# DEVELOPMENT OF CONSENSUS INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF) CORE SETS FOR LYMPHEDEMA

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### ABSTRACT

To understand the challenges of patients with lymphedema it is important to describe functioning and to measure the effectiveness of treatment in changing functioning. The International Classification of Functioning, Disability and Health (ICF) offers an international framework to classify functioning of persons in their personal environment. ICF Core Sets are lists of selected ICF categories concerning those important aspects of functioning that are most likely to be affected by a specific health problem or disease. These Core Sets make it easier and faster to describe and communicate the patient's problems and to define treatment goals. Furthermore, they are available to health care providers of all professions, researchers, health insurance companies and policy-makers. The objective of this document is to present the outcomes of a consensus conference held to determine the first versions of the ICF Core Sets for lymphedema. Frequency rankings were made of the ICF categories derived from four preparatory studies, being: a) a systematic

review; b) a qualitative study; c) an expert survey; and d) a cross-sectional study. By means of working group discussions and plenary sessions, a final consensus on ICF categories was achieved and Comprehensive and Brief Core Sets for lymphedema for the upper limb, lower limb, and midline lymphedema were defined. These ICF Core Sets contain different items in each region. Future validation of these Core Sets for health professions and for countries is needed.

**Keywords:** International Classification of Functioning, Disability and Health (ICF), ICF Core Set, lymphedema, function, disability, consensus

Professionals working in lymphology (e.g., health professionals, researchers, health insurance companies and policy makers) often have different terminologies, frameworks, and approaches, which can make the communication regarding health problems challenging. A common generally accepted framework and terminology (term sets) could facilitate comparability of research findings

and clinical outcomes (1) and improve the communication process among health professionals, researchers, health insurance companies, the government, and patient organizations (2). Such a framework can be provided by the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO) (3). The approval of the ICF in 2001, provides a universal conceptual framework of domains and classifications to describe the functioning of individuals suffering from lymphedema. The ICF describes functioning and disability of a patient as a result of the interaction between different components: body functions (b), body structures (s), activities and participation (d), environmental factors (e), and personal factors (4). The system contains a hierarchical structure, using first, second, third, and fourth levels. However, using the entire ICF with over 1,400 categories is very time-consuming, and its use in daily practice is not very practical. Therefore, focused lists of items (categories) that are relevant and important for patients with lymphedema (Core Sets) are needed (5,6). There are two versions of the ICF Core Sets: a Comprehensive and a Brief set of categories and codes. The Comprehensive Core Set is a list of ICF categories that describes the problems in functioning of patients with lymphedema in a multidisciplinary assessment. The Brief ICF Core Set is a list of ICF categories that are essential to describe the impairments, limitations, and restrictions in functioning and the environment of patients with lymphedema, and at the same time short enough to be practical in clinical studies or trials (4,7). These sets of ICF categories allow health professionals to classify and describe an individual's functioning using a universal and standardized language. In this way the Core Sets offer a chance for international studies and the possibility to compare the impact of different conditions, especially if used in electronic health care records.

To date, ICF Core Sets have been

developed for several chronic conditions (4,7-9). The objectives of this paper are: (1) to describe the consensus process, and (2) to present the lists of ICF categories and codes within the Comprehensive and Brief ICF Core Sets for lymphedema.

#### **METHODS**

The development of ICF Core Sets for lymphedema started as a cooperative effort in a Steering group of the Erasmus Medical Centre (Department of Dermatology) in Rotterdam and the Dutch Institute of Allied Health Care in Amersfoort, under guidance of the Dutch WHO Collaborating Centre for the Family of International Classifications (WHO-FIC) in Bilthoven (all in the Netherlands) (Fig. 1).

