

BURDEN OF MS IN EUROPE

**FIRST RESULTS ON HEALTH AND COSTS FROM
14366 PATIENTS IN 11 (OF 16) COUNTRIES**

ACKNOWLEDGEMENTS

The study is endorsed by EMSP, organised jointly by European Health Economics and MAPI, and financed by Biogen Inc.

Study team: Jenny Berg, Mia Gannedahl, Jennifer Eriksson, Gisela Kobelt

It is actively supported by 18 national member organisations of EMSP in 16 countries as well as a number of MS clinics

Clinical experts in each country participate;

Overall clinical expert: Professor Alan Thompson from UCL (London)

After publication of the results, the data base will be owned by EMSP and its members. However, neither EMSP nor Biogen can publish new analyses without prior information of the other party

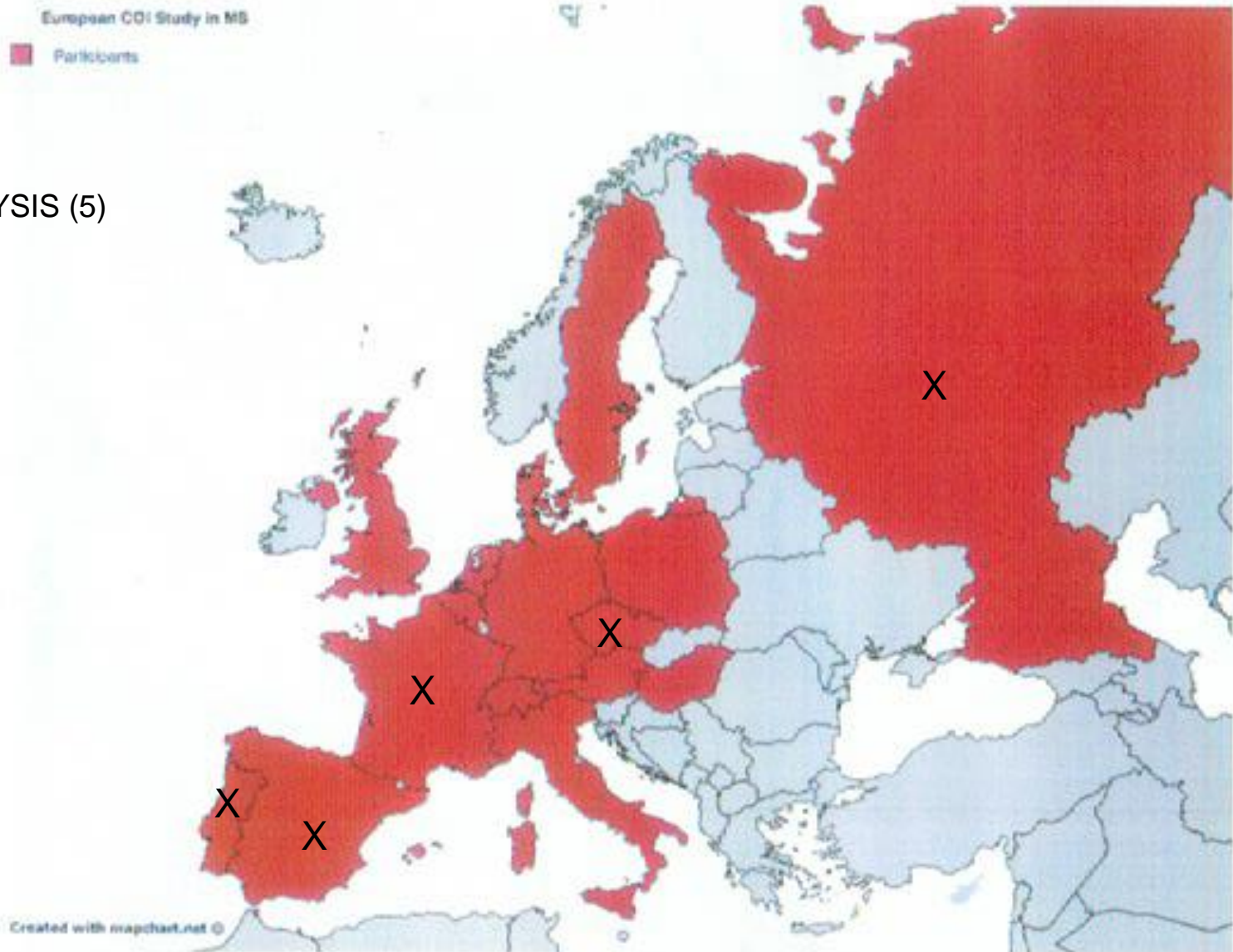
None of the participants declares any conflict of interest

PARTICIPATING COUNTRIES (16)

European COI Study in MS

Participants

X = IN ANALYSIS (5)



PRESENTATION OUTLINE

1. Definition of cost/burden of illness studies
2. What do they say? What not? How can we use the data?
3. Study methods
4. Results
 1. Demographic and disease data
 2. “PROs”
 3. Resource utilization
 4. Costs
5. Discussion / Q&A

DEFINITIONS

COST / BURDEN OF ILLNESS STUDIES

- **Observational**
- **Two types**
 - Incidence studies: look at developments over time from diagnosis to cure/death for a group of patients
 - Prevalence studies: look at the situation for all patients with the disease in a given year
 - (Current study neither!)
- **Two main methods**
 - Collect data prospectively over a given time frame
 - Collect data cross-sectionally and retrospectively
- **Descriptive studies**
 - Not possible to conclude on causality

COST / BURDEN OF ILLNESS STUDIES

- **Costs (resources used or lost)**
 - Define what resources are used or lost by PwMS (e.g. consultations with a neurologist; sick-leave, invalidity)
 - Collect the quantities used for each resource over a defined time (e.g. 1 week, 1, 3, 12 months, depending on recall) from a representative group
 - Collect a unit cost for each resource (e.g. price of a visit to the neurologist; the cost of loss of work)
 - Multiply the resource quantities with their unit cost
- **Burden**
 - Define quality of life instruments
 - Define items that can be collected with a visual analogue scale
 - Create questions to specify certain items

THE MS COI STUDY 2016

- **Observational, cross sectional, retrospective**
- **Data collection with a specific questionnaire from patients by paper and internet**
- **Fully anonymous answers, no possibility to complete missing data or perform queries**
- **Convenience sample, not representing prevalence**
- **Substantial differences in the samples**
 - Sample size (solidity of results)
 - Age, disease duration, EDSS (resource consumption)
 - GDP, purchasing power, national workforce participation (costs)
 - Health care system (inpatient care, services, pensions)
 - Medical traditions (resource consumption)
 - Family traditions (informal care)

DOs AND DON'Ts

WE CANNOT DISCUSS...

- **Causalities**

- We cannot test hypotheses and conclude about any reasons why the data look as they do
 - E.g. treatment, treatment outcome, education/work, family life/fatigue, etc

- **Comparisons between countries**

- It is meaningless to compare any of the mean results for the samples because these are different
 - In particular not total costs, employment levels, treatments, quality of life

- **Direct comparison to 2005 study**

- Samples differ, some cost calculations differ, some payment systems have changed

- **Interpretation**

- The samples do not represent national prevalence
 - The objective was to assess costs and QoL at each level of EDSS
- Our results are not the “ultimate truth”, but estimates
 - Costs depend on EDSS, on age, on prices
 - Quality of life depends on EDSS, personal conditions

DOS AND DON'TS

WE CAN DISCUSS...

WITH DIFFERENCE AUDIENCES/STAKEHOLDERS WITHIN A COUNTRY

- **The cost structure**
 - How we spend our resources within a country
 - Health care versus other resources
- **Costs of important items**
 - Work capacity, services, informal care, out-of-pocket expenses, medication, MRI
- **Quality of life**
 - How MS affects the life of people
 - Over time with disease progression
 - Compared to the general population
- **Fatigue and cognition**
 - Important problems that are often forgotten
 - Present at all levels of MS
- **Time to diagnosis**
- **etc**

METHODS

STUDY METHODS

- **Patients contacted by MS Societies either by e-mail, postal mailing, or within news-bulletins; reminders in some countries**
- **Specific questionnaire (updated from 2005) verified by the international clinical expert, translated and re-verified by local clinical experts, MS Societies and health economists**
- **Ethics approval obtained in all countries**
- **Sample size definition: 50-100 participants by EDSS level**
- **Participation on-line or by paper questionnaire**
- **Fully anonymous; no imputation of missing data; questionnaires without disease information excluded**

ANALYSES

- **Descriptive analyses; exploration of correlations (not causation) of certain variables with costs**
- **Costs**
 - Resource utilization/cost for each resource type
 - Sample, severity groups (mild, moderate, severe), EDSS
 - Total mean annual costs by EDSS
 - Health care, community informal care, loss of work
 - Average cost of relapse
- **Disease burden**
 - Fatigue levels, impact of fatigue
 - Level of self assessed cognitive difficulties
 - Overall quality of life; factors most negatively affected

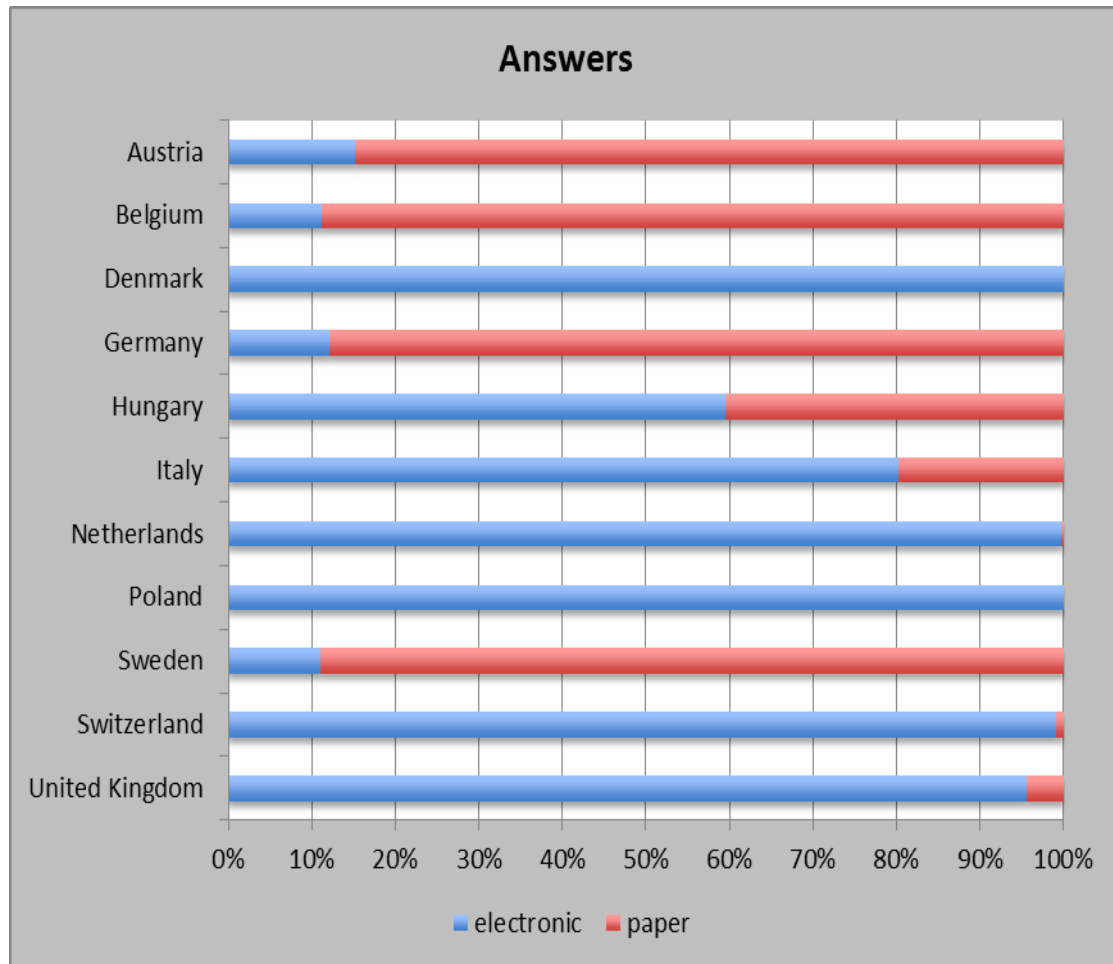
RESULTS

DESCRIPTION OF PARTICIPANTS

PARTICIPANTS

	contacted	answered
Austria	3500	15%
Belgium	6500	29%
Denmark	2663	21%
Germany	45000	12%
Hungary	4000	13%
Italy	4000	25%
Netherlands	1000	38%
Poland	TBC	TBC
Sweden	2663	70%
Switzerland	2800	26%
United Kingdom	5928	13%

