

# Pan-European survey on course of illness for ME-patients

## Focus on the Netherlands

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# Outline

- 1) The survey and respondents (severity)
- 2) Year of onset and diagnostic period (from onset to diagnosis)
- 3) Course of illness and factor affecting that (in particular, CBT)
- 4) Experiences with health and other public services

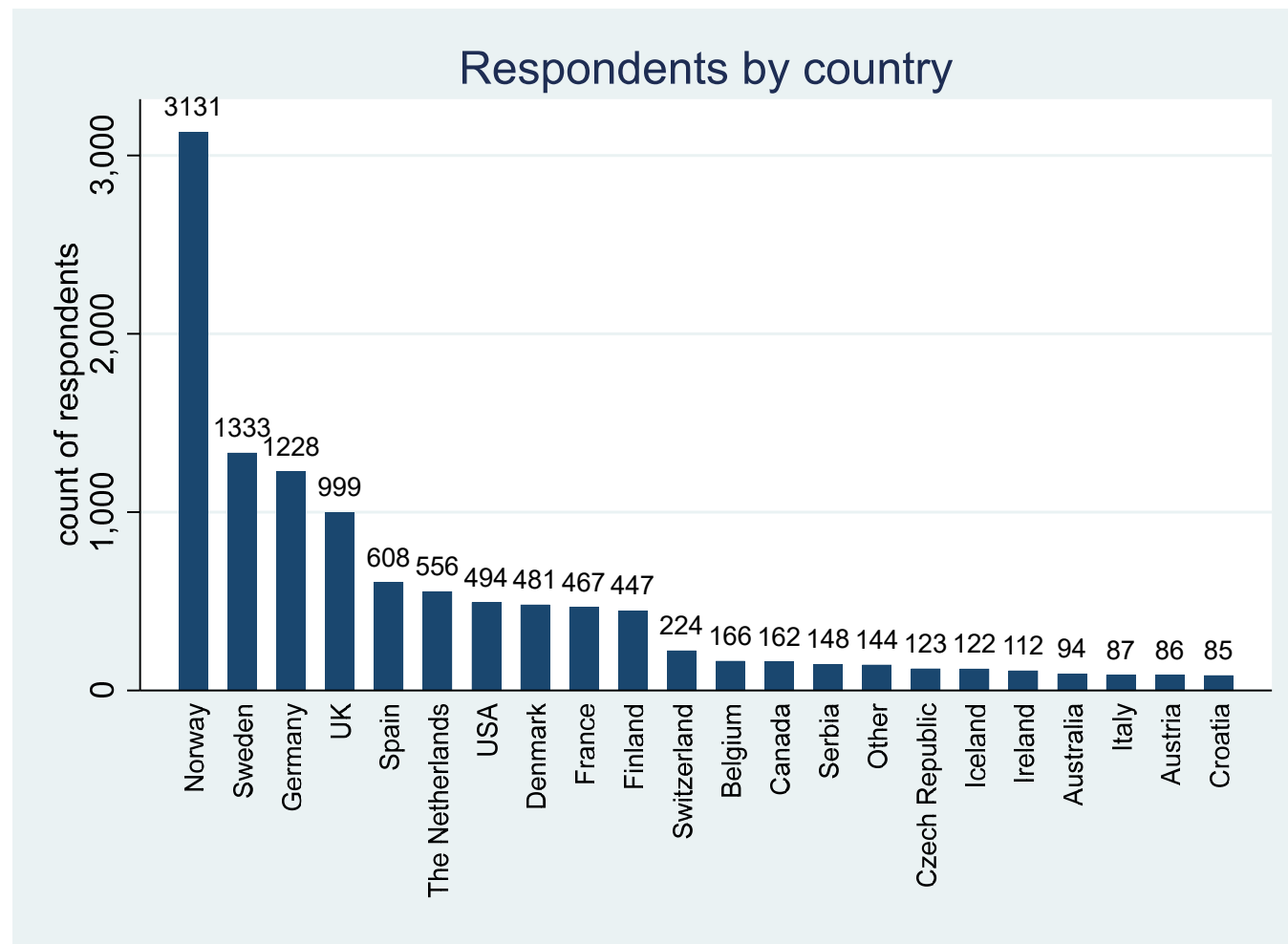
# 1. Pan-European patient survey

- Norwegian ME Association has assumed the main responsibility for implementation and analysis
- In collaboration with EMEA (17 countries)
- 18 questions (8 min): years onset & diagnosis, course of illness & factors affecting it, support, **triggers, comorbidities**
- Translated to 15 languages:  
Norwegian, Swedish, Danish, Icelandic, Finnish, English, German, Dutch, French, Spanish, Italian, Croatian, Serbian, Czech, and Hungarian
- First European comparative survey of ME-patients



# Respondents

- In total: **11 297** (more or less) complete responses
- More than 400 participants from 10 countries
- 84 % women



