

# ASAS/WHO ICF Core Sets for ankylosing spondylitis (AS): how to classify the impact of AS on functioning and health

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## ABSTRACT

**Objective:** To report on the results of a standardised consensus process agreeing on concepts typical and/or relevant when classifying functioning and health in patients with ankylosing spondylitis (AS) based on the International Classification of Functioning and Health (ICF).

**Methods:** Experts in AS from different professional and geographical backgrounds attended a consensus conference and were divided into three working groups. Rheumatologists were selected from members of the Assessment of SpondyloArthritis international Society (ASAS). Other health professionals were recommended by ASAS members. The aim was to compose three working groups with five to seven participants to allow everybody's contribution in the discussions. Experts selected ICF categories that were considered typical and/or relevant for AS during a standardised consensus process by integrating evidence from preceding studies in alternating working group and plenary discussions. A Comprehensive ICF Core Set was selected for the comprehensive classification of functioning and a Brief ICF Core Set for application in trials.

**Results:** The conference was attended by 19 experts from 12 countries. Eighty categories were included in the Comprehensive Core Set, which included 23 *Body functions*, 19 *Body structures*, 24 *Activities and participation* and 14 *Environmental factors*. Nineteen categories were selected for the Brief Core Set, which included 6 *Body functions*, 4 *Body structures*, 7 *Activities and participation* and 2 *Environmental factors*.

**Conclusion:** The Comprehensive and Brief ICF Core Sets for AS are now available and aim to represent the external reference to define consequences of AS on functioning.

Ankylosing spondylitis (AS) predominantly affects the axial skeleton with inflammation of the sacroiliac joints and spine as the hallmark.<sup>1</sup> Peripheral arthritis, enthesitis, uveitis, psoriasis and inflammatory bowel disease can add to the burden of the disease. Pain, stiffness, fatigue and limitations in spinal mobility are the main impairments and result in a variety of limitations in activities and restrictions in participation in life situations.<sup>2</sup> The relationships between impairments, activity limitations and participation restrictions can be influenced by contextual factors, including social support, job demands and personal factors.

Recommendations for outcome assessment of AS were proposed by the ASAS/OMERACT group.<sup>3,4</sup> The nine selected domains comprise pain, stiffness, physical function, fatigue, spinal

mobility, peripheral joints, enthesitis, x rays of the spine and laboratory assessment of inflammation. The ASAS/OMERACT Core Set was not primarily developed to assess the impact of the disease on functioning but to measure *all* aspects of outcome. Drug toxicity, employment and wellbeing, for example, were part of the candidate domains but not selected in the final core set. Moreover, the ASAS/OMERACT Core Set aims to be a recommendation for the *minimal* domains to be measured *in trials* or for *clinical record keeping* realising that other domains might be relevant. Interestingly, the finally selected domains all belong to the broad concept "functioning". It is important to realise that the selected domain "function" was limited to physical function and that it was not further detailed which aspects of physical function are relevant for the assessment. The selection of the ASAS/OMERACT domains did not include the perspective of non-rheumatologist health professionals or patients and it ignores the relationships among domains. Taken together, it would have advantages in identifying all aspects of "what to measure" when examining the impact of AS on global functioning, based on the perspectives of all stakeholders and departing from a specific model that recognises the complexity of global functioning. Such a detailed selection of subdomains or "building stones" that are relevant for functioning could serve as an external reference. It can be the starting point for the global assessment of patients and also for studying functioning and health and for the development of new instruments.<sup>5,6</sup>

With the approval of the International Classification of Functioning, Disability and Health (ICF),<sup>7,8</sup> one can rely on a universally agreed and understood framework and classification to define the spectrum of problems in functioning of patients. The *framework* endorses the bio-psycho-social model, recognising the influence of contextual (environmental and personal) factors on functioning and disability. The *classification* offers a detailed list of ICF categories necessary to describe functioning. In the ICF's hierarchical classification system, each *component* (body functions, body structures, activities and participation and environmental factors) is described by *chapters* that contain altogether 1545 *categories* of the second, third and fourth levels. The third and fourth level categories are specifications of the less specific second level.<sup>9</sup> It would be neither feasible nor informative to assess all aspects of functioning when knowing that these are not

typical or relevant for that disease. Therefore, to be able to apply the ICF classification in medicine, the so called ICF Core Sets are developed which are lists of ICF categories specific for that disease.<sup>10 11</sup> The disease-specific Comprehensive ICF Core Set (C-ICF-CS) are selections of ICF categories to guide multidisciplinary assessments and facilitate research on functioning and health,<sup>12</sup> while the Brief ICF Core Set (B-ICF-CS) can be used to describe patients during clinical studies. ICF Core Sets are developed according to a standardised consensus procedure (SCP), enhancing comparability across disease.<sup>13</sup>