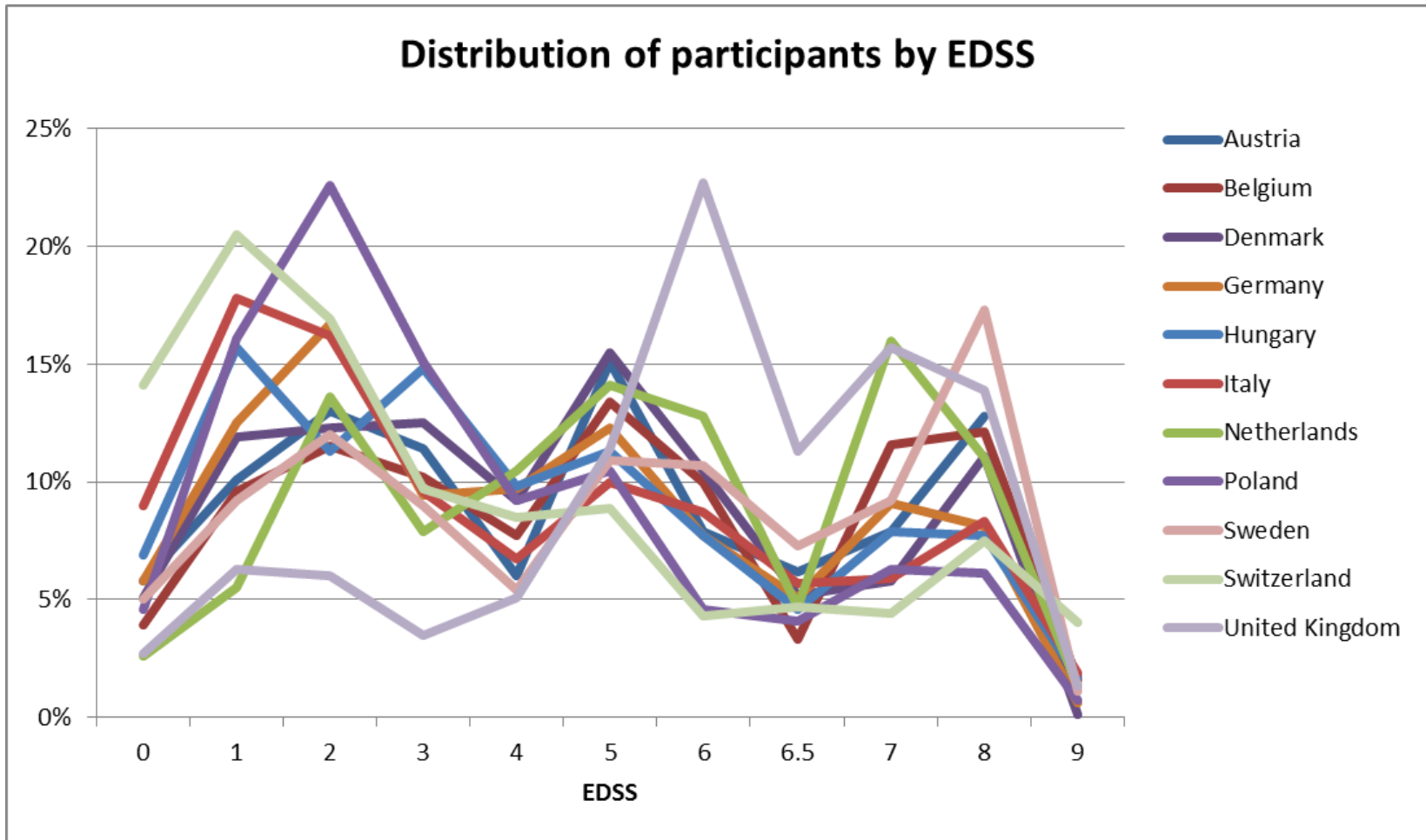
Note: We do not have the number of persons contacted for Poland



DEMOGRAPHICS

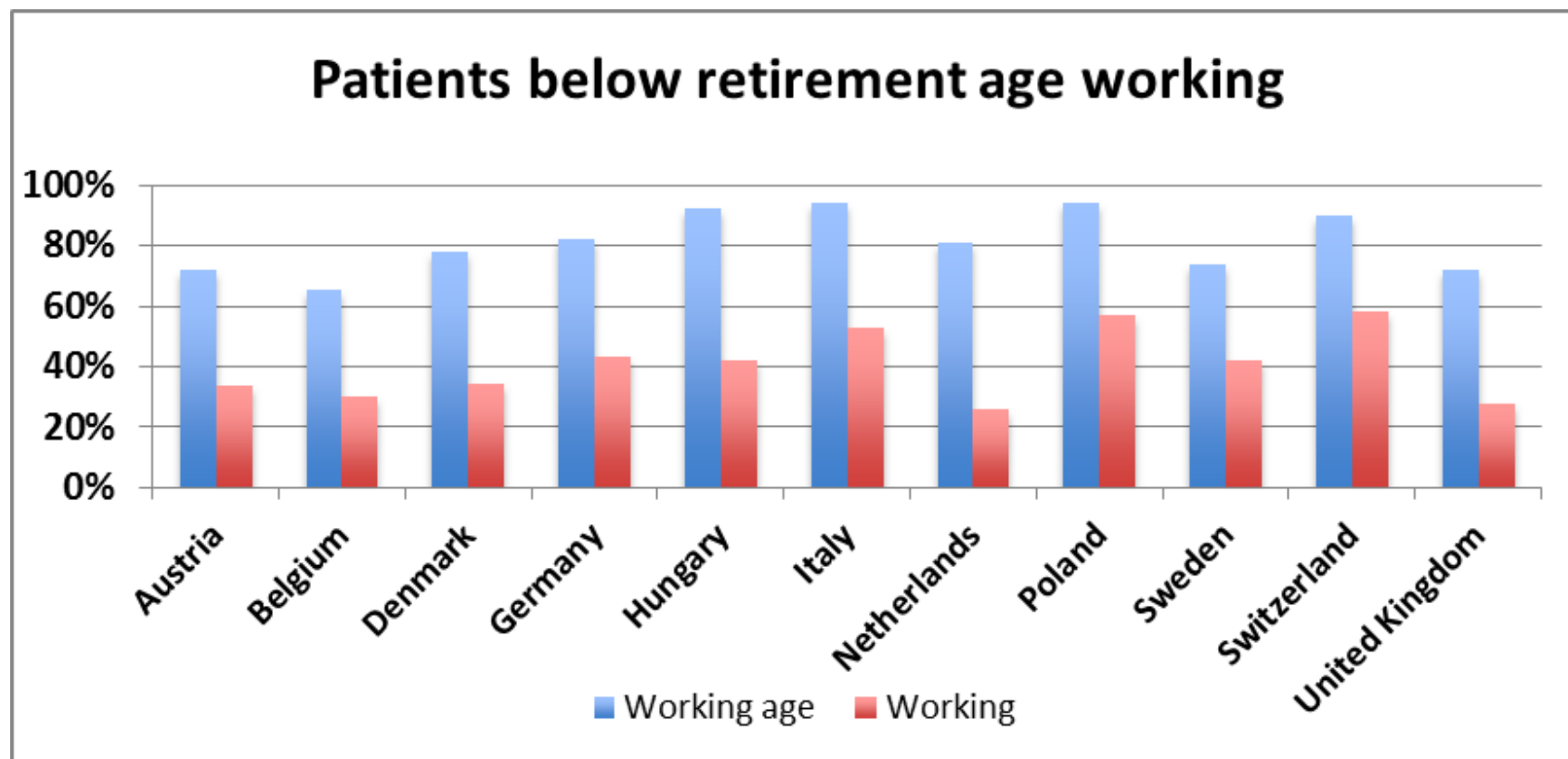
	Age	Working age	Diagnosis age	Symptom age	Women	Living alone	Relapses
Austria	52	72%	35	30	73%	22%	10.9%
Belgium	54	66%	38	32	70%	21%	16.1%
Denmark	54	78%	38	30	74%	25%	11.4%
Germany	52	82%	36	31	74%	22%	11.4%
Hungary	47	92%	34	29	78%	14%	24.8%
Italy	45	94%	34	29	70%	12%	14.1%
Netherlands	54	81%	40	32	72%	19%	17.5%
Poland	40	94%	32	27	74%	17%	18.5%
Sweden	56	74%	41	33	78%	23%	8.3%
Switzerland	48	90%	37	32	74%	26%	6.8%
United Kingdom	57	72%	40	32	70%	19%	18.1%