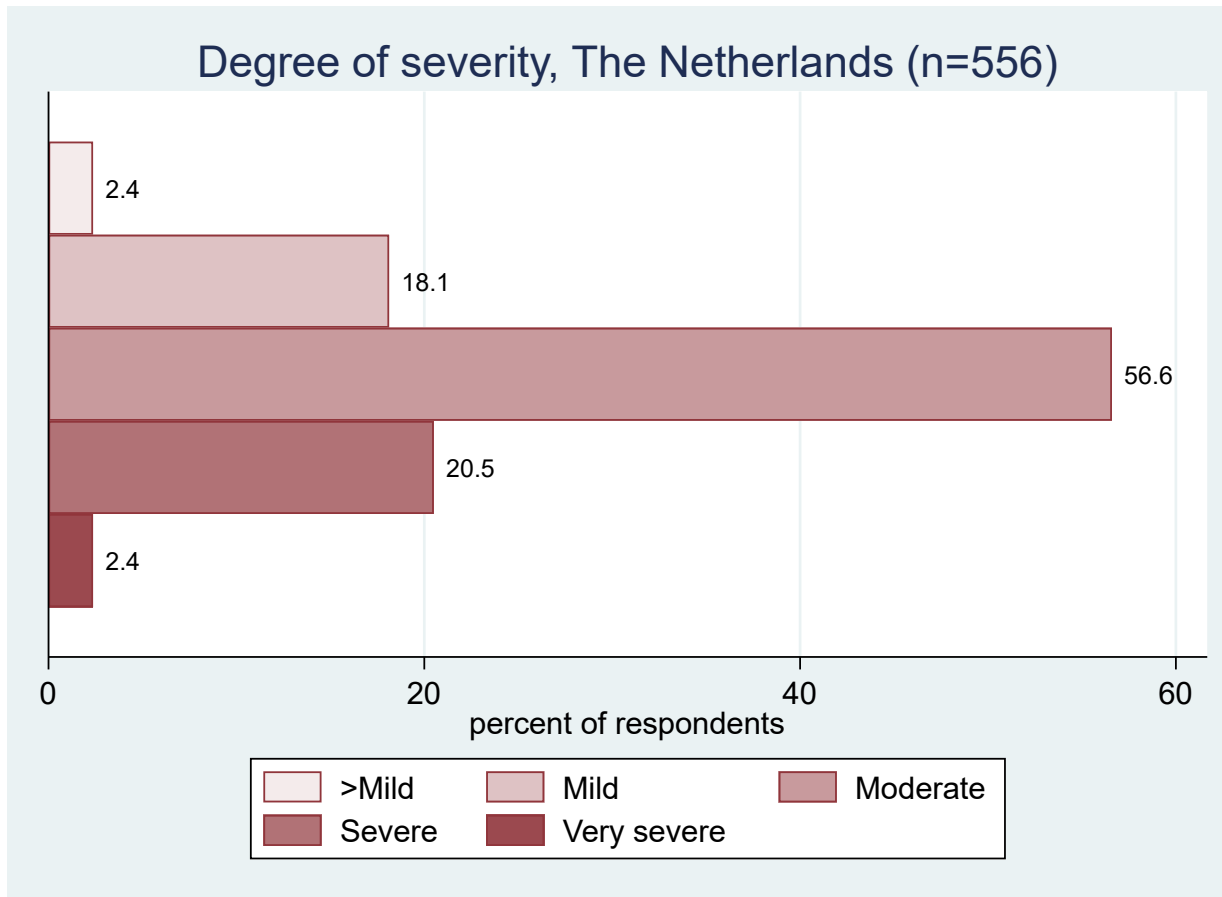
# Defining degrees of severity

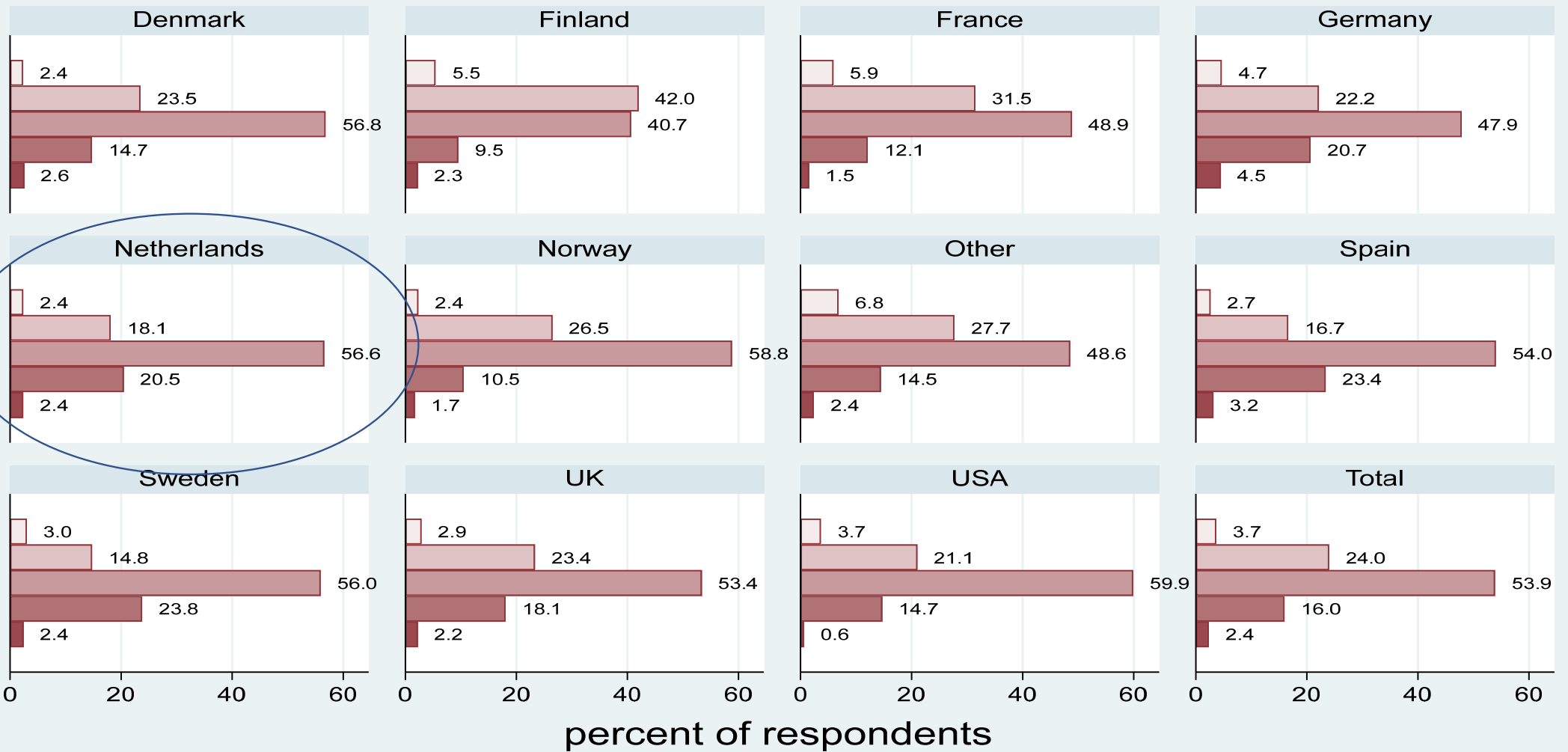
Based on ICC

- **Very severe:** totally bedridden and need help with basic functions
- **Severe:** mostly bedridden
- **Moderate:** mostly housebound
- **Mild:** >50% reduction in pre-illness activity level
- **Better than “mild”,** but not completely recovered
- **Completely recovered**