The objective of this paper is to report on the results of the SCP that integrates evidence from preceding studies to develop Comprehensive and Brief-ICF-CS for AS.

## METHODS

Following an SCP, experts in AS from different geographical areas integrated evidence from preceding studies into ICF Core Sets during a 3 day consensus conference (online supplementary figure).

Expert rheumatologists were selected from the full member list of the Assessment SpondyloArthritis international Society (ASAS), assuring representation of all world regions. ASAS members have an established record in the field of AS as membership requires a dedicated interest in spondylitis and a minimum of publications in the field.<sup>14</sup> Non-rheumatologist expert health professionals were recommended by ASAS members. In line with the standardised approach for all ICF consensus conferences, it was intended to establish three working groups, each consisting of five to seven participants. This number assures representation of the different health professionals and geographical areas and enhances the possibility of contribution of each individual in the discussions.

Preceding studies included *qualitative* studies to identify which aspects are typical and/or relevant for functioning in AS according to health professionals (Delphi exercise), patients (focus interviews) and outcome research (literature review).<sup>11</sup> The concepts revealed in these steps were linked to the closest ICF category. In addition, empirical data collection with the ICF checklist among patients provided *quantitative* information on the relevance of the category for patients.<sup>12</sup> Overall, 374 ICF categories at the second, third and fourth ICF level were identified in the preceding studies with 93 (24%) categories on *Body functions*, 58 (15%) on *Body structures*, 146 (38%) on *Activities and participation* and 77 (20%) on *Environmental factors*.

After the training in the ICF, participants were asked to read the compiled categories from the preceding studies. For each second level category, they were asked to give an individual vote (yes/no) as to whether this category was relevant and/or typical for AS and should be included in the C-ICF-CS. Subsequently, the SCP was started, which involved alternating group and plenary discussions. The Appendix (online supplementary figure) explains in detail the steps and the agreement rules for inclusion and exclusion of the categories. In part I categories from the preceding studies for the C-ICF-CS and in part II categories for the B-ICF-CS were selected. For the C-ICF-CS categories were selected from the list of categories obtained from the preceding studies. The first cycle was intended to decide on inclusion or exclusion of the second level categories and the second cycle to decide on inclusion or exclusion of the more specific third or fourth level categories. Selection of categories for the B-ICF-CS was limited to categories included in the C-ICF-CS and involved individual ranking followed by plenary agreement on the number of categories for each component to be included. For the C-ICF-CS, participants were

instructed to choose as few categories as possible but as many as necessary for global assessment. For the B-ICF-CS participants had to consider the minimum number of categories important for clinical trials.

## RESULTS

Nineteen experts (13 rheumatologists, three physiotherapists, one specialist nurse, one occupational therapist and one psychologist) from 12 different countries (12 from Europe, four from North America, one from Asia and one from Mexico and South America each) attended the consensus conference that was held in September 2007 in Nottwill, Switzerland. Each working group comprised rheumatologists, one physiotherapist and one other health professional. Each working group was chaired by a person from a different world region (IEvdHB, Europe; WM, North-America and FH, Asia). The plenary discussions were facilitated by the coordinator (JB).

### Comprehensive ICF Core Set

Tables 1–4 show the ICF categories included in the C-ICF-CS. The 80 categories comprised two categories at the first level (chapters), 54 categories at the second level, 12 at the third level and 12 at the fourth level. The 56 higher level categories (first and second level) were made up of 12 (21%) categories from the component *Body functions*, seven (13%) from *Body structures*, 24 (43%) from *Activities and participation* and 13 (23%) from *Environmental factors*. When combining the point of decision on inclusion in the table with decision process described in the Appendix, it is possible to have an approximate impression of the level of agreement for each specific category.

