



# Strengthening Participation in Work and Social Life Environmental Factors described by Austrian and Swiss People with Multiple Sclerosis in a Delphi Study



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## Background:

- Participation, defined as involvement in life situations in the ICF by the WHO in 2001, is an important determinant for a persons' quality of life and health.
- Environment, with physical, psychosocial and attitudinal aspects, has a significant impact on participation.
- The main burden of multiple sclerosis (MS) occurs mostly when people are particularly socially active and at the peak of their careers.
- Participation of people with MS in work and social life is important from an individual and a socio-economic perspective.

## Objectives:

- to obtain consensus on which environmental factors are influencing participation in work and social life for a large group of people with MS in Austria (AUT) and Switzerland (CH)
- to compare results cross-nationally

## Methods:

- Delphi study (consensus process)
- mixed method design: qualitative and quantitative parts
- multistage approach: 3 subsequent rounds
- national and cross-national parts

## Study Procedure:

### 1<sup>st</sup> round:

- qualitative data gathering by questionnaires
- national thematic content analysis using ICF as framework

### 2<sup>nd</sup> round:

- presentation of trans-national results from 1<sup>st</sup> round in questionnaires
- quantitative data gathering
- descriptive statistics

### 3<sup>rd</sup> round:

- presentation of national results from 2<sup>nd</sup> round in questionnaires
- quantitative data gathering
- descriptive statistics
- identification of national consensus factors (>75% per item)

## Summary qualitative data:

Environmental Factors	Total number	Products Technologies	Natural environment	Support Relationships	Attitudes	Services Systems Policies
after 1 <sup>st</sup> round	673	31 %	5 %	14 %	16 %	34 %
after 2 <sup>nd</sup> round	768	32 %	5 %	13 %	16 %	34 %

## Samples:

- people with MS
- convenience sample:
  - widespread recruitment
  - all volunteers who replied during one month and met the inclusion criteria
- inclusion criteria:
  - living in Austria or Switzerland
  - official diagnosis by a neurologist
  - adult
- exclusion criteria:
  - living in an institutional setting

## Characteristics of Samples:

	AUT	CH
Number	112	109
Age (mean)	46	46
SD (min/max)	12 (21/83)	9 (24/79)
Female	70 %	69 %
Male	30 %	31 %
Living conditions		
living alone	24 %	21 %
living with others	76 %	79 %
urban area	66 %	39 %
rural area	31 %	61 %
Working conditions (multiple choice possible)		
employed	30 %	50 %
self employed	3 %	8 %
education/ vocational training	5 %	4 %
unemployed	3 %	1 %
Retired		
due to MS	44 %	26 %
due to age	4 %	6 %
Self-estimation of restrictions in ability to participate		
1 = no restriction	6 %	7 %
2	20 %	24 %
3	28 %	28 %
4	26 %	18 %
5	14 %	17 %
6 = severest restrictions	6 %	6 %

## Summary consensus process (quantitative data):

Comparing the national results of the consensus process, only few differences occurred, mainly related to different cultural habits and national policies.

Consensus Factors	after 2 <sup>nd</sup> round		after 3 <sup>rd</sup> round	
	AUT	CH	AUT	CH
Total number (% of env. factors of this round)	94 (14%)	130 (19%)	176 (23%)	177 (23%)
Products/ Technologies	41 %	49 %	38 %	45 %
Natural environment	6 %	5 %	5 %	7 %
Support/ Relationships	13 %	9 %	9 %	7 %
Attitudes	22 %	15 %	20 %	18 %
Services/Systems/Policies	18 %	22 %	28 %	23 %

## Conclusions:

- Addressing all dimensions of environment is essential for enhancing participation of people with MS.
- Participation of large group of people with MS in both countries would benefit from addressing specific consensus factors obtained from this study within (political) decision making and rehabilitation efforts.
- Rehabilitation professionals should see their task broader. Issues relevant for (large) groups of their clients should be attempted to be influenced on community, regional or even national level.
- A large number of consensus factors is similar and in line with results of other countries' research. Cross-national efforts could be undertaken to overcome commonly experienced environmental barriers, and to strengthen such facilitators.

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