# Severity

- “Moderate” as the dominant group



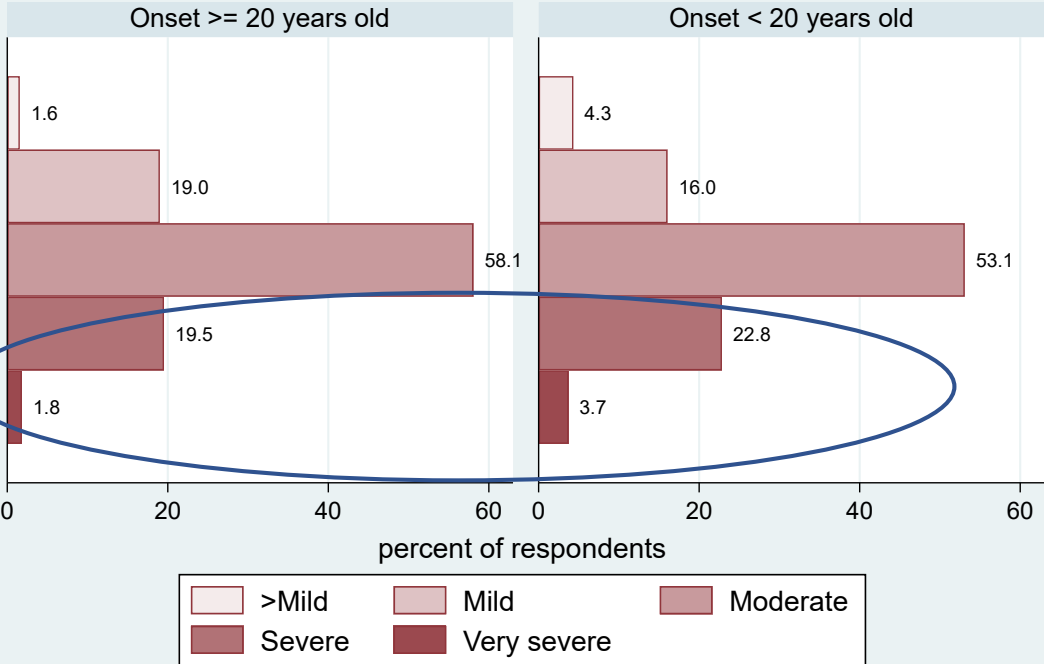


Graphs by country25

# Severity and age at onset (<20 years): A strong link

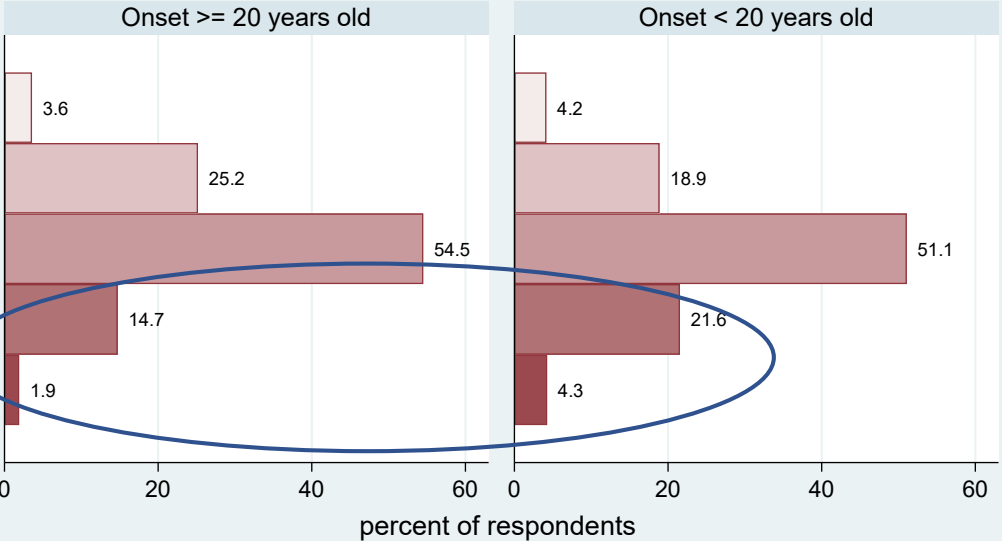
... as found in other surveys & studies