Within the *Body functions*, the majority of identified categories belong to chapter 7 *Neuromusculoskeletal and movement-related functions* and chapter 2 *Sensory functions and pain*. In the plenary discussions it was noted that b6601 *Functions related to pregnancy* was identified as relevant in the Delphi by 84%. In a final vote this category was not selected, favouring the opinion of those who felt frequency of impairments in pregnancy were insufficiently examined to decide whether this is typical. Similarly, several experts reminded the group that patients were more susceptible to infections or allergies (b435 *Immunological system functions*). In the final vote this category was not selected, favouring the argument that this susceptibility is probably subjective, and not supported by research evidence. Further, the category b1801 *Body image* was discussed. Some argued that patients might suffer emotionally from their altered posture. The final vote favoured those stating that the body image of patients with AS is realistic and not distorted and that the emotional aspects of this “true” change are reflected in b152 *Emotional functions*.

Of the seven categories at the second level of the component *Body structures*, five belonged to chapter 7 *Structures related to movement*. Most categories were further specified into more specific categories. The plenary discussion concentrated first on the relevance of enthesitis, osteoporosis and influence of muscle composition. This resulted in the inclusion of the category s770 *Additional musculoskeletal structures related to movement* with the three specifications s7700 *Bones*, s7702 *Muscles* and s7703 *Extra-articular ligaments* to cover these aspects of the disease. Further the point was raised that “postural change” is a typical structural impairment with relevant impact on functioning but not represented by a specific ICF category. It was decided to add this higher level structural impairment (structural impairment not covered; s-nc) to the component *Body structures*.

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**Table 1** International Classification of Functioning, Disability and Health (ICF)—categories of the component “*Body functions*” included in the Comprehensive ICF Core Set for ankylosing spondylitis

ICF code	ICF category title	Point of decision in voting cycle*
Chapter 1 <i>Mental functions</i>		
b130	Energy and drive functions	Cycle 1; vote <sub>1</sub>
b1300	Energy level	Cycle 2; vote <sub>2</sub>
b1301	Motivation	Cycle 2; plenary
b134	Sleep functions	Cycle 1; vote <sub>1</sub>
b152*	Emotional functions	Cycle 1; plenary vote
Chapter 2 <i>Sensory functions and pain</i>		
b210*	Seeing functions	Cycle 1; plenary vote
b280	Sensation of pain	Cycle 1; vote <sub>1</sub>
b28010	Pain in head and neck	Cycle 2; vote <sub>2</sub>
b28011	Pain in chest	Cycle 2; vote <sub>2</sub>
b28013	Pain in back	Cycle 2; vote <sub>2</sub>
b28014	Pain in upper limb	Cycle 2; plenary
b28015	Pain in lower limb	Cycle 2; vote <sub>2</sub>
b28016	Pain in joints	Cycle 2; plenary
b28018	Pain body part, other specified	Cycle 2; plenary
Chapter 4 <i>Functions of cardiovascular, immunological and respiratory system</i>		
b440	Respiration functions	Cycle 1; vote <sub>1</sub>
b4402	Depth of respiration	Cycle 2; plenary
b455	Exercise tolerance functions	Cycle 1; vote <sub>1</sub>
Chapter 6 <i>Genitourinary and procreation system</i>		
b640	Sexual functions	Cycle 1; vote <sub>2</sub>
Chapter 7 <i>Neuromusculoskeletal and movement-related functions</i>		
b710	Mobility of joint functions	Cycle 1; vote <sub>1</sub>
b740*	Muscle endurance functions	Cycle 1; plenary vote
b770	Gait pattern functions	Cycle 1; vote <sub>1</sub>
b780	Sensations related to muscles and movement functions	Cycle 1; plenary vote
b7800	Sensation of muscle stiffness	Cycle 2; vote <sub>2</sub>

\*Categories that would not have been selected based on the individual votes; vote<sub>1</sub>, category selected in the first working group discussions of a cycle; vote<sub>2</sub>, category selected in the second working group discussions of a cycle; plenary vote, category selected during the plenary discussion.

