

# The comprehensive musculoskeletal post-acute ICF core set as a tool to formulate a questionnaire and internally consistent sum variables describing people with skeletal dysplasia

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## Background:

- Skeletal dysplasias often lead to severe short stature and different disabilities
- No specific International Classification of Functioning, Disability and Health (ICF) core set for skeletal dysplasia

## Aim:

1. To assess if the comprehensive musculoskeletal post-acute ICF core set can be used to formulate a questionnaire
  2. To assess if internally consistent sum variables can be formed using ICF-classification
- To find out, how functioning of people with skeletal dysplasia can be assessed and described

## Methods:

Comprehensive musculoskeletal post-acute ICF core set (70 categories) as a tool to form a questionnaire



Interviews of 14 people with skeletal dysplasia

- meaningful concepts linked to the ICF categories
- Core set fulfilled with additional categories



All the ICF categories operationalized into the items according to the ICF linking rules

- Validated PROMIS® (Patient-Reported Outcomes Measurement Information System) items and items of the Finnish Regional Health and Well-being Study were used
- Remaining categories operationalized into new items using ICF definition and existing PROMIS item formats or utilizing Craig Hospital Inventory of Environmental Factors and Measure of the Quality of the Environment items



The questionnaire draft evaluated for its content validity and feasibility by people with skeletal dysplasia



Statistical testing and clinical consideration used to determine, if internally consistent sum variables can be formed according to widened ICF core set

## Conclusions:

1. Expertise of the people with skeletal dysplasia must be considered to ensure the content validity of the questionnaire
  2. The content of ICF blocks was homogenous but wide enough to decrease the number of variables and to form internally consistent sum variables
- Operationalizing widened ICF-core set into the items according to the ICF linking rules by using valid and cognitively tested items and forming sum variables according to ICF blocks might be a reasonable way to describe functioning of people with skeletal dysplasia and to assess it comprehensively

## Results:

1. The final questionnaire included items from 15 categories and from 1 chapter in addition to the comprehensive musculoskeletal post-acute ICF core set
  - Additional categories were from the ICF components “Activities and participation” and “Environmental factors”
  - Additional chapter were from “Body structures”
  - Altogether, functioning of people with skeletal dysplasia can be assessed with total of 34 ICF blocks/chapters
2. 20 internally consistent sum variables (Cronbach’s alpha >0.7) could be formed according to the ICF blocks
  - Reasons not to form a sum variable were a low Cronbach alpha (2 variables), only one variable in the ICF block or nominal scale variable (12 variables)

Categories added to the comprehensive musculoskeletal post-acute ICF core set

Name of the category	Code of the category	Block or chapter
Moving around	d455	Walking and moving
Using transportation	d470	Moving around using transportation
Acquisition of goods and services	d620	Acquisition of necessities
Preparing meals	d630	Household tasks
Doing housework	d640	
Informal social relationships	d750	Particular interpersonal relationships
Remunerative employment	d850	Work and employment
Recreation and leisure time	d920	Community, social and civic life
Human rights	d940	
Products and technology for personal use in daily living	e115	Products and technology
Time-related changes	e245	Natural environment and human-made changes to environment
Strangers	e345	Support and relationships
Individual attitudes of strangers	e445	Attitudes
Individual attitudes of other professionals	e455	
Societal attitudes	e460	

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