Onset & severity, the Netherlands



Graphs by age\_ill\_below20

Onset and severity, all countries



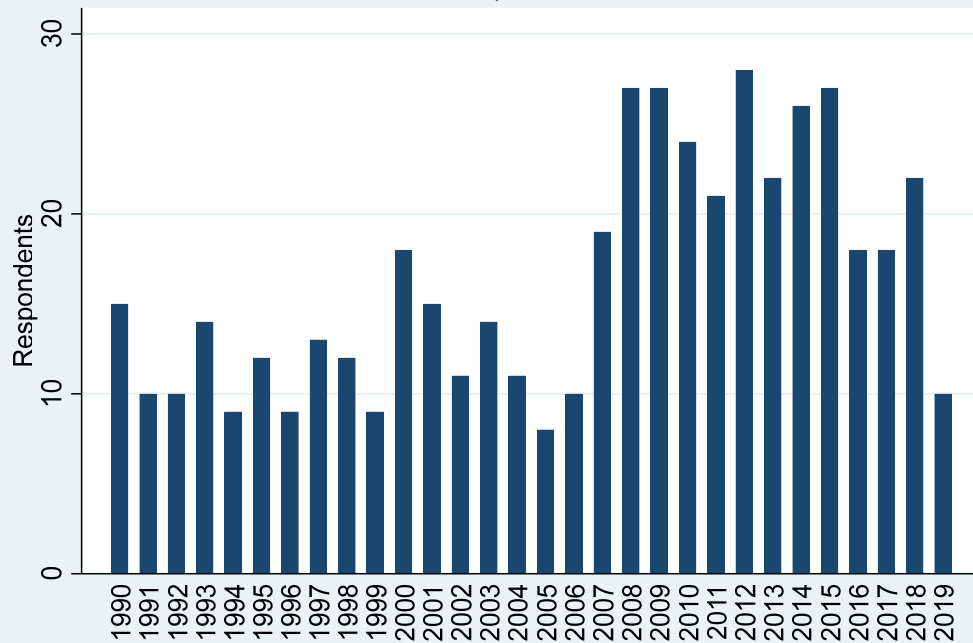
Graphs by age\_ill\_below20



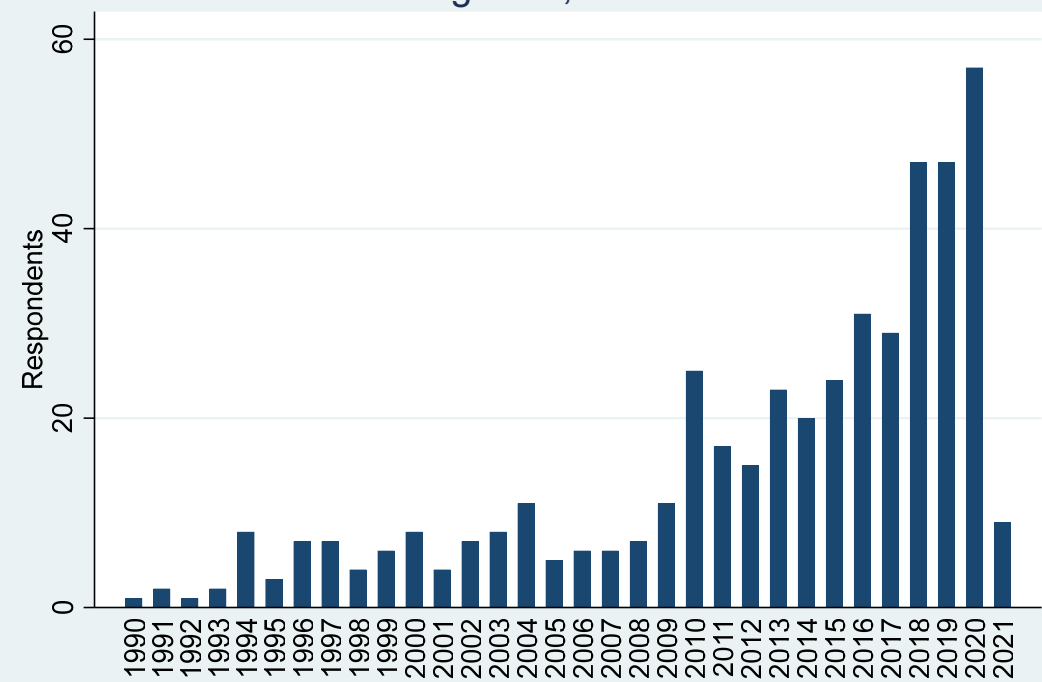
## 2. When did they become ill (year of onset)?