DISEASE SEVERITY DISTRIBUTION

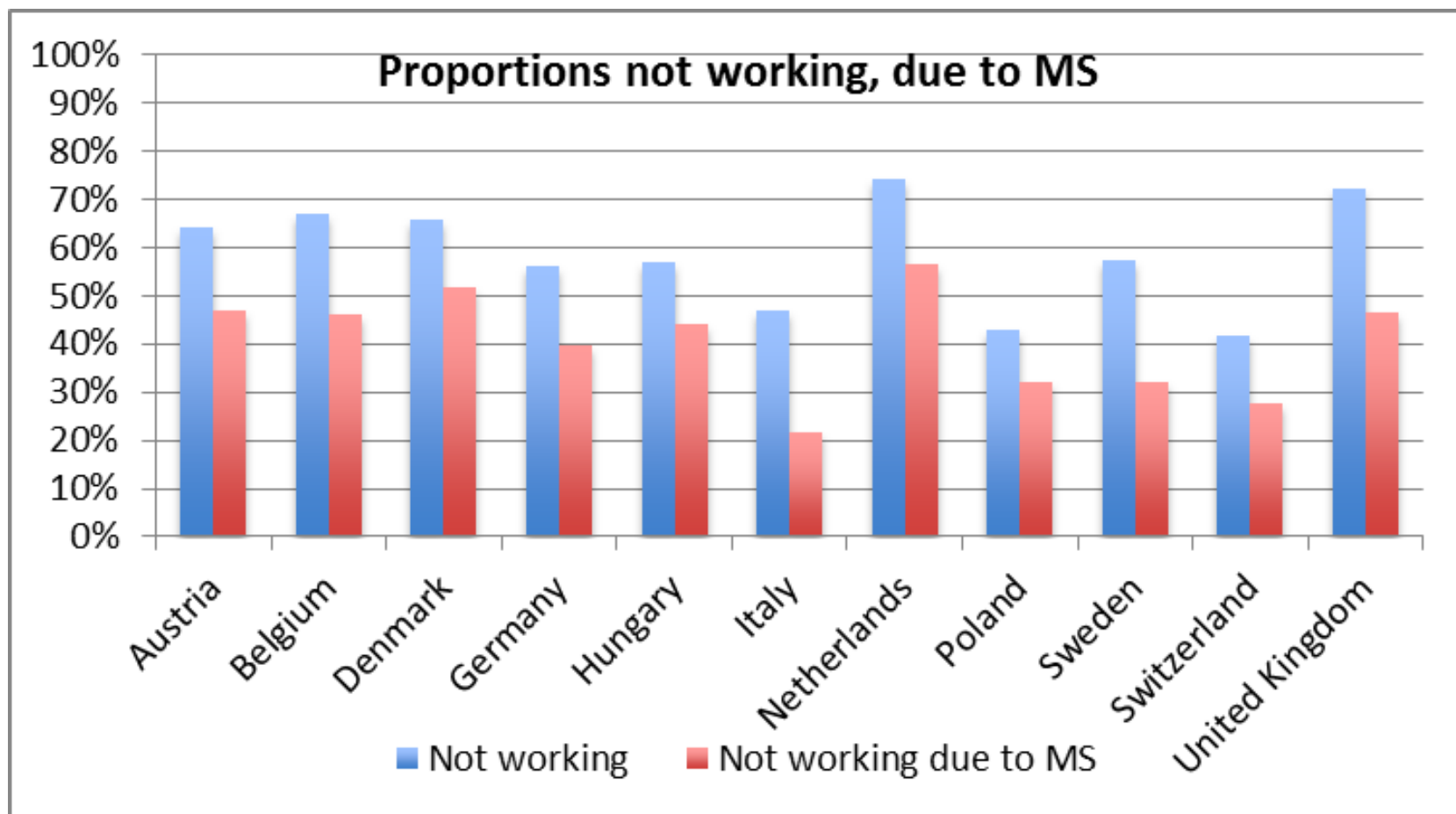


EMPLOYMENT

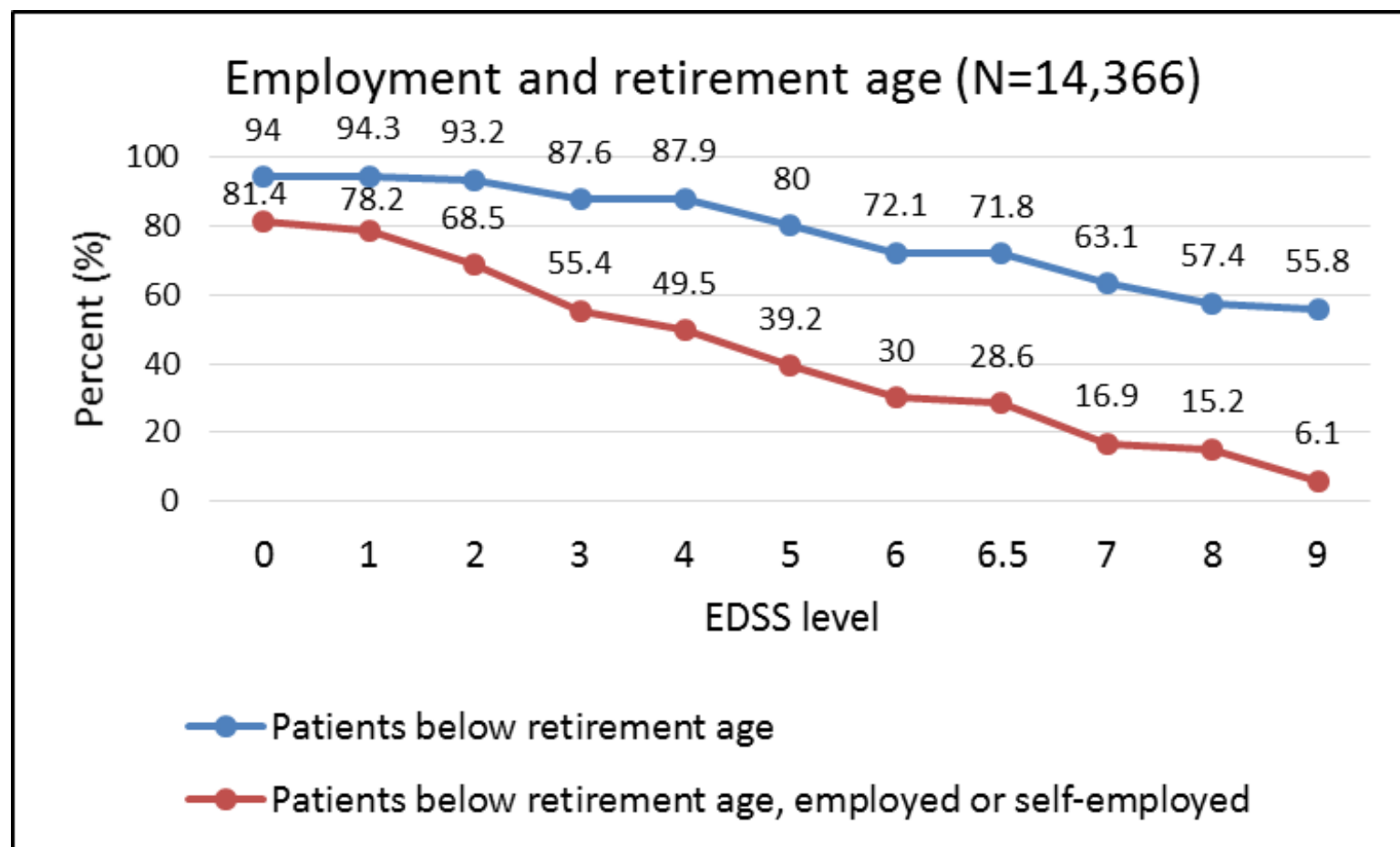
EMPLOYMENT



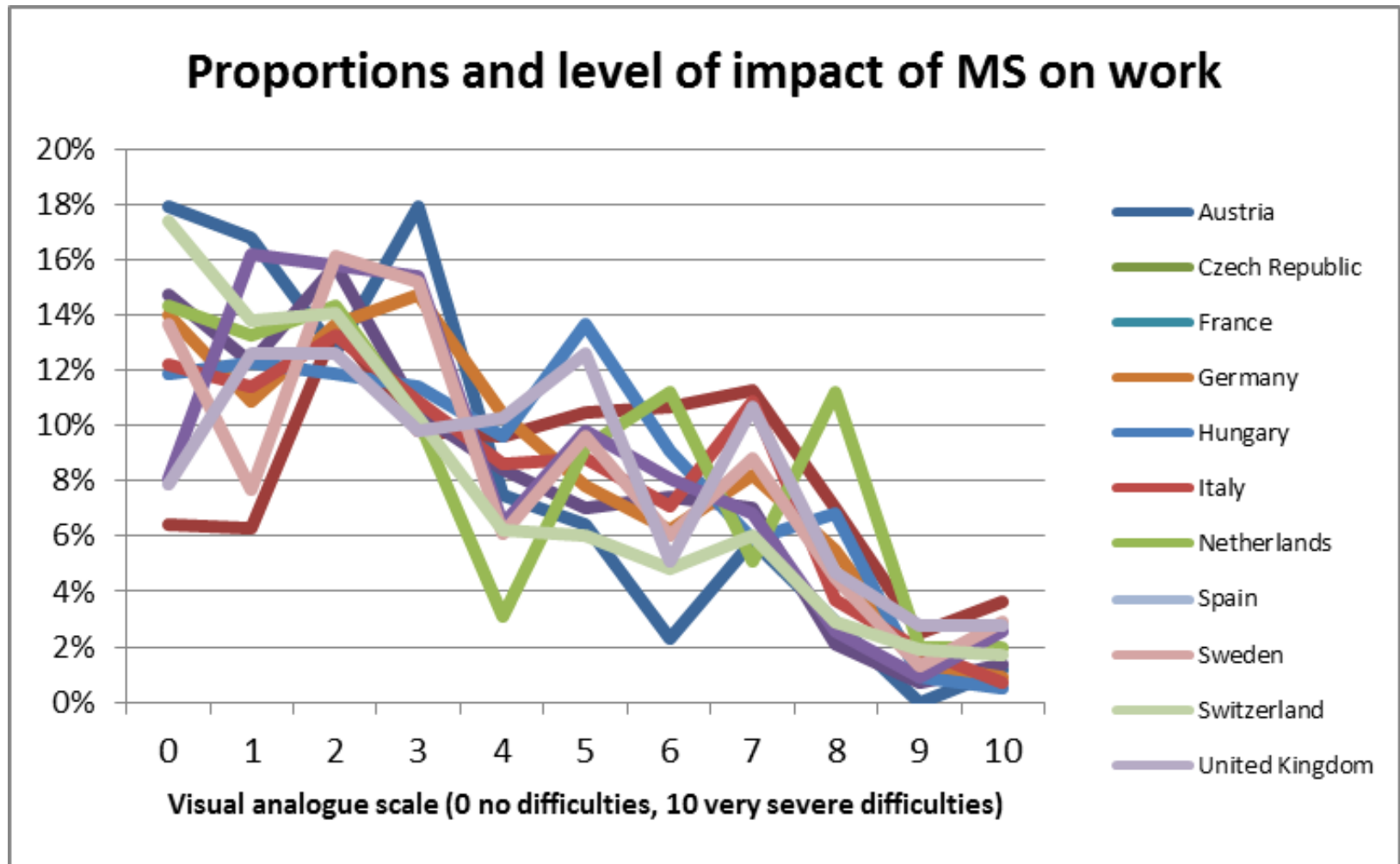
EMPLOYMENT



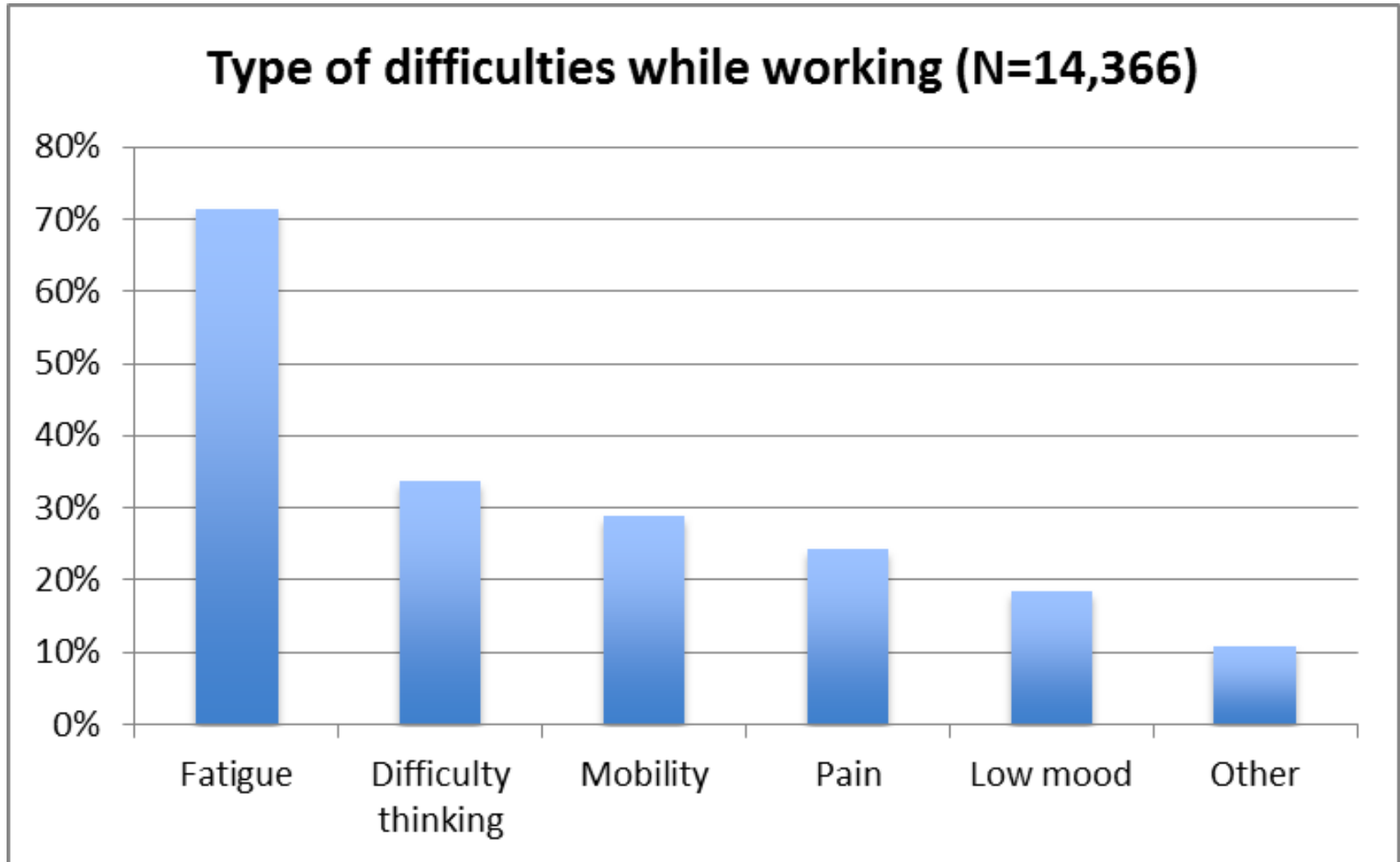
EMPLOYMENT



EFFECT OF MS WHILE WORKING

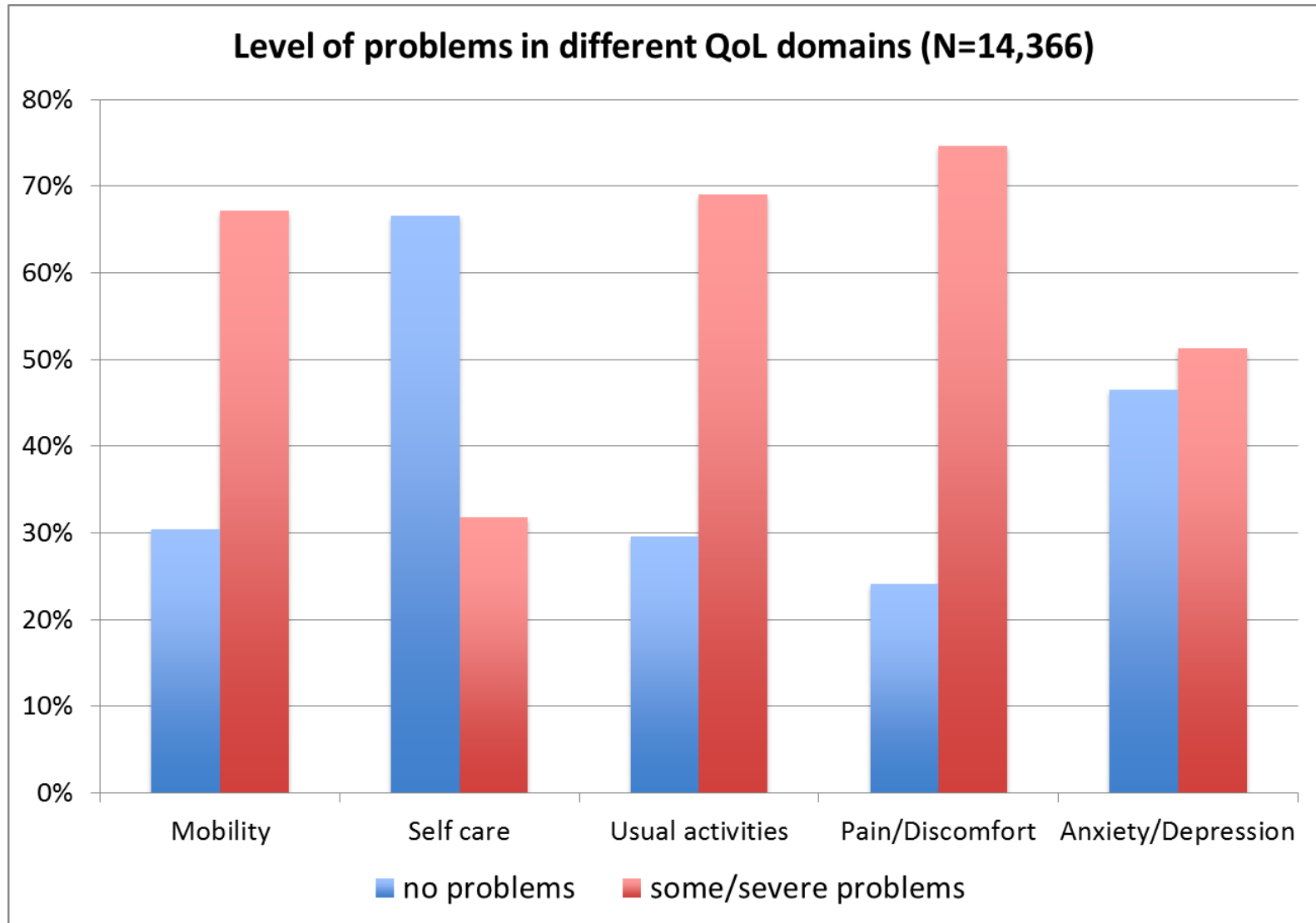


EFFECT OF MS WHILE WORKING



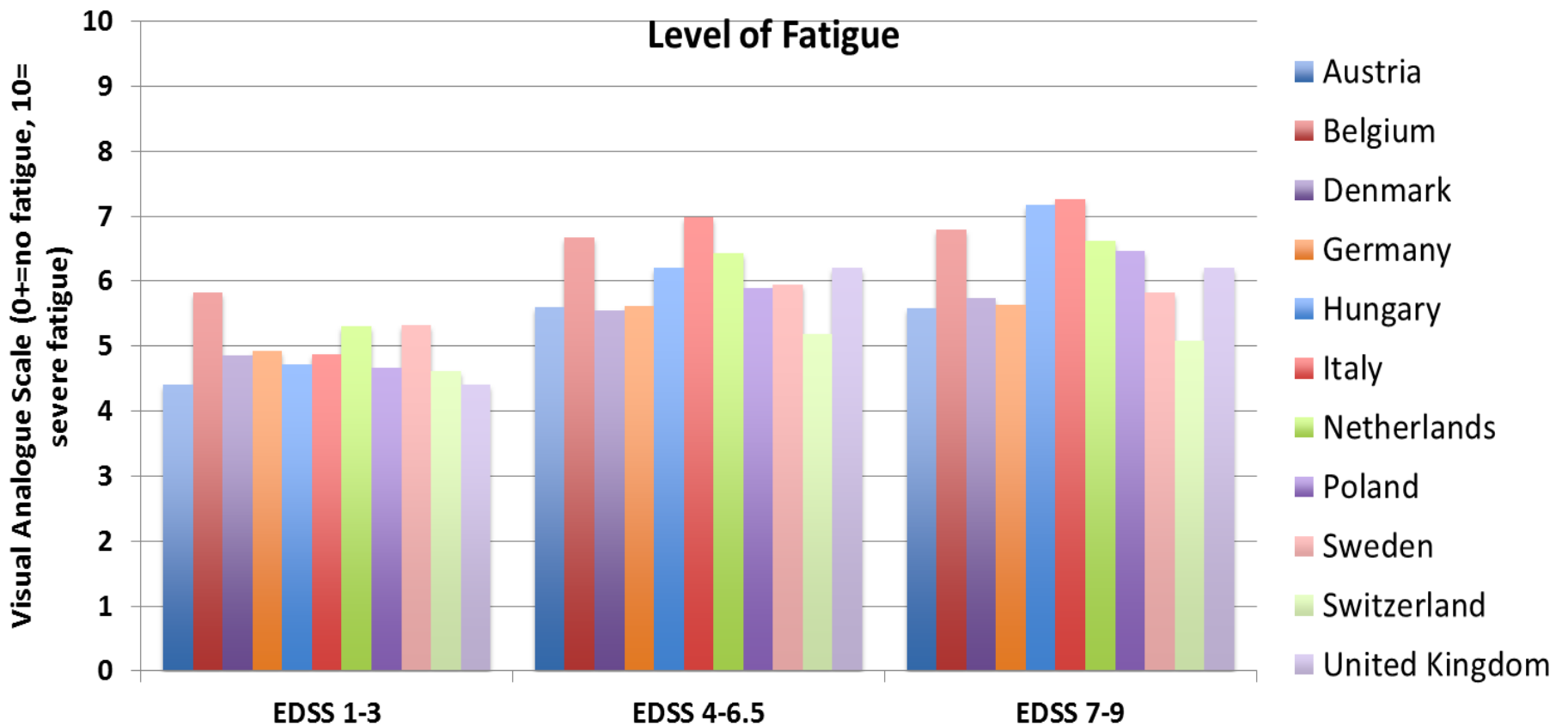
HRQOL, FATIGUE, COGNITION

QUALITY OF LIFE DOMAINS IN MS



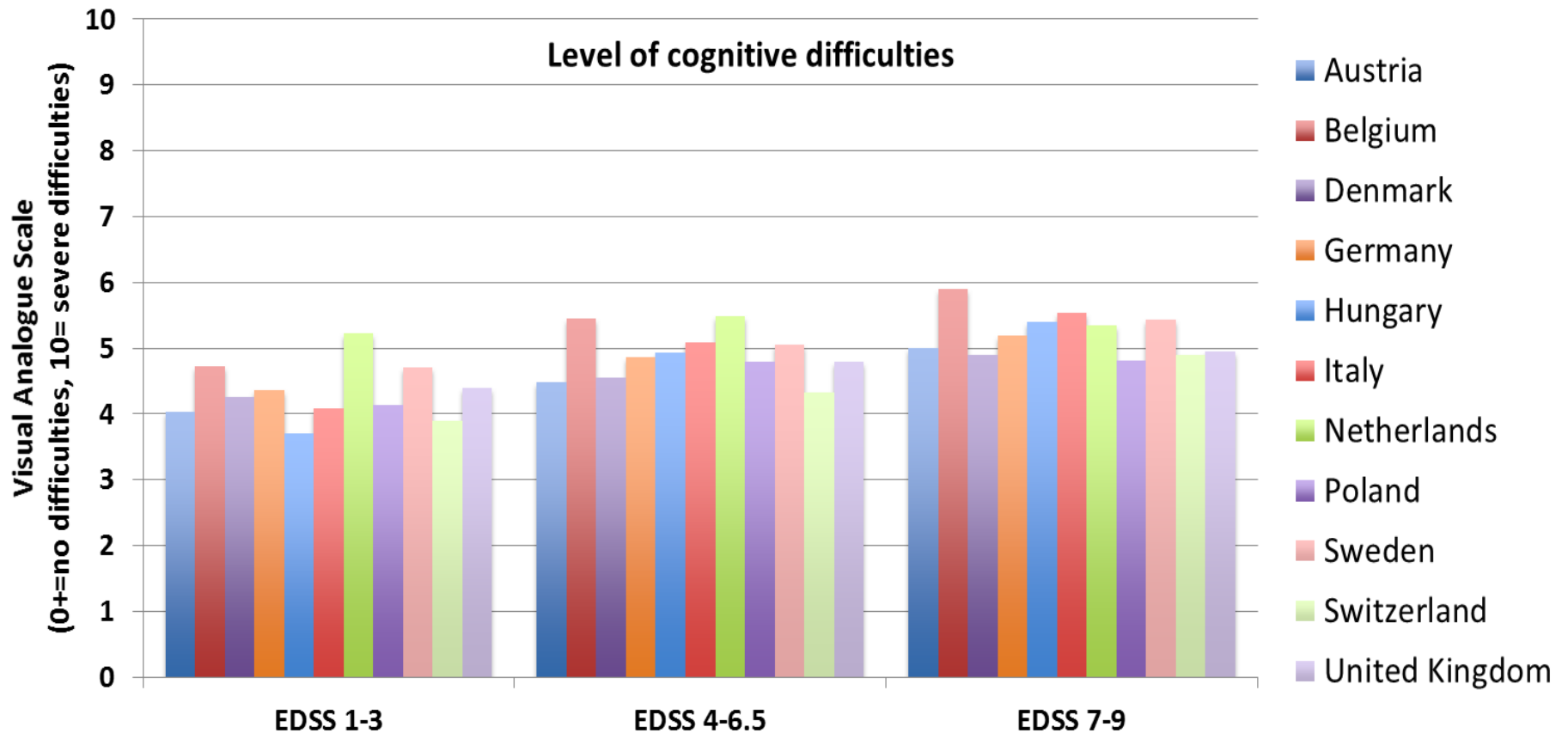
FATIGUE

95% OF ALL PATIENTS