## Overview of the Process

The ICF Consensus Conference took place on the 4th of June, 2014 preceding the 5th congress of the International Lymphedema Framework in Glasgow, United Kingdom. Data from four preparatory studies were sent to experts before the conference, and outcomes of the preparatory studies were briefly reported at the beginning of the process. Preparatory studies included a systematic review of questionnaires used in lymphedema studies (10), a survey of international experts involved in lymphedema (n = 142) (publication in preparation), a study of focus group of patients with lymphedema (qualitative study) (11), and a cross sectional study which took place in both The Netherlands (n= 200) (12) and in Australia (n = 93) (publication in preparation). A division in three regions was made: upper limb, lower limb, and midline lymphedema, because each of these lymphedema regions might cause specific functioning problems. Afterwards, the frequencies of every occurring ICF category were ranked for each study region, with the most occurring frequency given the lowest rank (number 1) and so on. The frequencies

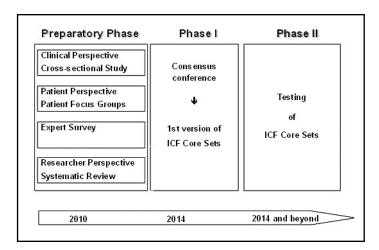


Fig. 1. Development of ICF Core Sets for lymphedema: phases of the project.

of registered ICF categories from the Netherlands and Australian cross sectional studies were combined to obtain a total data set. Next, the total ranking numbers between the separate studies were equalized due to different numbers of ICF categories per study. Then, frequency rankings of the defined ICF category of all studies were summed up resulting in a final list of ranked ICF categories for each region separately. These ranking lists were divided into three parts: the first 100 and second 100 categories (divided by a red line) and the remaining categories (divided by a blue line). Finally, these rankings of ICF categories were presented to the consensus participants (experts) as an Excel file. In column 1, the ICF code was provided and the title of the code was shown under column 2. In column 3 the total frequency was provided and in column 4 the ranking of the total. The frequency of the ICF categories, as well as the rankings found in each separate study (empirical study, expert survey, systematic review and qualitative study) were also presented (columns 5 to 12).

# Recruitment of Conference Participants

Experts in the field of lymphedema were invited to participate in the consensus.

No remuneration or honorarium was paid to the experts who agreed to attend. In order to identify the most active experts, a steering committee formed before development of ICF Core sets was consulted. Furthermore, invitation was based on scientific publications, professional background, informal network, and region of residence (13).

#### Consensus Process

Four weeks preceding the conference, the expert participants were provided with information on the ICF and the Excel documents were sent by email. At the beginning of the conference, results of the four preparatory studies were presented and printed copies were given to the participants. Afterwards, the procedural steps of the consensus meeting were explained and the participants were divided into three expert groups (i.e., upper limb, lower limb, and midline). Each group was moderated by a member of the Steering Group and a secretary was allocated to each group. Both the moderator and the secretary were not allowed to participate in the discussion and voting process. In each group, experts openly discussed arguments in favor of or against the uptake of the ICF category in the Comprehensive Core Set. In a first

step, each group had to come to a Comprehensive Core Set. Experts had to choose from the first 100 rankings (above the red line) those ICF categories that they considered essential. They could argue to add ICF categories from the second 100 rankings (above the blue line) and – only with very strong arguments - from the categories below the blue line. When the group came to consensus (i.e., when more than 50% of the members of the working group were in favor), a first version of the Comprehensive Core Set was defined. In a second step, experts individually had to choose 10 categories from the Comprehensive Core Set which they felt to be important in lymphedema, being a part of the Brief Core Set. Afterwards, these categories were discussed in the working group and consensus had to be reached. When both the Comprehensive and the Brief Core Set were defined in each working group, a plenary session took place. In this session, experts had the opportunity to discuss the Core Sets findings of the other working groups as the final consensus discussion. After the conference, the Steering Group discussed both the process as well as the results and had the opportunity for small alterations to the final versions.

### RESULTS

Twenty-three experts participated in the consensus conference. Six were physicians, seven physical therapists, three nurses, five stocking suppliers, one occupational therapist, and one skin therapist. The countries where they practiced were: Australia, Belgium, Canada, Germany, Israel, Italy, The Netherlands, Sweden, the United Kingdom, and United States. These countries represent WHO regions: North America, Europe, and Western Pacific. Based on results for the three lymphedema regions using first, second, third, and fourth level classifications from the four preparatory studies, Comprehensive and Brief ICF Core Set for lymphedema were developed.

