ICF Core Sets Conference resulted in the definition of the Brief ICF Core Set and the Comprehensive ICF Core Set for multi-disciplinary assessment.

A major challenge was raised at the beginning of the consensus process regarding the inclusion of asthma in the definition of the umbrella term OPD. Symptoms of asthma are considerably more episodic and of sudden onset in contrast to those of chronic OPD, and periods of prolonged remission may be typical. However, many symptoms presented by patients do not clearly relate exclusively to either asthma or chronic OPD, and the distinction between these conditions can become quite difficult, especially when chronic OPD is complicated by acute viral or irritant-induced bronchospasm, for example. It was decided to include asthma under the umbrella term OPD by keeping in mind the need to focus on patients in more severe stages with some degree of fixed airflow obstruction. Although chronic OPD and asthma account for most obstructive lung diseases, a broad spectrum of disorders, including bronchiectasis, upper-airway lesions, bronchiolar diseases and some interstitial lung diseases are associated with airflow obstruction. It was decided not specifically to consider these less common forms of obstructive lung diseases.

A general point raised on multiple occasions during the consensus process was the time sequence of functional limitations and disability in OPD. As supported by the high rates of undiagnosed chronic OPD in patients (32, 33), chronic OPD might be present with very few symptoms at the onset of the disease. In later disease stages, patients experience a variety of functional limitations, body-structure changes and limitations of activity, and restrictions of participation. Therefore, the Comprehensive ICF Core Set may contain functioning and disability categories related to the health condition OPD not necessarily relevant to all patients.

The condition group noticed that some individual clinical and aetiological factors are difficult to describe adequately in the ICF. It was not clear how important surrogate parameters, such as forced expiratory volume in the first second (FEV₁), which are frequently used in clinical-trial settings, are to be represented. Also genetic factors associated with asthma (34) and chronic OPD (35) cannot be classified, as they are personal factors. The classification of personal factors, although part of the ICF framework, has not been developed by the WHO.

Another important issue discussed during the conference was the behaviour smoking, which was considered not to have been clearly included in the ICF. It was argued that smoking is partly covered by the *body-function* category b1303 *craving and the environmental-factor* category e260 *air quality* and that it can even be considered as a personal factor when smoking is deemed a habit. Therefore, although some participants might have wished to include it explicitly in the ICF Core Sets, smoking has not yet been included. This should, therefore, be considered during the testing phase of the ICF Core Sets.

A number of issues were raised with respect to the 4 main components of the ICF.

The selection of *body functions* included in the Comprehensive ICF Core Set showed results consistent with the organ functions usually involved in OPD and in agreement with the evidence from the preliminary studies. Thus, especially the categories of the respiratory system are covered in great depth.

Several categories that are part of the *digestive, metabolic and endocrine systems* and *neuromusculoskeletal and movement-related functions* were not included in the ICF Core Sets. The reasons are given in Table IV.

The selection of *body structures* included those structures most affected by OPD, obviously the *structure of respiratory system* (36–38) and the *structure of trunk* containing inspiratory muscles. There was a controversy concerning *structure of head and neck and shoulder region*. These 2 categories were not included in the Brief ICF Core Set because of a considerable redundancy with *structure of trunk*.

The areas that are covered by the *activities and participation* component represent key issues for patients with OPD. *Mobility, domestic life, and self care*, are represented in depth in the Comprehensive ICF Core Set and also in the Brief ICF Core Set. Similarly, these domains are also covered in health-status measures frequently used for patients with chronic OPD (39–41).

Regarding *environmental factors*, it is significant that 23 categories, representing 32% of the categories of the Comprehensive ICF Core Set, belong to the component *environmental factors*. There was a general agreement that *air quality*, as well as *products and substances for personal consumption* (e110, including *drugs*), affect the clinical course in OPD. Accordingly, both ICF Core Sets include the chapter *products and technology for personal use in daily living* (e115), including inhaler devices and *natural environment (climate) and human-made changes to environment (air quality)*. Whether the category *domesticated animals* (e350) should be included was controversial.

The aim to create a mandatory Brief ICF Core Set short enough to be practical in clinical studies resulted in a noticeable reduction to 17 categories. Since the category *respiration functions* (b440) was considered too general to cover the item FEV₁, the experts recommended specification of this domain.

The condition group experienced some difficulties in determining cut-offs for the Brief ICF Core Set, i.e. some experts suggested including only the category *structure of respiratory system* (s430) as part of the component *body structures* of the Brief ICF Core Set.

The breadth of ICF chapters contained in the Comprehensive ICF Core Set reflects the important and complex impairments, activity limitations, and participation restrictions in patients with OPD, as well as numerous interactions with *environmental factors*. Regarding the comprehensiveness of the ICF, it is most interesting to note that the panel of experts did not identify problems of patients not contained in the ICF, except the specification of the respiratory parameter including FEV₁. This emphasizes the validity of the ICF classification, which was based on an international development process.

Although the participants could have defined the categories not only by the second, but also by the third or fourth levels of the classification, it was decided, with the exception of 4 categories, to keep the items included in the ICF Core Sets at the second level.

The organizers of the consensus process took much care in the selection of the experts and were successful in recruiting 17 experts with different professional backgrounds and from 8 different countries. Nevertheless, the results of any consensus process may differ with different groups of experts. This emphasizes the importance of the extensive validation of this first version of the ICF Core Sets from the perspectives of different professions and in different countries. The validation studies will enable the inclusion of social and cultural factors, which may have not been sufficiently considered during the conference. The first version of the ICF Core Sets will also be tested from the patients points of view and in different clinical settings. It is important to note that this first version of the ICF Core Sets is only recommended for validation or pilot studies.

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