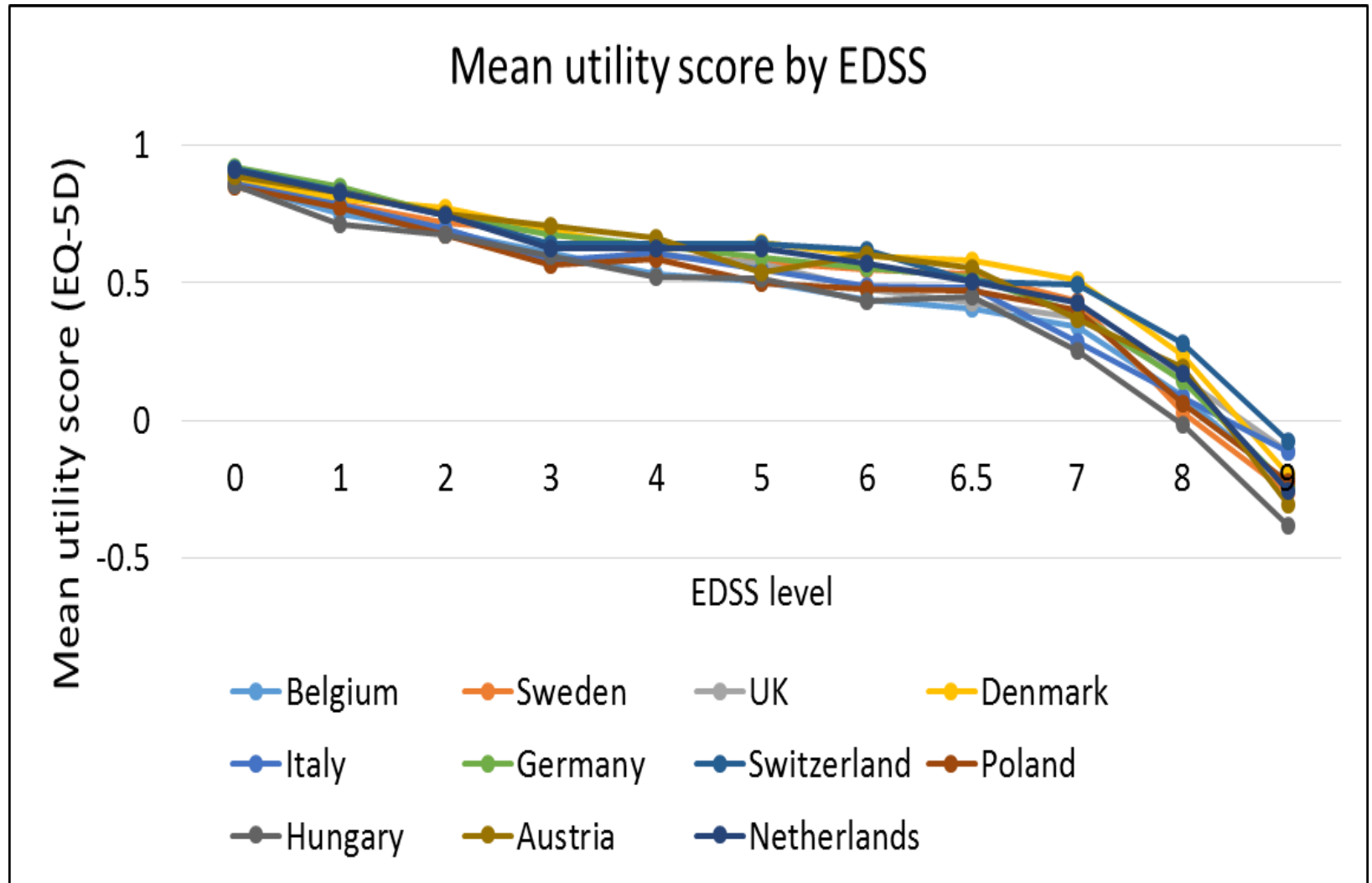
COGNITIVE DIFFICULTIES

70% OF ALL PATIENTS



QUALITY OF LIFE

RELATED TO DISEASE SEVERITY



USE OF SELECTED RESOURCES

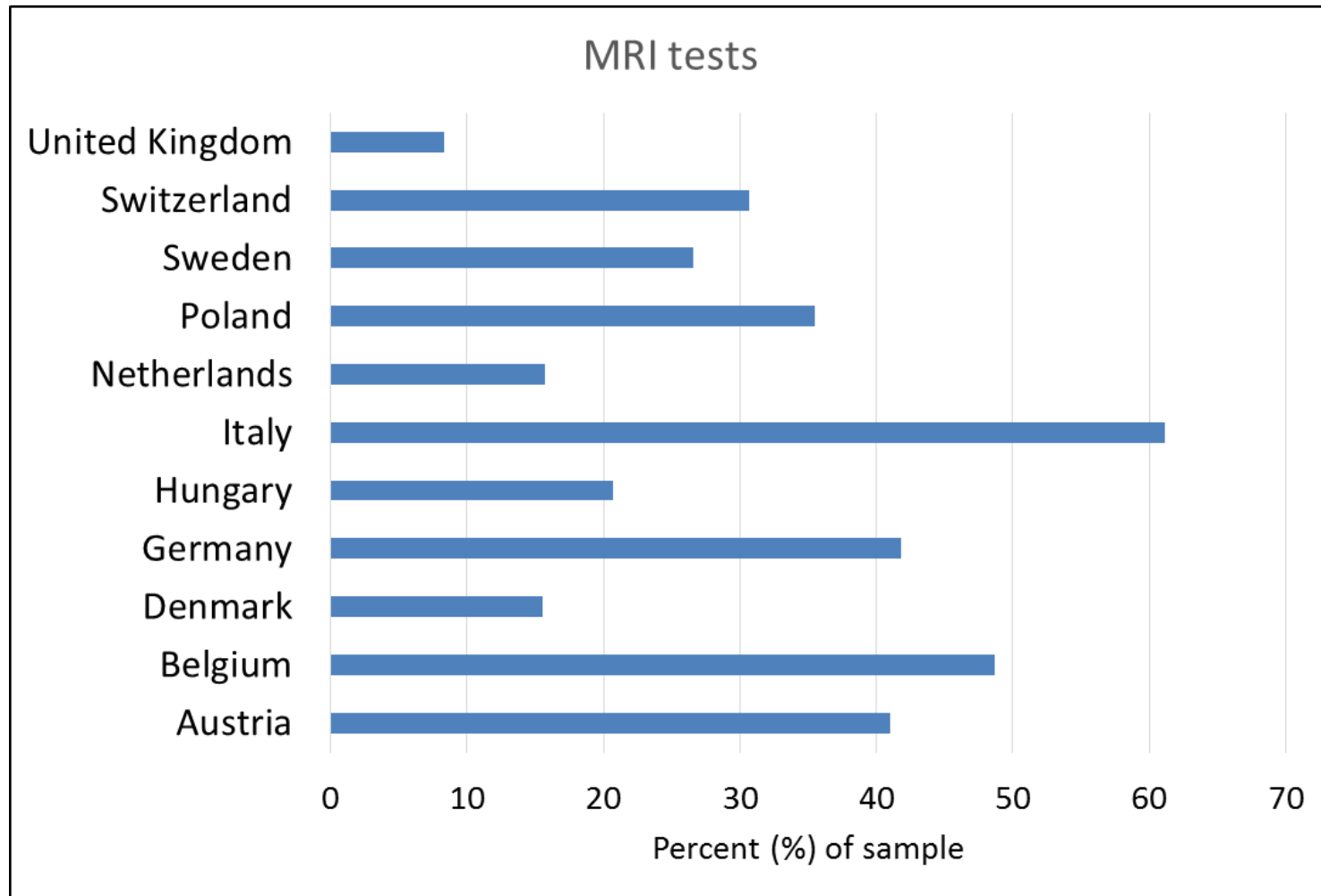
HOSPITALISATION

	Inpatient stays	Day admissions	Rehabilitation	Nursing home
Austria	9.1%	4.8%	12.8%	1.6%
Belgium	9.9%	17.1%	9.2%	2.4%
Denmark	3.1%	4.2%	4.7%	0.2%
Germany	9.7%	3.8%	4.9%	1.5%
Hungary	15.5%	8.3%	6.5%	1.7%
Italy	4.6%	18.5%	9.7%	1.1%
Netherlands	5.0%	9.2%	1.8%	1.0%
Poland	21.4%	19.5%	12.4%	1.5%
Sweden	2.7%	9.5%	8.1%	0.5%