The numbers of categories in the Comprehensive Core Sets were for the upper and lower extremity and midline (101, 111, and 89, respectively). For the Brief Core Sets they were 23, 18 and 20, respectively. *Table 1* shows the ICF categories that were included in the Comprehensive and Brief Core Sets. In *Table 2* the division of the ICF components is shown. *Table 3* shows the division of ICF levels in the different Core Sets. No first levels were selected, except for the Core Sets for the upper limb. Most of the categories came from the second and third level. Only 1 fourth level (in the Comprehensive Core Set for the lower limb) was included.

Concerning the Comprehensive Core Sets, some categories are mentioned in all Core Sets: 14 from the component Body Functions, three from Body Structure, 14 from Activities and Participation, and 15 from Environmental Factors. For the Brief Core Set the division is: two from Body Functions, two from Activities and Participation, and three from Environmental Factors. Because midline lymphedema can occur in different body parts (i.e., head and neck, breast and genital region), some categories for the Midline Core Sets concern all body parts and some are only applicable for those particular regions. For the Comprehensive Core Sets, 23 categories are applicable for all regions, 11 for the head and neck, and nine for the genital region. For the Brief Core Set, nine are applicable for all regions, one for the head and neck, one for the breast, and two for the genital region (see Fig. 2).

# **DISCUSSION**

Lymphedema is a complex health condition which presents itself in several ways. It can affect functioning of a patient in various ways, areas, and levels, and it involves different health professions, organizations, and policies. The ICF is a conceptual framework and classification system by the WHO with which this complexity can be

TABLE 1
Comprehensive and Brief Core Sets for the Upper Limb (UL), Lower Limb (LL) and Midline Region (M)

ICF code	Description	UL	LL	M
b1	CHAPTER 1 MENTAL FUNCTIONS	X		
b126	Temperament and personality functions			X(M)
b1261	Agreeableness		X	
b1263	Psychic stability	X (B)	X	
b1264	Openness to experience	X		
b1265	Optimism	X		
b1266	Confidence	X	X	
b130	Energy and drive functions			X (M)
b1301	Motivation	X	X (B)	
b134	Sleep functions	X	X	X
b152	Emotional functions	X	X (B)	X
b164	Higher-level cognitive functions	X (B)		X
b1644	Insight	X	X	X
b1646	Problem-solving		X	
b1670	Reception of written language		X	
b180	Experience of self and time functions			X(M)
b1801	Body image	X(B)	X(B)	X(B)
b260	Proprioceptive function	X	X	
b265	Touch function	X		X(M)
b2702	Sensitivity to pressure	X	X	
b280	Sensation of pain	X(B)	X(B)	X(B)
b415	Blood vessel functions		X	
b4150	Functions of arteries		X	
b435	Immunological system functions	X	X (B)	X (B)(M)
b4350	Immune response		X	X (M)
b4352	Functions of lymphatic vessels	X	X	X
b4353	Functions of lymph nodes		X	
b440	Respiration functions			X (M)
b455	Exercise tolerance functions		X (B)	X (B)(M)
b4550	General physical endurance	X (B)		
b4552	Fatiguability	X (B)	X	X
b5104	Salivation			X (H)
b5105	Swallowing			X (H)

<b>b530</b>	Weight maintenance functions	X	X	X
b540	General metabolic functions		X	X (M)
b5403	Fat metabolism	X		
b550	Thermoregulatory functions		X	
b620	Urination functions			X (G)
b640	Sexual functions	X	X	X (B)(M)
b7	CHAPTER 7 NEUROMUSCULOSKELETAL AND MOVEMENT-RELATED FUNCTIONS	X		
b710	Mobility of joint functions	X (B)		X(M)
b7101	Mobility of several joints		X (B)	
b730	Muscle power functions	X (B)		X (M)
b7303	Power of muscles in lower half of the body		X (B)	
b770	Gait pattern functions		X	X (G)
b780	Sensations related to muscles and movement functions	X	X	X
b810	Protective functions of the skin	X	X	X
b820	Repair functions of the skin	X	X	X
b840	Sensation related to the skin	X	X	X
d155	Acquiring skills	X	X	X (B)(M
d170	Writing	X		
d230	Carrying out daily routine	X(B)	X(B)	X(B)
d240	Handling stress and other psychological demands			X (B)(M)
d2400	Handling responsibilities	X		
d3	CHAPTER 3 COMMUNICATION	X		
d330	Speaking			X (H)
d350	Conversation			X (H)
d360	Using communication devices and techniques	X		
d4	CHAPTER 4 MOBILITY	X		
d410	Changing basic body position	X	X	X
d4100	Lying down		X	X (G)
d4101	Squatting		X	
d4102	Kneeling		X	
d4103	Sitting		X	
d4104	Standing		X	
d4105	Bending		X	
d415	Maintaining a body position	X		
	Maintaining a sitting position		X	X (G)
d4153			X	X (G)
d4153 d4154	Maintaining a standing position		^	A (G)
	Maintaining a standing position  Lifting and carrying objects	X	X	X