- Lag in diagnoses
- Steady increase in the number of diagnoses

Year of onset, The Netherlands



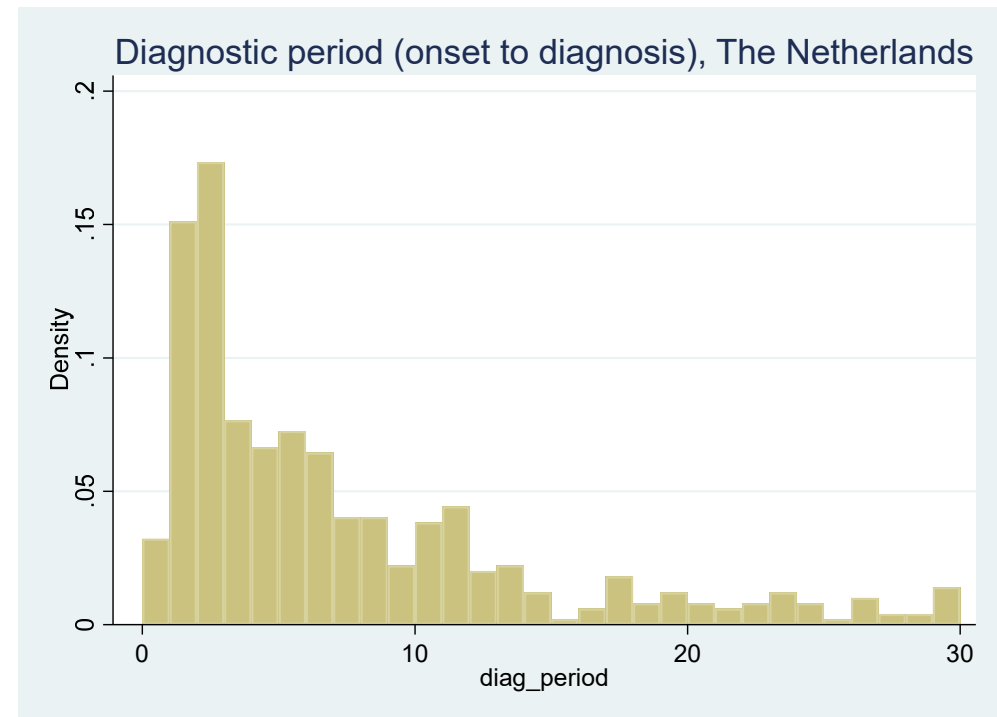
Year of diagnosis, The Netherlands



# Diagnostic period, the Netherlands

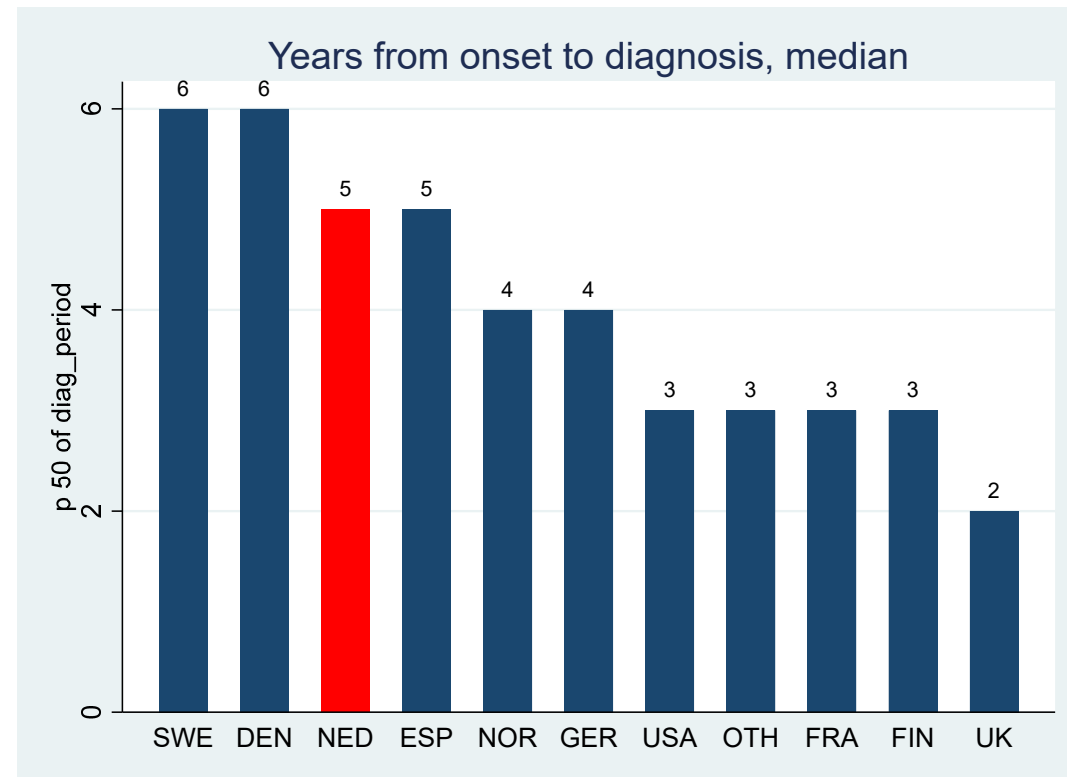
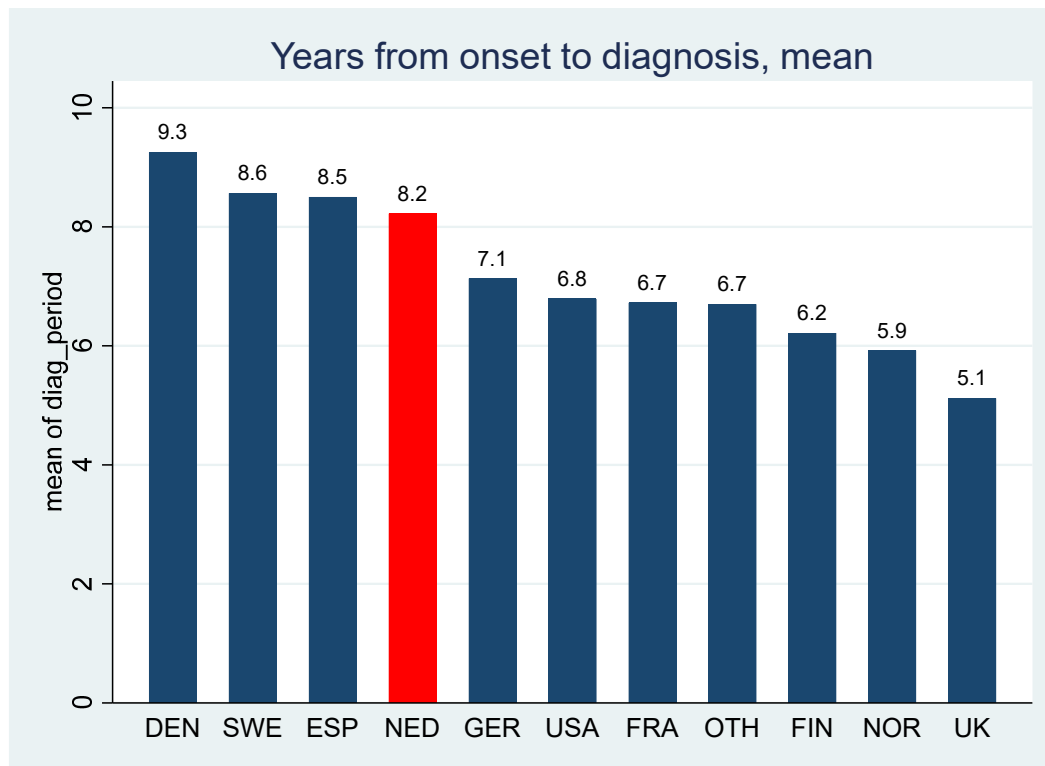
Mean 8.2 years  
Median: 5 years

diag_period	Freq.	Percent	Cum.
0	16	3.08	3.08
1	75	14.42	17.50
2	86	16.54	34.04
3	38	7.31	41.35
4	33	6.35	47.69
5	36	6.92	54.62
6	32	6.15	60.77
7	20	3.85	64.62
8	20	3.85	68.46
9	11	2.12	70.58
10	19	3.65	74.23
11	22	4.23	78.46
12	10	1.92	80.38
13	11	2.12	82.50
14	6	1.15	83.65
15	1	0.19	83.85