Of the 24 categories of the component *Activities and participation* most belong to chapter 4 *Mobility* (seven categories) and chapter 5 *Self-care* (five categories). In the plenary discussions there was split opinion on the inclusion of d240 *Handling stress*. Some stated that AS does not impair the possibility to handle stress. The plenary vote favoured the argument that there is increasing evidence that acute and chronic inflammation alters the stress response and therefore the disease itself poses an additional challenge to handling stress.

The component *Environmental factors* was represented by 13 categories at the first or second level of the ICF hierarchy. Most belong to chapter 1 *Products and technologies* (six categories) and chapter 5 *Services, systems and policies* (five categories). In the plenary discussion it was specified that the category e580 *Health services, systems and policies* covers the concept “delay in diagnosis”, which had been raised in the Delphi among experts as well as during focus interviews with patients as an important barrier. Further, it was decided to include chapter 3 *Support and relationships* and chapter 4 *Attitudes* at the chapter level without specification into lower-level categories (specifying the group of people whose attitudes and support are relevant such as family, friends, health professionals, people in position of authority, etc) because experts found it difficult to decide whose attitudes and support are most relevant for patients. Finally, experts discussed category e225 *Climate*. Despite some evidence that

**Table 2** International Classification of Functioning, Disability and Health (ICF)—categories of the component “*Body structures*” included in the Comprehensive ICF Core Set for ankylosing spondylitis

ICF code	ICF category title	Point of decision in voting cycle*
Chapter 2 <i>Eye, ear and related structures</i>		
s220	Structure of eyeball	Cycle 1; plenary vote
s2202	Iris	Cycle 2; vote <sub>2</sub>
Chapter 4 <i>Structures cardiovascular, immunological or respiratory system</i>		
s430	Structure of respiratory system	Cycle 1; vote <sub>1</sub>
s4302	Thoracic cage	Cycle 2; vote <sub>2</sub>
Chapter 7 <i>Structures related to movement</i>		
s-nc*	Postural change	
s720	Structure of shoulder region	Cycle 1; vote <sub>1</sub>
s740	Structure of pelvic region	Cycle 1; vote <sub>1</sub>
s750	Structure of lower extremity	Cycle 1; vote <sub>1</sub>
s75001	Hip joint	Cycle 2; vote <sub>2</sub>
s75011	Knee joint	Cycle 2; plenary
s75021	Ankle joint and joints of foot and toes	Cycle 2; plenary
s760	Structure of trunk	Cycle 1; vote <sub>1</sub>
s7600	Structure of vertebral column	Cycle 2; vote <sub>2</sub>
s76000	Cervical vertebral column	Cycle 2; vote <sub>2</sub>
s76001	Thoracic vertebral column	Cycle 2; vote <sub>2</sub>
s76002	Lumbar vertebral column	Cycle 2; vote <sub>2</sub>
s770	Additional musculoskeletal structures related to movement	Cycle 1; vote <sub>1</sub>
s7700	Bones	Cycle 2; vote <sub>2</sub>
s7702	Muscles	Cycle 2; plenary
s7703	Extra-articular ligaments, fasciae, extramuscular aponeuroses, retinacula, septa, bursae, unspecified	Cycle 2; vote <sub>2</sub>

\*Categories that would not have been selected based on the individual votes; s-nc, category not covered in the component body structures; vote<sub>1</sub>, category selected in the first working group discussions of a cycle; vote<sub>2</sub>, category selected in the second working group discussions of a cycle; plenary vote, category selected during the plenary discussion.

working in cold and humid environment hampered worker participation, it was concluded that this was an atypical/uncommon situation and that for overall functioning or health, climate was not a typical (objective) facilitator or barrier.

The asterisks in tables 1–4 denote the categories that would not have been selected based on the individual votes, when accepting a threshold of 75% agreement. This threshold was chosen because this was the threshold for consensus of a category for the first working group vote. Nine categories were included in the C-ICF-CS that would not have been selected based on the individual votes only.

**Brief ICF Core Set**

Of the 56 second level categories from the C-ICF-CS, 19 (35%) were selected for the B-ICF-CS, of which six (32%) were from the component *Body functions*, four (21%) from *Body structures*, seven (37%) from *Activities and participation* and two (11%) from *Environmental factors* (table 5). No category was specified at the lower level.