d445	Hand and arm use	X (B)		
d4452	Reaching	X		
d450	Walking	X	X (B)	X
d4500	Walking short distances		X	
d4501	Walking long distances		X	
d455	Moving around			X (B)(G)
d4551	Climbing		X	
d4552	Running		X	
d4554	Swimming	X		
d4600	Moving around within the home		X	
d4602	Moving around outside the home and other buildings		X	
d470	Using transportation			X(G)
d4702	Using public motorized transportation	X	X	
d475	Driving	X		X (G)
d4750	Driving human-powered transportation		X	
d4751	Driving motorized vehicles		X	
d5	CHAPTER 5 SELF-CARE	X (B)		
d510	Washing oneself	X	X	X
d520	Caring for body parts		X	X (B)(M)
d5200	Caring for skin	X	X	
d5202	Caring for hair	X		
d530	Toileting	X	X	X
d540	Dressing	X	X	X
d5402	Putting on footwear		X	
d5404	Choosing appropriate clothing	X		
d550	Eating			X (H)
d560	Drinking			X(H)
d570	Looking after one's health	X(B)	X(B)	X(B)
d5700	Ensuring one's physical comfort	X		
d5701	Managing diet and fitness	X (B)	X	
d5702	Maintaining one's health	X	X	
d620	Acquisition of goods and services			X (M)
d6200	Shopping	X	X	
d630	Preparing meals	X	X	
d640	Doing housework	X (B)	X	X
d6400	Washing and drying clothes and garments	X		
d6505	Taking care of plants, indoors and outdoors	X		
d660	Assisting others	X	X	

d7	CHAPTER 7 INTERPERSONAL INTERACTIONS AND RELATIONSHIPS	X		
d750	Informal social relationships			X (M)
d770	Intimate relationships	X (B)	X	X
d845	Acquiring, keeping and terminating a job		X (B)	
d850	Remunerative employment	X (B)	X	X (B)(M)
d870	Economic self-sufficiency	X		X (M)
d920	Recreation and leisure	X (B)	X	X (B)(M
d9201	Sports	X		X(M)
d9205	Socializing	X	X	X
e1101	Drugs	X	X	X
e1150	General products and technology for personal use in daily living	X	X	X
e1151	Assistive products and technology for personal use in daily living	X(B)	X(B)	X(B)
e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation		X	
e1300	General products and technology for education	X		
e135	Products and technology for employment		X	
e150	Design, construction and building products and technology of buildings for public use	X	X	
e155	Design, construction and building products and technology of buildings for private use	X	X	X
e1650	Financial assets		X	
e210	Physical geography		X	
e225	Climate	X	X	X
e2250	Temperature	X		X (M)
e3	CHAPTER 3 SUPPORT AND RELATIONSHIPS	X		
e310	Immediate family	X(B)	X(B)	X(B)
e320	Friends	X (B)	X	X (B)(M
e325	Acquaintances, peers, colleagues, neighbours and community members	X	X	X
e330	People in positions of authority	X	X	X
e340	Personal care providers and personal assistants	X	X	X
e355	Health professionals	X(B)	X(B)	X (B)
e410	Individual attitudes of immediate family members		X	X (M)
e420	Individual attitudes of friends	X	X	X
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	X (B)	X	X
e450	Individual attitudes of health professionals	X		X (M)
e460	Societal attitudes	X	X	X
e465	Social norms, practices and ideologies			X (M)
e555	Associations and organizational services, systems and policies			X (M)