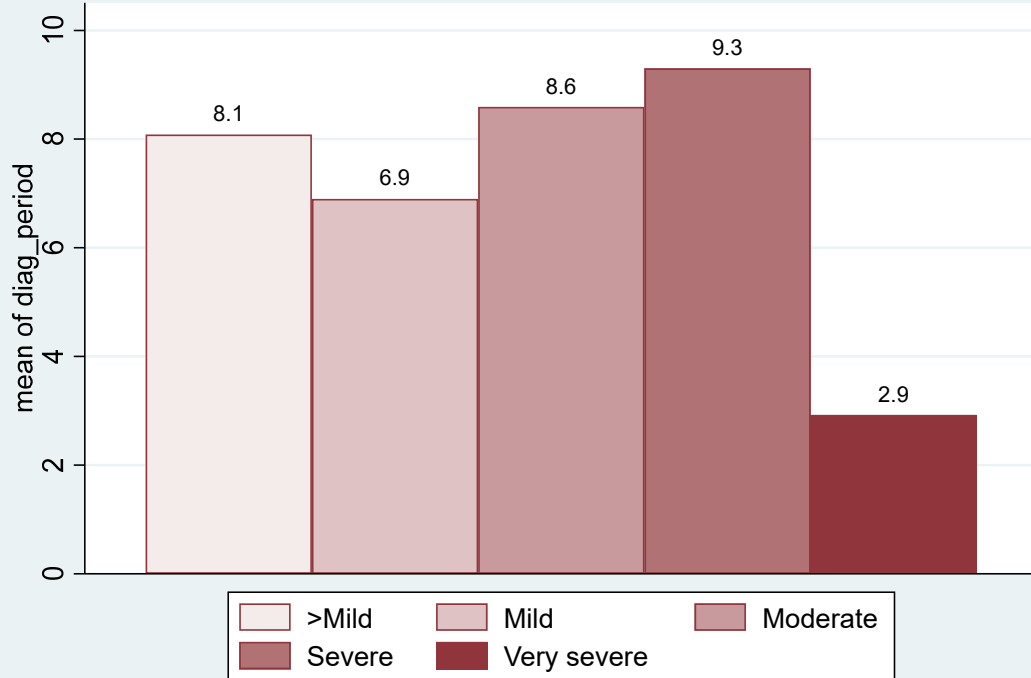
# Diagnostic period across countries

- Sweden and Denmark the longest, UK the shortest

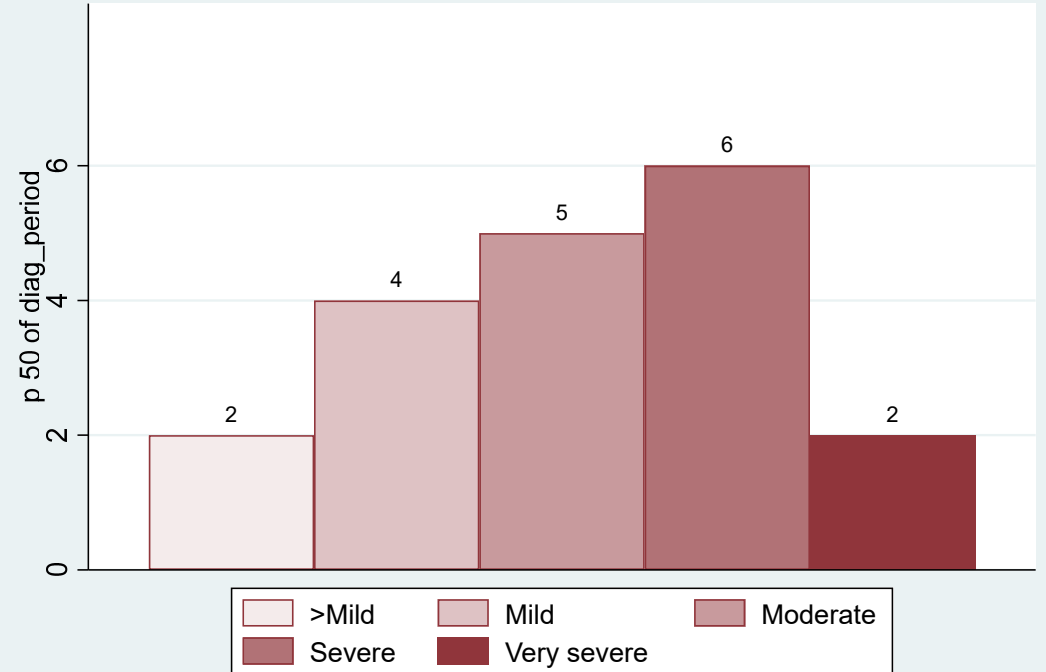


# Diagnostic period and severity

Diagnosis period (mean) by severity, The Netherlands