Although rheumatologists favoured the inclusion of *Seeing functions* and *Structures of the eye* as typical for AS, most other health professionals argued against inclusion since they felt attacks are usually temporary without major impairments and that treatment-resistant uveitis is rare. In the final vote *Seeing functions* were not selected for the Brief Core Set. Using the same argument, the category *Structures of the respiratory cage* was discussed and not selected.

**Table 3** International Classification of Functioning, Disability and Health (ICF)—categories of the component “Activities and participation” included in the Comprehensive ICF Core Set for ankylosing spondylitis

ICF code	ICF category title	Point of decision in voting cycle*
Chapter 2 <i>General tasks and demands</i>		
d230	Carrying out daily routine	Cycle 1; vote <sub>2</sub>
d240	Handling stress and other psychological demands	Cycle 1; plenary vote
Chapter 4 <i>Mobility</i>		
d410	Changing basic body position	Cycle 1; vote <sub>1</sub>
d415	Maintaining a body position	Cycle 1; vote <sub>1</sub>
d430	Lifting and carrying objects	Cycle 1; plenary vote
d450	Walking	Cycle 1; vote <sub>1</sub>
d455	Moving around	Cycle 1; vote <sub>1</sub>
d470	Using transportation	Cycle 1; vote <sub>1</sub>
d475	Driving	Cycle 1; vote <sub>1</sub>
Chapter 5 <i>Self-care</i>		
d510	Washing oneself	Cycle 1; vote <sub>1</sub>
d520	Caring for body parts	Cycle 1; vote <sub>1</sub>
d530	Toileting	Cycle 1; plenary vote
d540	Dressing	Cycle 1; vote <sub>1</sub>
d570	Looking after one's health	Cycle 1; plenary vote
Chapter 6 <i>Domestic life</i>		
d620	Acquisition of goods and services	Cycle 1; plenary vote
d640	Doing housework	Cycle 1; vote <sub>1</sub>
d660	Assisting others	Cycle 1; plenary vote
Chapter 7 <i>Family and interpersonal relationships</i>		
d760	Family relationships	Cycle 1; plenary vote
d770	Intimate relationships	Cycle 1; plenary vote
Chapter 8 <i>Major life areas</i>		
d845*	Acquiring, keeping and terminating a job	Cycle 1; vote <sub>1</sub>
d850	Remunerative employment	Cycle 1; vote <sub>1</sub>
d870*	Economic self-sufficiency	Cycle 1; plenary vote
Chapter 9 <i>Community, social and civic life</i>		
d910*	Community life	Cycle 1; plenary vote
d920*	Recreation and leisure	Cycle 1; vote <sub>1</sub>

\*Categories that would not have been selected based on the individual votes; vote<sub>1</sub>, category selected in the first working group discussions of a cycle; vote<sub>2</sub>, category selected in the second work group discussions of a cycle; plenary vote, category selected during the plenary discussion.

## DISCUSSION

An SCP integrating expert knowledge on AS and evidence from preceding studies, has led to the definition of the ICF Core Sets for AS. The core sets aim to represent what is *typical and relevant* for functioning and health in AS. The C-ICF-CS is meant for multidisciplinary assessment and outcome research and the B-ICF-CS for clinical studies. By using the universally accepted language of the ICF and a standardised approach, comparisons across disease will now become possible.<sup>15</sup> Since ICF Core Sets will have unique but also shared categories across diseases, this will offer opportunities to specify or generalise intervention programmes or research across disease.

In view of the clinical heterogeneity of AS, experts first agreed that spinal and extraspinal articular disease as well as uveitis were unique and typical manifestations of AS that should be considered when defining the core sets. Other AS-related comorbidities such as clinical inflammatory bowel disease and psoriasis were considered to add to the burden of disease and it was preferred to assess these in separate core sets.