Switzerland	3.6%	7.6%	5.3%	1.4%
United Kingdom	3.6%	7.1%	2.2%	2.2%

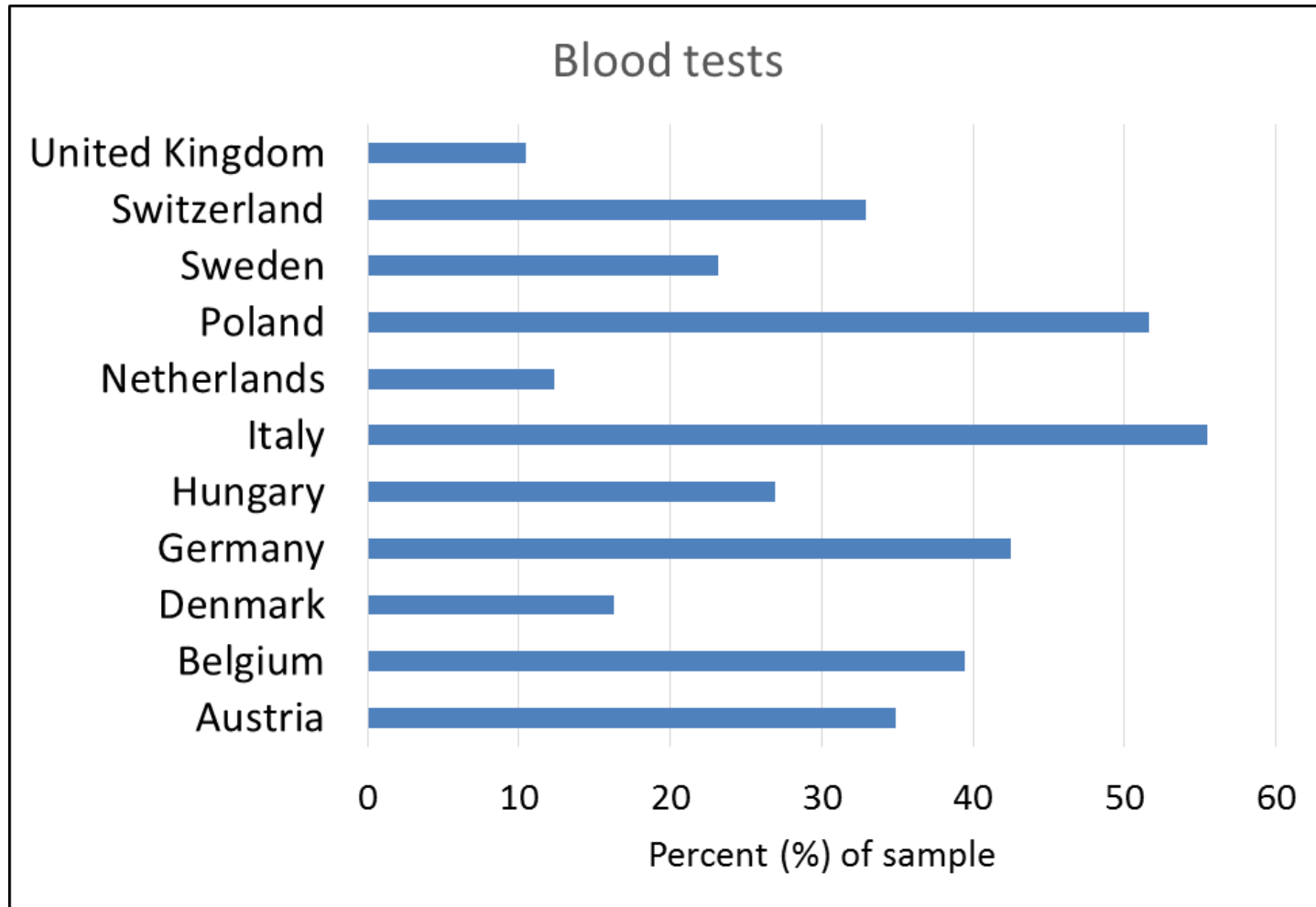
CONSULTATIONS

	All visits	Neurologist	Gen.Practitioner	Physiotherapist
Austria	74.8%	57.6%	33.7%	22.3%
Belgium	88.2%	67.9%	42.9%	58.0%
Denmark	65.2%	33.0%	13.1%	25.9%
Germany	89.9%	81.0%	35.3%	45.3%
Hungary	80.0%	69.3%	32.2%	18.0%
Italy	81.2%	70.6%	18.7%	20.7%
Netherlands	70.2%	43.7%	14.7%	33.0%
Poland	77.1%	67.4%	14.4%	10.5%
Sweden	59.9%	33.8%	9.1%	21.4%
Switzerland	71.0%	54.8%	28.0%	16.1%
United Kingdom	67.3%	25.0%	33.6%	19.3%