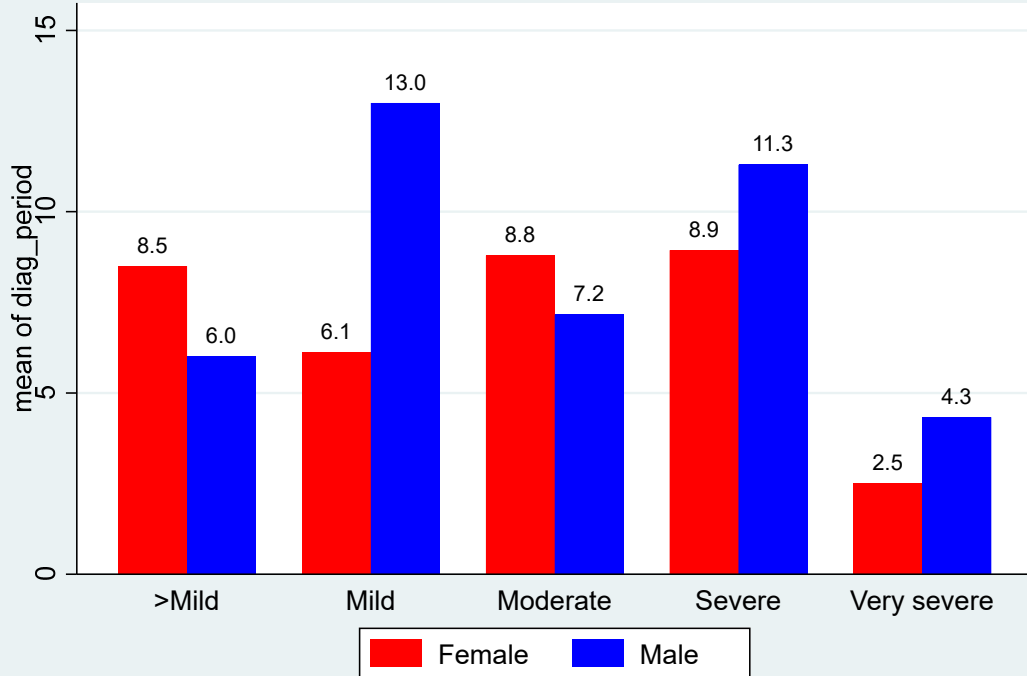
Diagnosis period (median) by severity, The Netherlands



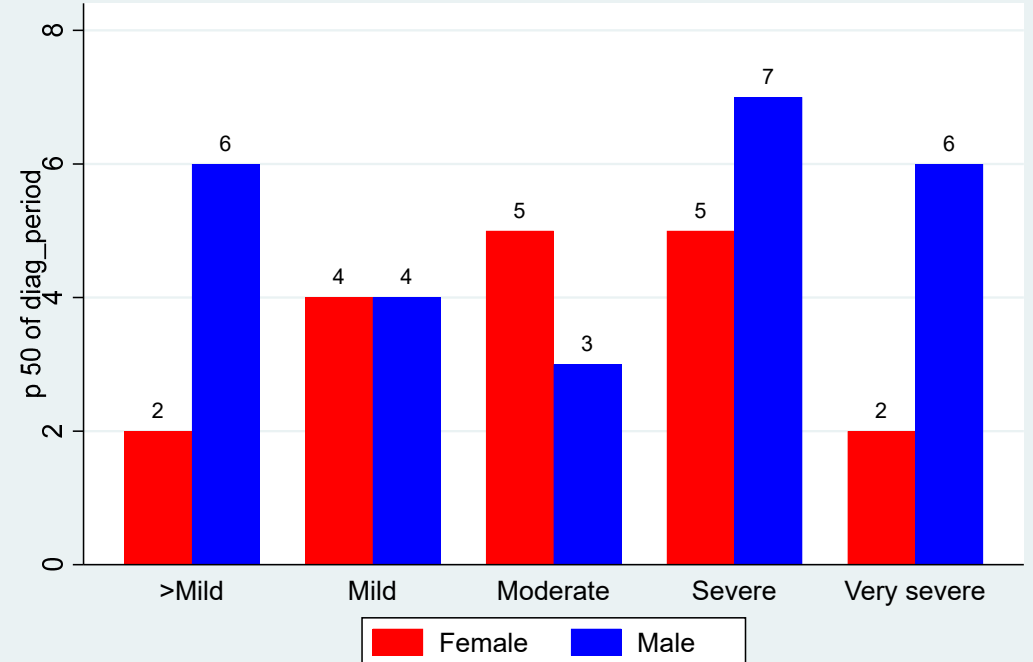
# ... by gender

- Unlike other countries, average (mean) diagnostic period is slightly lower for women than for men (8.1 vs 8.8 years)