Altogether, 80 categories were selected for the C-ICF-CS and 19 for the B-ICF-CS. Consistent with the consequences of the inflammatory process in the spine, peripheral joints and entheses, the majority of the categories relate to pain, movement and

**Table 4** International Classification of Functioning, Disability and Health (ICF)—categories of the component “Environmental factors” included in the Comprehensive ICF Core Set for ankylosing spondylitis

ICF code	ICF category title	Point of decision in voting cycle*
Chapter 1 <i>Products and technologies</i>		
e110	Products or substances for personal consumption	Cycle 1; vote <sub>1</sub>
e1101	Drugs	Cycle 2; vote <sub>2</sub>
e115	Products and technology for personal use in daily living	Cycle 1; vote <sub>1</sub>
e120	Products and technology for personal indoor and outdoor mobility and transportation	Cycle 1; vote <sub>1</sub>
e135	Products and technology for employment	Cycle 1; vote <sub>1</sub>
e150	Design, construction and building products and technology of buildings for public use	Cycle 1; plenary vote
e155	Design, construction and building products and technology of buildings for private use	Cycle 1; plenary vote
Chapter 3 <i>Support and relationships</i>		
e3	Support and relationships	Cycle 1; plenary vote
Chapter 4 <i>Attitudes</i>		
e4	Attitudes	Cycle 1; plenary vote
Chapter 5 <i>Services, systems and policies</i>		
e540	Transportation services, systems and policies	Cycle 1; vote <sub>2</sub>
e570	Social security services, systems and policies	Cycle 1; plenary vote
e575*	General social support services, systems and policies	Cycle 1; plenary vote
e580	Health services, systems and policies	Cycle 1; plenary vote
e590*	Labour and employment services, systems and policies	Cycle 1; vote <sub>1</sub>

\*Categories that would not have been selected based on the individual votes; vote<sub>1</sub>, category selected in the first working group discussions of a cycle; vote<sub>2</sub>, category selected in the second work group discussions of a cycle; plenary vote, category selected during the plenary discussion.

mobility. In addition, impairments in energy and drive, sleep and emotional functions as well as restrictions in a large number of activities and life situations (participation) were considered important for the core set. Consistent with the bio-psycho-social model of disease, 17% of all selected categories belonged to the component environmental factors. Experts felt strongly about the role of drugs and of support and relationships as reflected by the inclusion of this category and chapter respectively in the Brief Core Set.

The organisers of the conference took great care to invite experts in AS from different professional backgrounds and different countries. Although not an easy task, it proved useful as became clear during the plenary discussions of categories for which no consensus was achieved in the working group votes. For example, physiotherapists had a strong input to reasons for including b740 *Muscle endurance functions* and d920 *Recreation and leisure*, the psychologist contributed arguments when discussing b152 *Emotional functions*, b1801 *Body image* and d240 *Handling stress*, the rheumatology nurse added arguments for inclusion of d910 *Community life*.

Experts enjoyed the SCP and felt they had achieved an important step in defining functioning in AS. One of the main advantages that were mentioned is that it will help in the study of the complexity of functioning in AS (*see article on page 108*).<sup>15</sup> Notwithstanding they also had concerns. The ICF classification and language is not always easy to understand. Also, when selecting categories for the B-ICF-CS, experts encountered difficulties, partly because perspectives of different

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**Table 5** International Classification of Functioning, Disability and Health (ICF)—categories included in the Brief ICF Core Set for ankylosing spondylitis