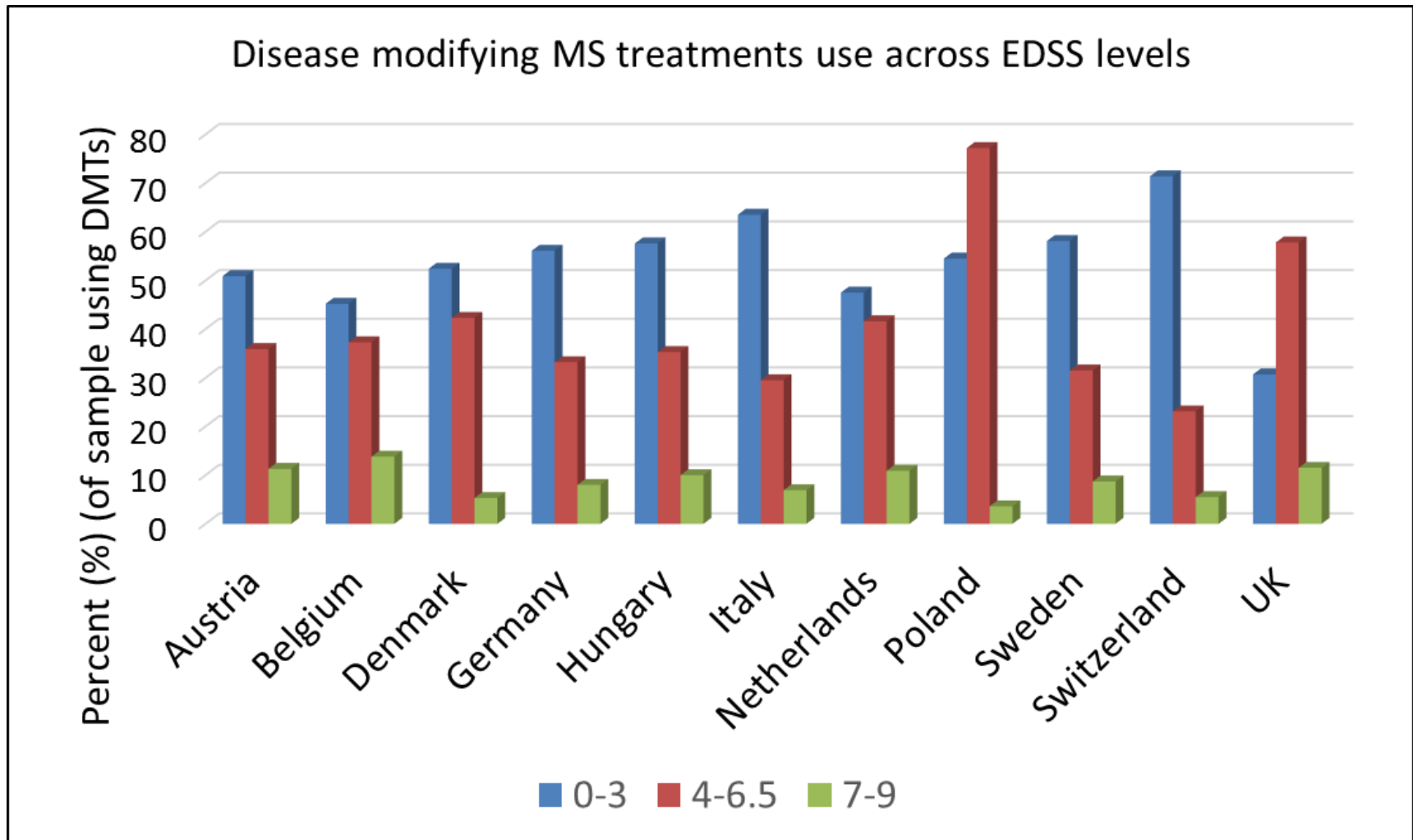
TESTS – MRI



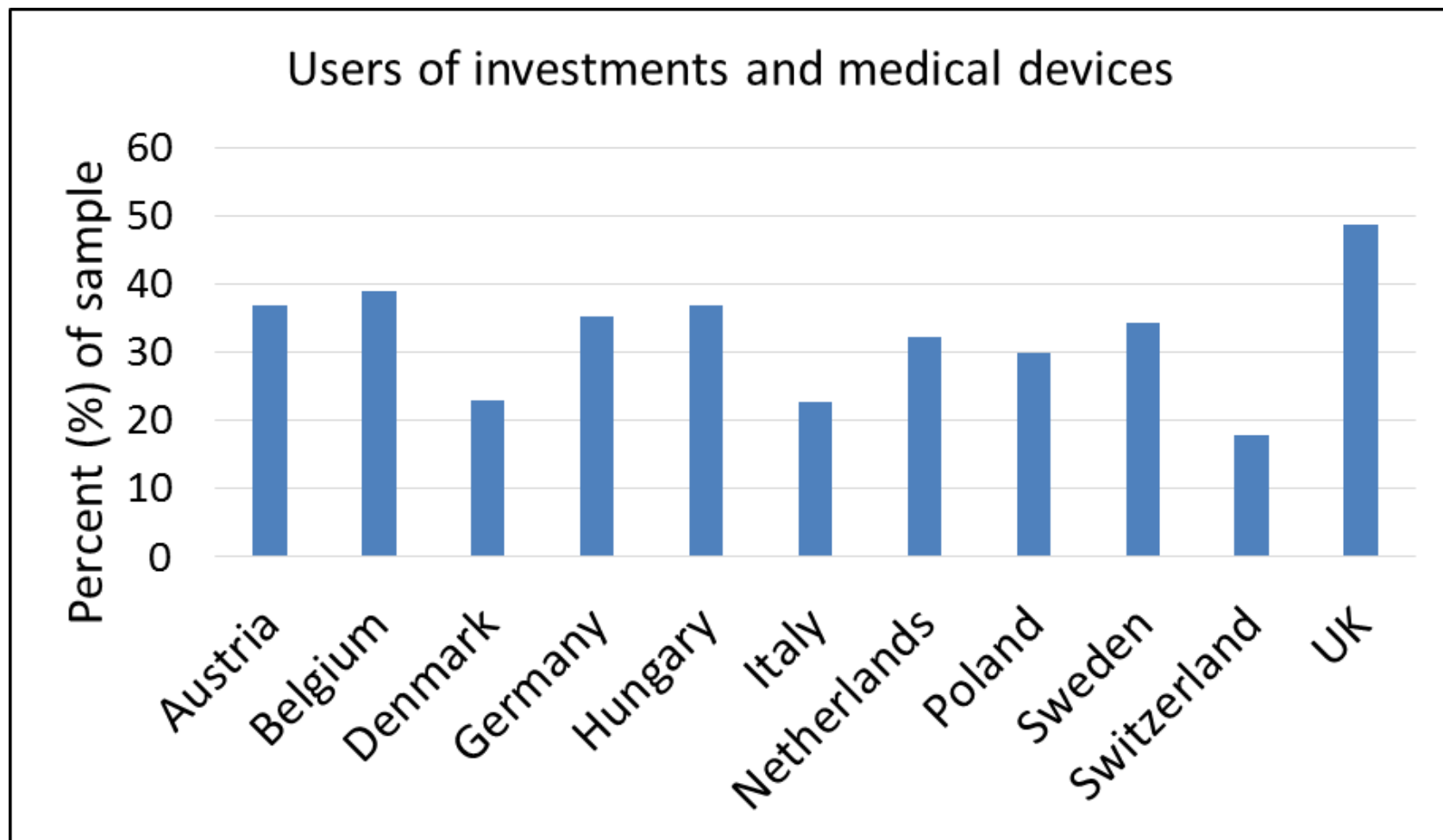
TESTS – BLOOD TESTS



MS TREATMENTS



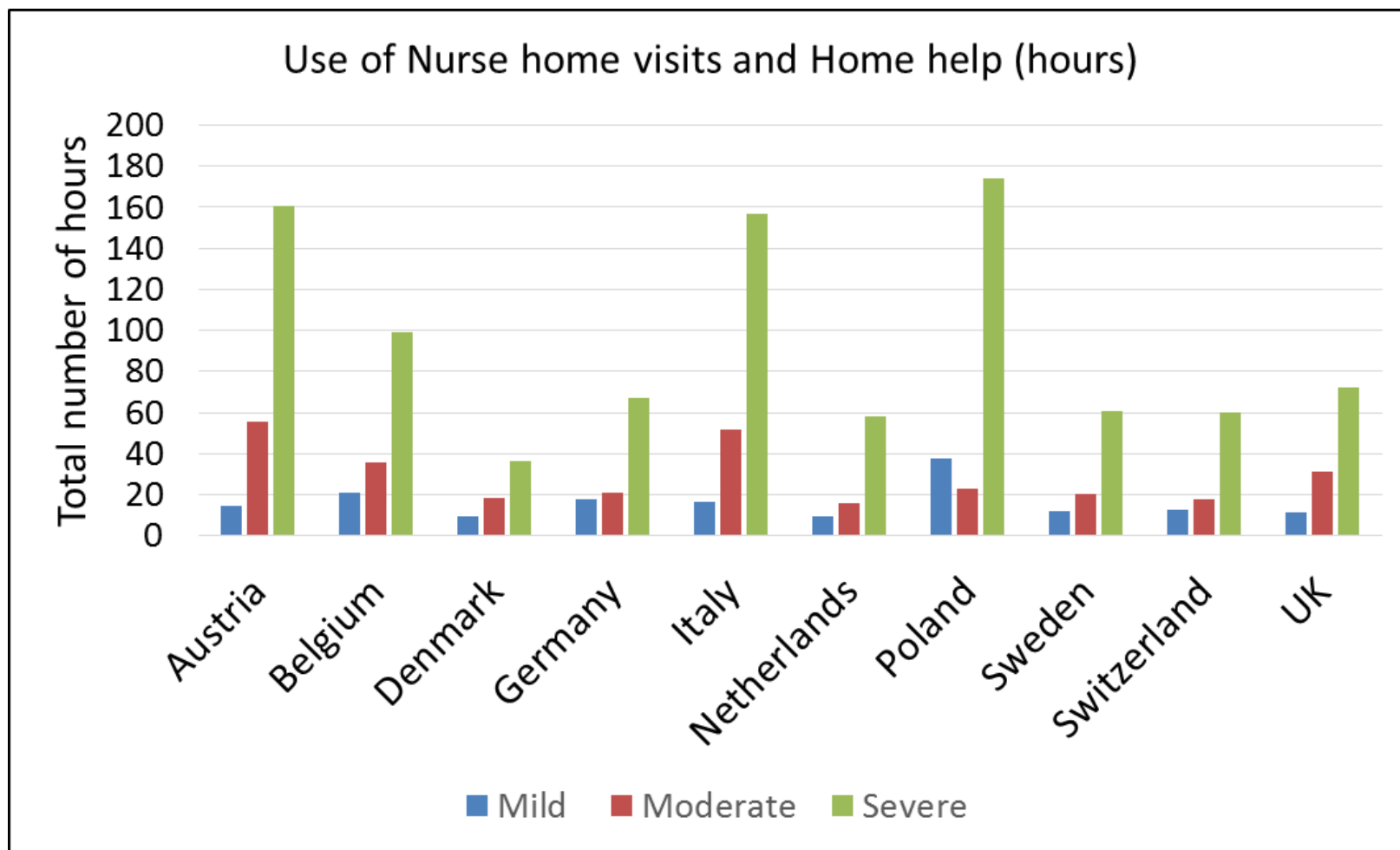
INVESTMENTS, DEVICES



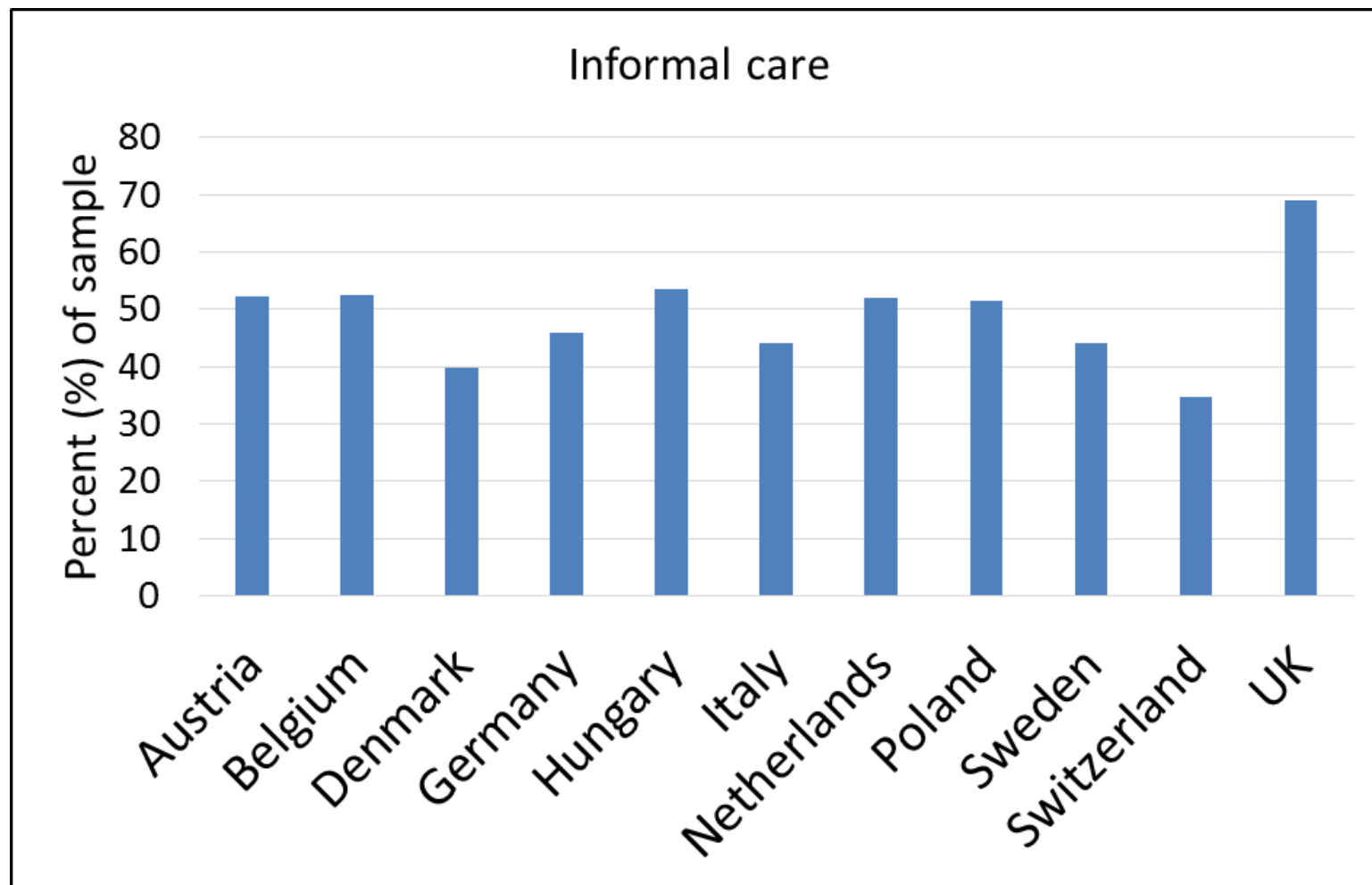
COMMUNITY/SOCIAL SERVICES

	Users	Nurse	Home help	Transport	Personal assistant
Austria	30.2%	7.9%	17.1%	12.8%	1.2%
Belgium	41%	15.8%	30.4%	12.7%	7.4%
Denmark	16.9%	2.5%	8.6%	6.3%	8.1%
Germany	21.3%	5.8%	16.0%	8.7%	0.7%
Hungary	23.2%	3.8%	14.8%	5.8%	TBC