e5550	Associations and organizational services	X	X	
e5600	Media services		X	
e570	Social security services, systems and policies	X		
e580	Health services, systems and policies		X (B)	X (M)
e5800	Health services		X	
e5801	Health systems	X		
e5850	Education and training services	X	X (B)	X
s330	Structure of pharynx			X (H)
s340	Structure of larynx			X (H)
s420	Structure of immune system	X	X	X
s4200	Lymphatic vessels	X	X	
s4201	Lymphatic nodes	X	X	
s630	Structure of reproductive system		X	X (M)
s6303	Structure of vagina and external genitalia		X	
s7	CHAPTER 7 STRUCTURES RELATED TO MOVEMENT	X		
s710	Structure of head and neck region	X		X (B)(H)
s720	Structure of shoulder region	X		X (H)
s730	Structure of upper extremity	X (B)		
s7300	Structure of upper arm	X		
s7302	Structure of hand	X		
s740	Structure of pelvic region		X	X (B)(G)
s750	Structure of lower extremity		X (B)	
s7500	Structure of thigh		X	
s7501	Structure of lower leg		X	
s75011	Knee joint		X	
s7502	Structure of ankle and foot		X	
s760	Structure of trunk	X	X	X (B)(Breast)
s7701	Joints		X	, , , , ,
s810	Structure of areas of skin	X	X	X

Bold = categories of the common part of the Comprehensive Core Set; Italics = categories of the common part of the Brief Core Set; (B) = Part of the Brief Core Set; (M) = categories of the common part of the midline region; (G) = categories of the genital region; (H) = categories of the head and neck region; (Breast) = category of the breast region.

addressed. With the use of the ICF, the consensus conference succeeded to identify Core Sets of variables that are important in lymphedema, with integrated data from preparatory studies. The results of this international consensus were: Comprehensive Core Sets for

Upper limb lymphedema (104 ICF categories), Lower limb lymphedema (111 ICF categories), and Midline lymphedema (89 ICF categories), and Brief Core Sets for upper limb (23 categories), Lower limb (8 categories), and Midline (20 categories) lymphedema.

TABLE 2
<b>Division of ICF Components in the Core Sets for Lymphedema</b>

	ICF components				
Core Set for lymphedema	<b>Body</b> functions	Body structures	Activities and Participation	Environmental factors	Total
Comprehensive UL	29	8	41	23	101
Comprehensive LL	32	14	40	25	111
Comprehensive M	29	9	30	21	89
Brief UL	8	2	9	4	23
Brief LL	8	1	4	5	18
Brief M	5	3	8	4	20
Total	111	37	132	82	362
UL = Upper Limb, LL =	Lower Limb, M	= Midline			

TABLE 3
Division of ICF Levels in the Core Sets for Lymphedema

	Number of levels of the ICF				
Core Set for lymphedema	1	2	3	4	Total
Comprehensive UL	8	56	40	0	104
Comprehensive LL	0	55	55	1	111
Comprehensive M	0	71	17	0	88
Brief UL	1	16	6	0	23
Brief LL	0	12	6	0	18
Brief M	0	18	2	0	20
Total	9	228	126	1	364

UL = upper limb, LL = lower limb, M = midline

The use of the ICF in patients with lymphedema is challenging because the ICF, which is based on the bio-psycho-social model, contains terms which can be used to describe not only functioning of the individual itself, but also the context in which he or she is living (3). Furthermore, the ICF provides a universal language and since lymphedema is a health condition which presents itself both in developed and on a large scale also in under-developed countries (14), its applicability in both cases is multifaceted.

The Core Sets contain all ICF components, stressing the variety and complexity of lymphedema. Unfortunately, personal factors, as part of the contextual factors, are not yet classified within the ICF, although various attempts have been made recently (15,16). Seven categories were mentioned in

all Core Sets leading to the most relevant topics in lymphedema, according to this group of experts: Body Image, Pain, Daily Routine, Hosiery, Family, Health Professionals, and Self-management. These items contain two categories from Body Functions, one from Activities and Participation, four from Environmental Factors and none of Body Structures. Although the shape of extremities and the midline region is important in lymphedema, experts seem to value the function of the lymphatics more than the form, which evidently is the outcome of the malfunction of the lymphatics. It is obvious that Environmental Factors are important, although the outcomes of the literature review show that these items are not examined on a large scale and are scarcely used in lymphedema specific questionnaires (10).