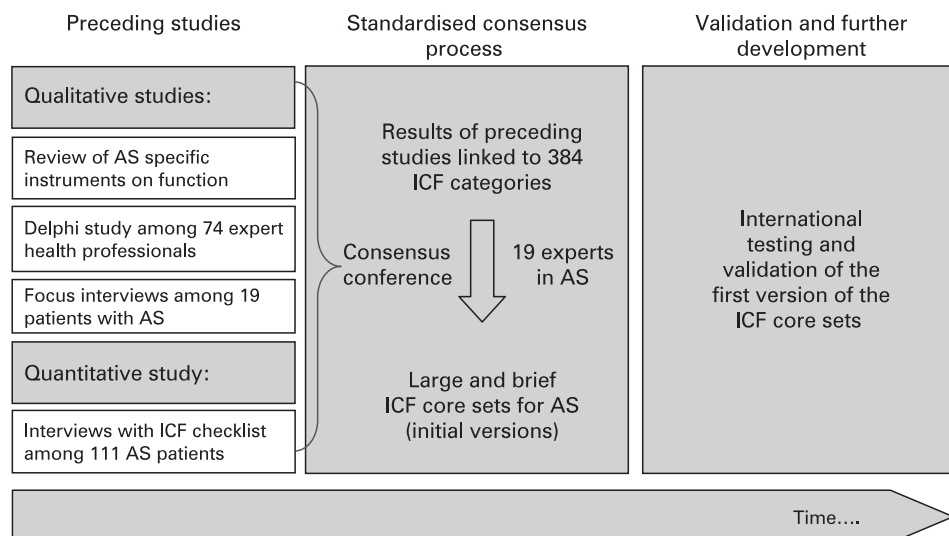
ICF component	ICF code	ICF category title
Body functions	b280	Sensation of pain
	b710	Mobility of joint functions
	b780	Sensations related to muscles and movement functions
	b130	Energy and drive functions
	b134	Sleep functions
	b152	Emotional functions
	b455	Exercise tolerance functions
	Body structures	s760
s740		Structures of pelvic region
s770		Additional musculoskeletal structures related to movement
s750		Structure of lower extremity
Activities and participation		d230
	d410	Changing basic body position
	d450	Walking
	d845	Acquiring, keeping and terminating a job
	d850	Remunerative employment
	d760	Family relationships
	d920	Recreation and leisure
	d475	Driving
Environmental factors	e110	Products or substances for personal consumption
	e3	Support and relationships

health professionals diverged, and partly, because it was difficult to judge which categories (within and across components) would actually provide redundant opposed to distinct information about the patients' abilities. It is clear that the core sets are first versions that will need extensive validation (fig 1) not only with regard to "truth" for the entire spectrum of patients and for all perspectives and geographical regions, but also with regard to reliability and feasibility. In rheumatoid arthritis

test-retest repeatability of the C-ICF-CS was moderate with agreement for all categories of the core set in 57% and 59% of patients for inter- and intrarater (2 week interval) reliability, respectively. Repeatability improved for some categories after collapsing the five-level qualifier system into three levels.<sup>16</sup> Probably, also the wording of the categories and unfamiliarity of professionals and patients with ICF interviews contribute to the moderate reliability.

Sensitivity to change of the C-ICF-CS 6 months after the start of disease-modifying antirheumatic drugs in rheumatoid arthritis was moderate and associations with changes in disease activity and other patient reported outcomes were weak.<sup>17</sup> It should be noted also that changes in established outcomes in this trial were low.

One of the future directions for the ICF, therefore, is to measure categories by items (and scores) from existing questionnaires. Applying item response theory (IRT), it was possible to constitute a psychometrically sound interval scale when integrating items from several existing instruments that deal with a similar ICF category; in this case example the category *b130 Energy and drive functions*.<sup>18</sup> IRT will also have a role in further validation of the ICF Core Sets to confirm that the categories belong to the same dimension "functioning and health" and identify whether certain categories are redundant. An exploratory study applying IRT to interviews of 111 patients with AS using a preliminary ICF checklist for AS (after exclusion of environmental factors), showed that four categories did not fit the unidimensionality. Category *d850 Remunerative employment* had a negative misfit, indicating the ability to work does not share the unidimensionality of "functioning" with the remaining categories. The categories (*d560 Drinking*; *d6200 Shopping* and *d830 Higher education*) had a negative misfit, which indicates they are too highly correlated or are redundant with other categories. These results need to be confirmed in large patient samples.<sup>5</sup> The large number of ICF categories included in the C-ICF-CS, with an assessment time between 30 and 45 min, might be a potential drawback. However, it should be realised that functioning is complex and we should not try to reduce the necessary categories with the risk of ignoring an important building block. Further, computer-assisted testing will help in the future to efficiently

**Figure 1** Illustration of the process to develop and further validate the International Classification of Functioning and Health (ICF) Core Set for ankylosing spondylitis (AS).

measure aspects of outcome in individual patients using only fragments of large computerised item pools.<sup>18</sup>

In conclusion, the C-ICF-CS for comprehensive classification and the B-ICF-CS for clinical studies in AS are now available. The core sets aim to represent the new reference to define functioning in AS and facilitate clinicians' and researchers' efforts to incorporate a patient-oriented, multilevel and comprehensive view on functioning with AS.

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