Italy	17.2%	2.3%	10.5%	8.0%	1.9%
Netherlands	17.8%	5.2%	12.8%	7.9%	1.6%
Poland	7.1%	1.9%	2.7%	4.4%	1.5%
Sweden	33.5%	4.3%	11.4%	22.6%	12.8%
Switzerland	18.2%	4.2%	15.0%	6.2%	1.1%
United Kingdom	21.6%	5.3%	13.6%	9.5%	NA

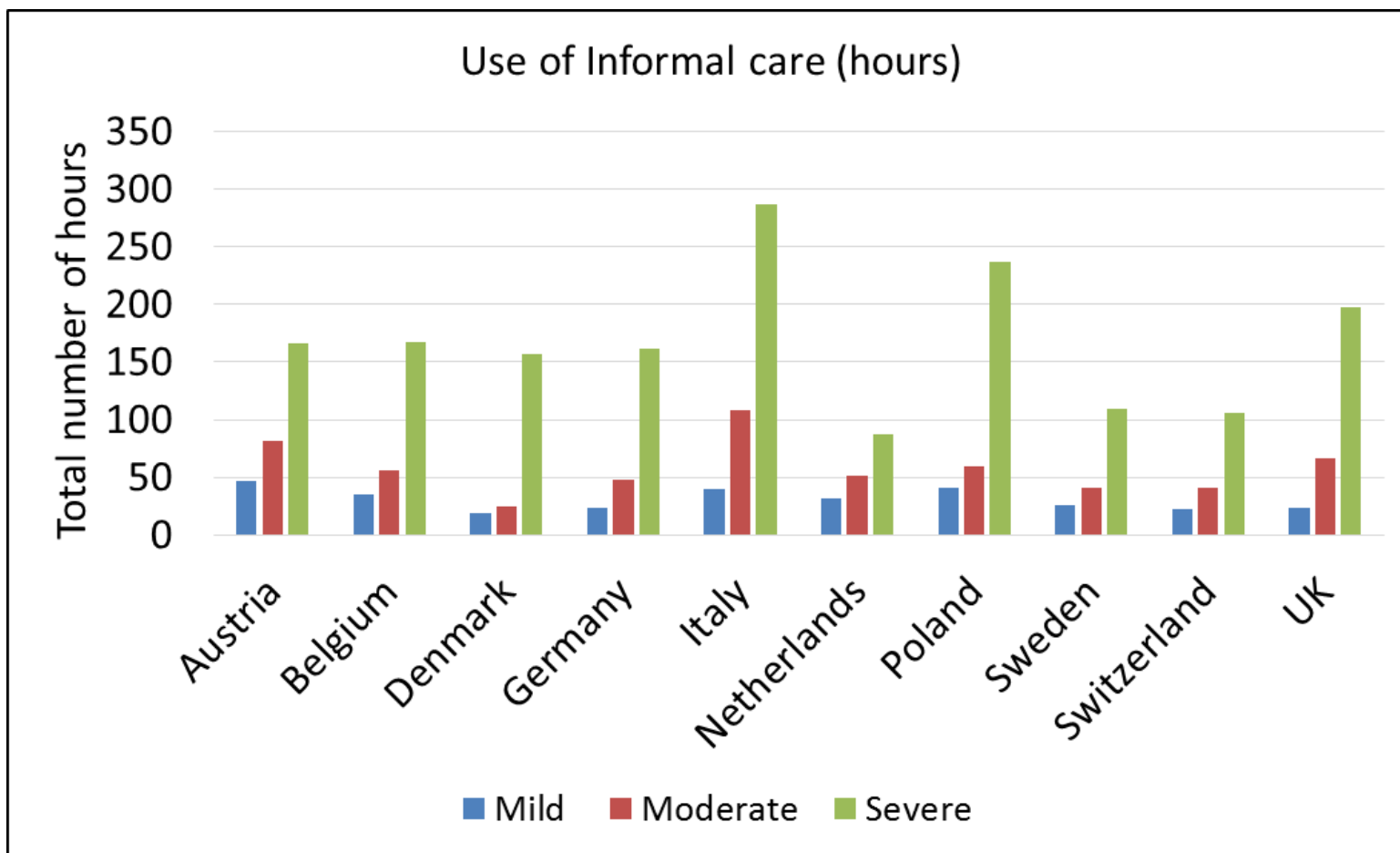
COMMUNITY/SOCIAL SERVICES



INFORMAL CARE



INFORMAL CARE



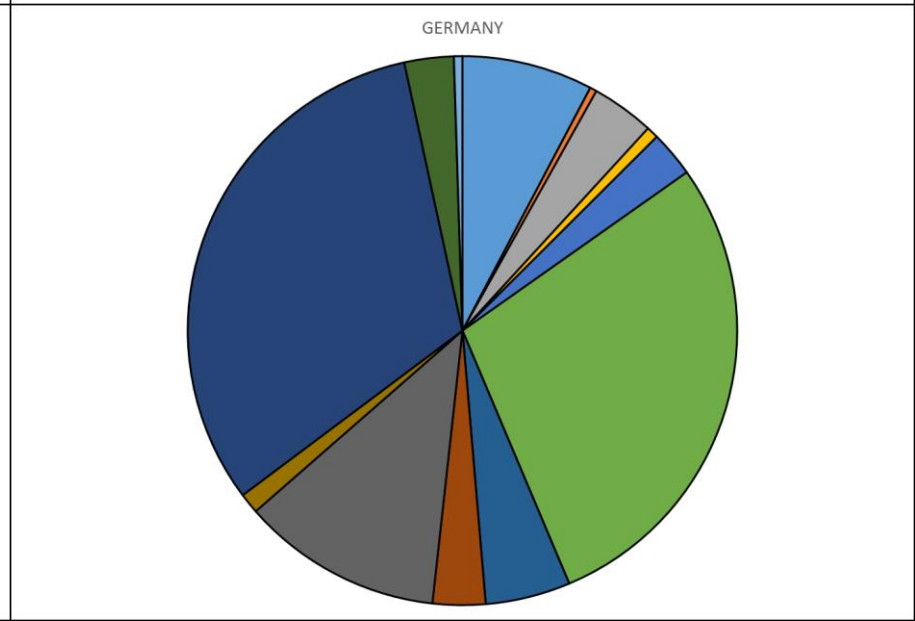
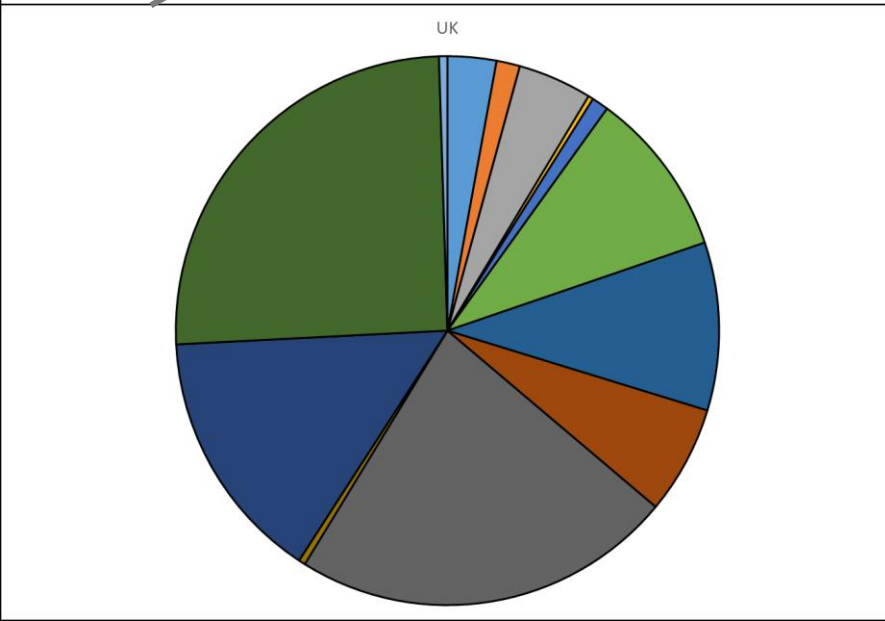
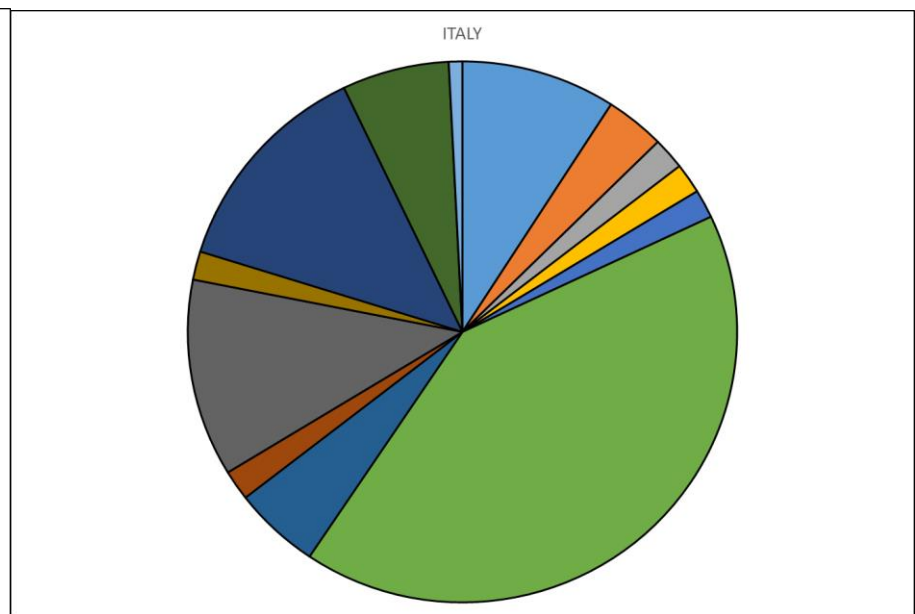
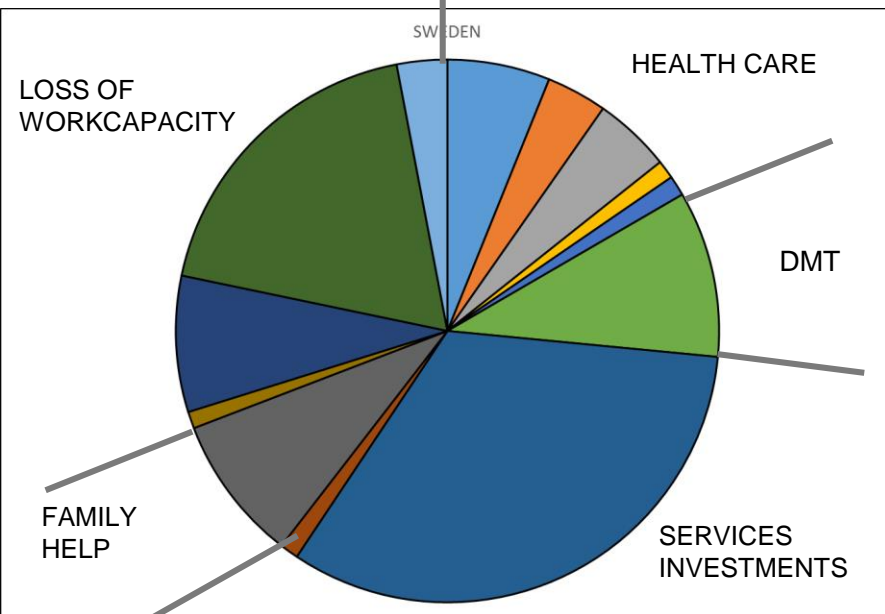
OUT OF POCKET EXPENSES