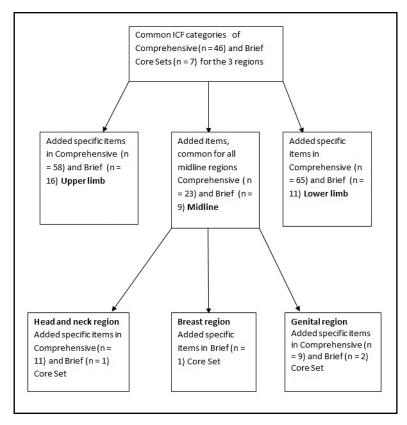


Fig. 2. Flow chart of the Comprehensive and Brief Core Sets.

The Brief Core Sets are developed to define a standard that can be used as the minimum dataset to be collected in patient evaluation or in clinical studies. When a minimum dataset in lymphedema is available, this could help in performing comparison across settings which would eventually enhance standardization of reporting evidence (e.g., treatment outcomes) (4). Currently the International Lymphedema Framework (ILF) is running a study to develop a minimal dataset as well (17). The Brief Core Sets could be implemented in this study.

Compared to other consensus conferences to develop ICF Core Sets (4,5), there are some points of special interest. Whereas other conferences lasted two or three days, this conference lasted only one day because of lack of financial support. The organization

managed to collect a representative group of experts for one day, preceding the 5th congress of the ILF in Glasgow. Despite the short time frame, it is expected that the developed Core Sets encompass a large proportion of the problems that patients with lymphedema encounter. Although other consensus procedures excluded first level categories in the Core Sets, in this Core Set first level categories appear in the Upper limb Core Sets. It was the definite will of this working group to include these first level categories. Future validation research will determine whether these categories will keep their place in the Core Sets. Another issue concerns the sample of experts being composed only from developed countries. This distribution of experts was quite similar to the pool of experts from the worldwide

expert survey which was also conducted as part of the Core Set development. The implication is that the Core Sets are developed with the focus on the health care systems in these countries. Future validation is needed in the under-developed countries to examine the usability of the Core Sets in these regions. Furthermore, the country of origin and skew distribution of the professional experts could be a confounder. Perhaps a greater number of skin therapists and occupational therapists could have led to more contribution from this point of view. Another limitation is the potential bias regarding patient selection in the preparatory qualitative and cross-sectional studies in The Netherlands (12). To compensate for this problem somewhat, one of the studies was also performed in Australia. Finally, a last bias can be the fact that quite a large proportion (9% of the Comprehensive Core Sets and 0.6% of the Brief Core Sets) of the ICF categories of below the blue line (rankings higher than 200, meaning these categories were scarcely mentioned in the preparatory studies), were included in the Core Sets. This could be due to the individual attitudes of experts in the working groups or to the fact that the working group decided to choose a higher level category to include a broader scope related to a health problem, leading to a subjective impact in these Core Sets. The Comprehensive ICF Core Sets for lymphedema integrate the experiences and needs of different health professions. The domains of the Core Sets can guide the patient-centered goal setting process in multidisciplinary settings, where resources and problems could be identified and profession-specific treatment goals can be identified. The identified categories help in multidisciplinary settings to assign patients to specific areas of expertise for evaluation and treatment, and for clinical-decision making (4). The categories of the Brief ICF Core Set can be used as a minimum set of domains to report in trials or intervention studies. It can also be used in independent clinical practice setting which would help clinicians compare

results and weigh the evidence of their results. (4). In the future, validation studies will be helpful in determining if there are subsets of the Core Sets that could be more meaningful given a certain setting and to investigate the Core Set's applicability across a range of health professions and cultures. International and national frameworks in lymphology should be involved to implement the ICF Core Sets for lymphedema.

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