	Users	Overall €	Consultations €	OTC drugs €	Investments €	Services €
Austria	77%	2,075	220	353	264	1,238
Belgium	82%	1,085	24	354	253	241
Denmark	67%	796	36	232	50	477
Germany	76%	903	49	212	77	565
Hungary	84%	455	39	300	17	176
Italy	74%	1,269	41	364	140	724
Netherlands	72%	1,014	69	231	217	497
Poland	84%	631	110	301	96	123
Sweden	73%	1,387	62	166	36	1,122
Switzerland	63%	1,603	239	370	149	845
United Kingdom	72%	628	60	144	51	373

COSTS

COST STRUCTURE

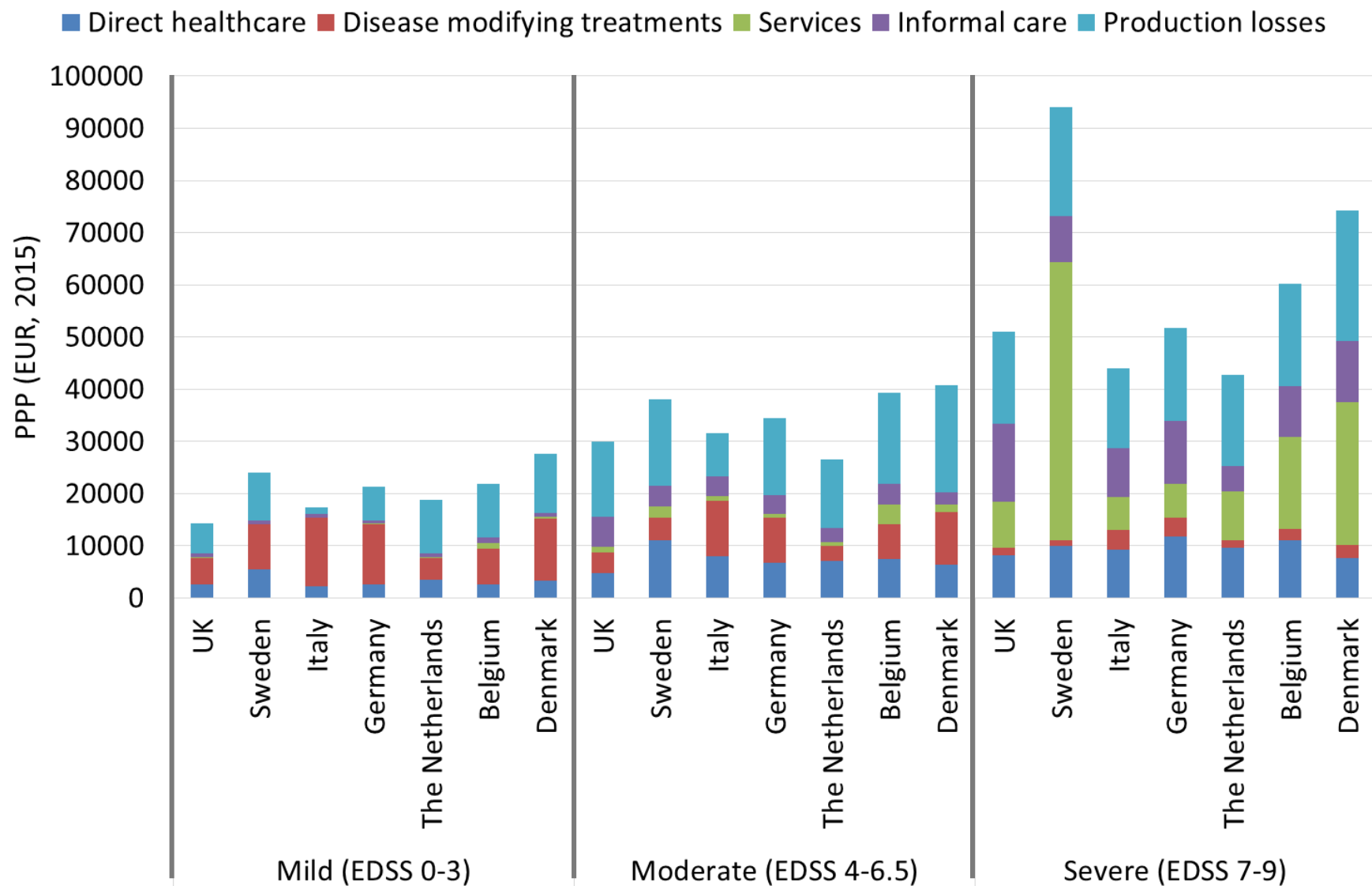
EXAMPLES: SWEDEN, ITALY, UK, GERMANY



(KEY FOR PREVIOUS SLIDE)

- Inpatient care
 - Day case admissions
 - Consultations
 - Tests and investigations
 - Medication
 - DMTs
 - Community and social services or assistance from MS patient organization
 - Investments, equipments and aids
 - Informal care
 - Short-term absence
 - Permanent sick-leave/invalidity pension
 - Early retirement
-

COSTS RELATED TO SEVERITY



TOTAL DIRECT COSTS – BY EDSS

EXAMPLE GERMANY

Table 40. Summary table: Annualized total costs and mean utilities by EDSS level (EUR, 2015)

Germany	EDSS 0 N=318 Mean(SD)	EDSS 1 N=684 Mean(SD)	EDSS 2 N=915 Mean(SD)	EDSS 3 N=514 Mean(SD)	EDSS 4 N=530 Mean(SD)	EDSS 5 N=672 Mean(SD)	EDSS 6 N=424 Mean(SD)	EDSS 6.5 N=280 Mean(SD)	EDSS 7 N=496 Mean(SD)	EDSS 8 N=444 Mean(SD)	EDSS 9 N=33 Mean(SD)
Mean utility	0.922 (0.116)	0.852 (0.138)	0.748 (0.171)	0.676 (0.198)	0.637 (0.181)	0.591 (0.220)	0.555 (0.234)	0.521 (0.246)	0.393 (0.285)	0.146 (0.349)	-0.237 (0.206)
Total costs	19096 (14392)	22100 (16733)	29569 (23172)	34703 (25876)	39626 (26280)	43091 (28650)	45880 (31427)	49561 (32359)	59141 (31677)	70395 (39231)	100995 (42194)
Total direct costs	15741 (11410)	17520 (11415)	19854 (16064)	20661 (17509)	23169 (16624)	24358 (20217)	25877 (23403)	28694 (25097)	36517 (25666)	48585 (32549)	68919 (37153)
Inpatient care	452 (2615)	565 (3041)	1496 (8483)	2150 (11543)	2346 (7707)	3182 (11276)	4068 (15573)	4835 (15646)	5659 (13726)	7089 (16819)	19555 (37750)
Day case admissions	36 (433)	94 (815)	161 (1062)	164 (888)	318 (3637)	183 (1023)	233 (1574)	112 (873)	170 (992)	304 (2230)	150 (410)
Healthcare consultations	479 (820)	721 (1003)	1212 (1468)	1355 (1418)	1655 (1563)	1713 (1723)	1676 (1594)	2030 (2132)	2209 (2471)	2039 (2115)	3098 (2790)
Tests and investigations	248 (366)	295 (410)	369 (447)	328 (426)	328 (460)	349 (482)	292 (444)	263 (404)	254 (430)	148 (319)	117 (324)
Medications	152 (325)	210 (477)	390 (796)	763 (1592)	1116 (1885)	1345 (2068)	1691 (2460)	1969 (2986)	2203 (3175)	2007 (3149)	1745 (3333)
Disease modifying treatments	14165 (10488)	15176 (10139)	14906 (10506)	13655 (11060)	13778 (11543)	11286 (11485)	9311 (11036)	7585 (10991)	5813 (9865)	3436 (8330)	578 (3322)
Community and social services or assistance from MS patient organization	5 (63)	37 (455)	262 (2522)	313 (2033)	391 (2360)	766 (3208)	1484 (5932)	2043 (5853)	3905 (9944)	12694 (21085)	17638 (18433)
Investments, equipments and aids	129 (1483)	79 (1141)	221 (1668)	512 (2519)	778 (3161)	1305 (4167)	1634 (3929)	2551 (5237)	3418 (5152)	3591 (6362)	1661 (2867)
Informal care (assistance from family and friends)	74 (657)	342 (2064)	836 (2866)	1421 (3249)	2459 (5111)	4229 (7666)	5489 (7977)	7305 (9520)	12886 (12875)	17277 (15726)	24377 (18895)

TOTAL INDIRECT COSTS – BY EDSS

EXAMPLE GERMANY

Table 40. Summary table: Annualized total costs and mean utilities by EDSS level (EUR, 2015)

	EDSS 0 N=318 Mean(SD)	EDSS 1 N=684 Mean(SD)	EDSS 2 N=915 Mean(SD)	EDSS 3 N=514 Mean(SD)	EDSS 4 N=530 Mean(SD)	EDSS 5 N=672 Mean(SD)	EDSS 6 N=424 Mean(SD)	EDSS 6.5 N=280 Mean(SD)	EDSS 7 N=496 Mean(SD)	EDSS 8 N=444 Mean(SD)	EDSS 9 N=33 Mean(SD)
Germany											
Total indirect costs	3355 (10682)	4580 (11789)	9715 (15858)	14042 (17772)	16458 (18498)	18733 (18800)	20002 (19073)	20868 (18921)	22624 (19193)	21810 (19499)	32077 (17239)
Short-term absence	119 (855)	586 (3111)	937 (3832)	833 (3329)	709 (3827)	420 (2414)	182 (1367)	235 (2197)	85 (1352)	141 (1610)	0 (0)
Permanent sick- leave/invalidity pension	3122 (10521)	3502 (10937)	7718 (15294)	12326 (17782)	14309 (18577)	16396 (18879)	18135 (19160)	19480 (19089)	19944 (19409)	20016 (19677)	26727 (19445)
Early retirement	114 (2041)	384 (3787)	750 (5316)	612 (4892)	1005 (6131)	1709 (8092)	1379 (7242)	1123 (6590)	2524 (9835)	1533 (7729)	5349 (14627)
Long term but not permanent sick-leave	0 (0)	109 (1896)	312 (2824)	274 (2975)	434 (3059)	209 (2192)	306 (3424)	30 (496)	70 (1009)	120 (1879)	0 (0)

THANK YOU