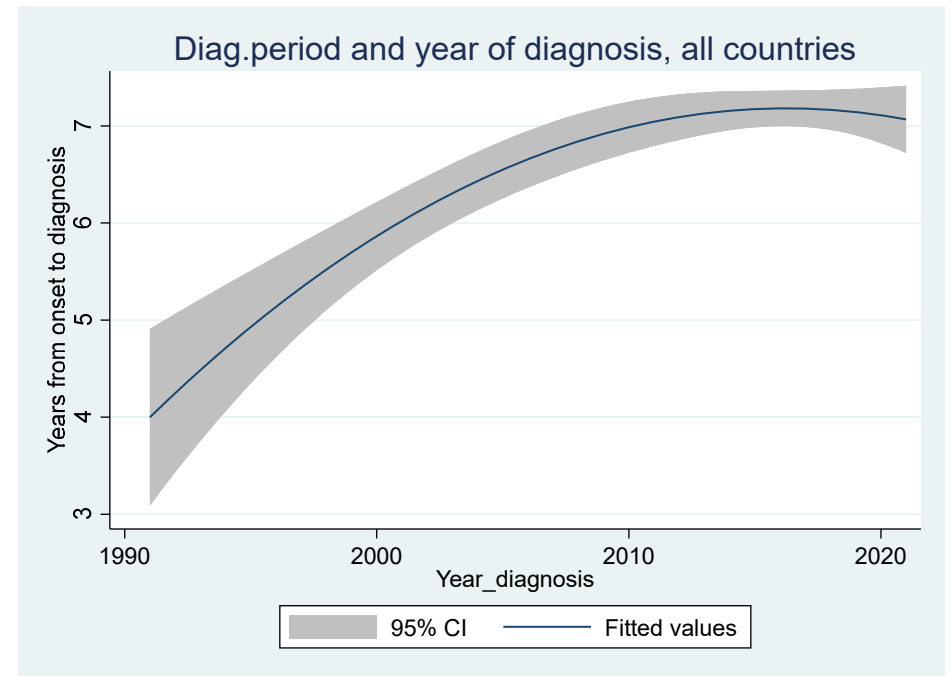
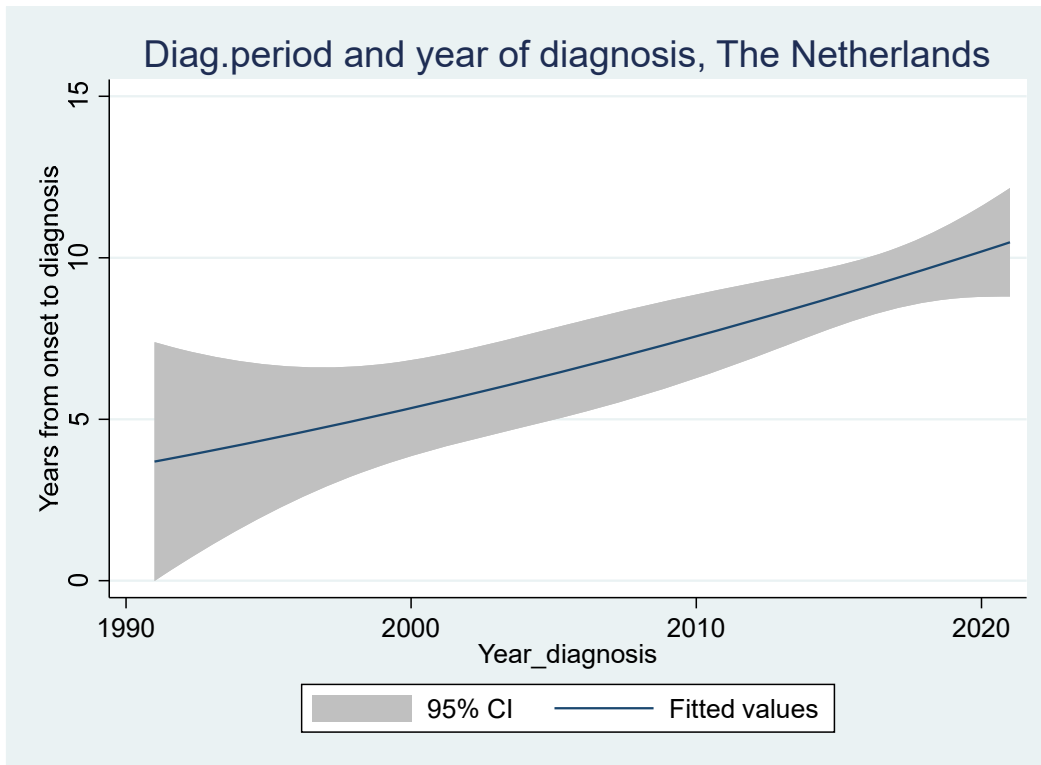
Diag. period (mean) by gender & severity, The Netherlands



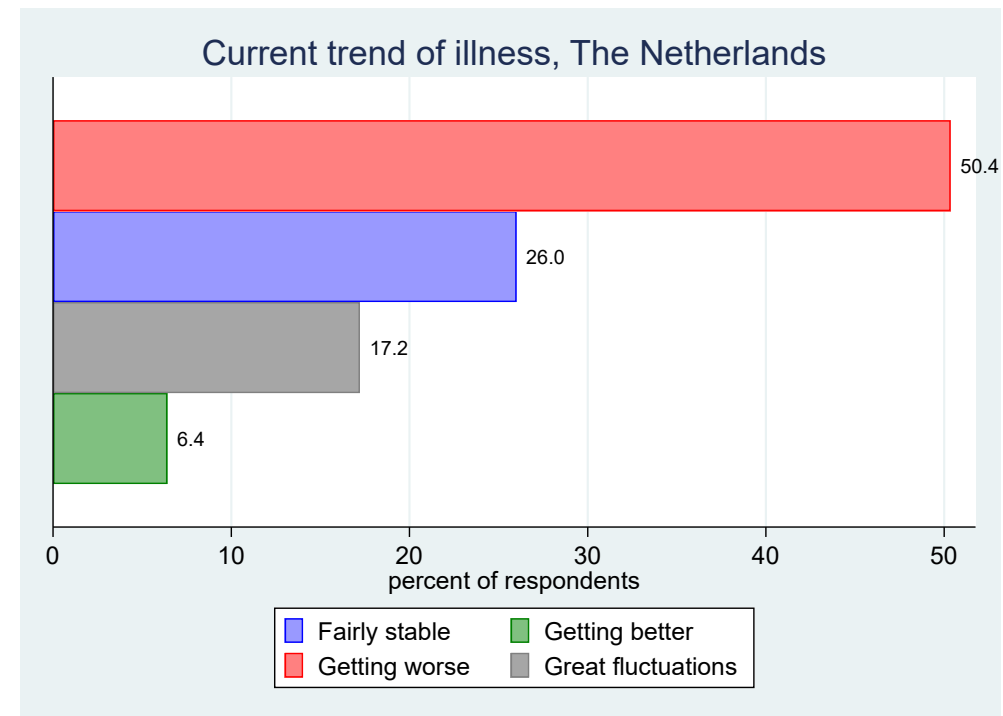
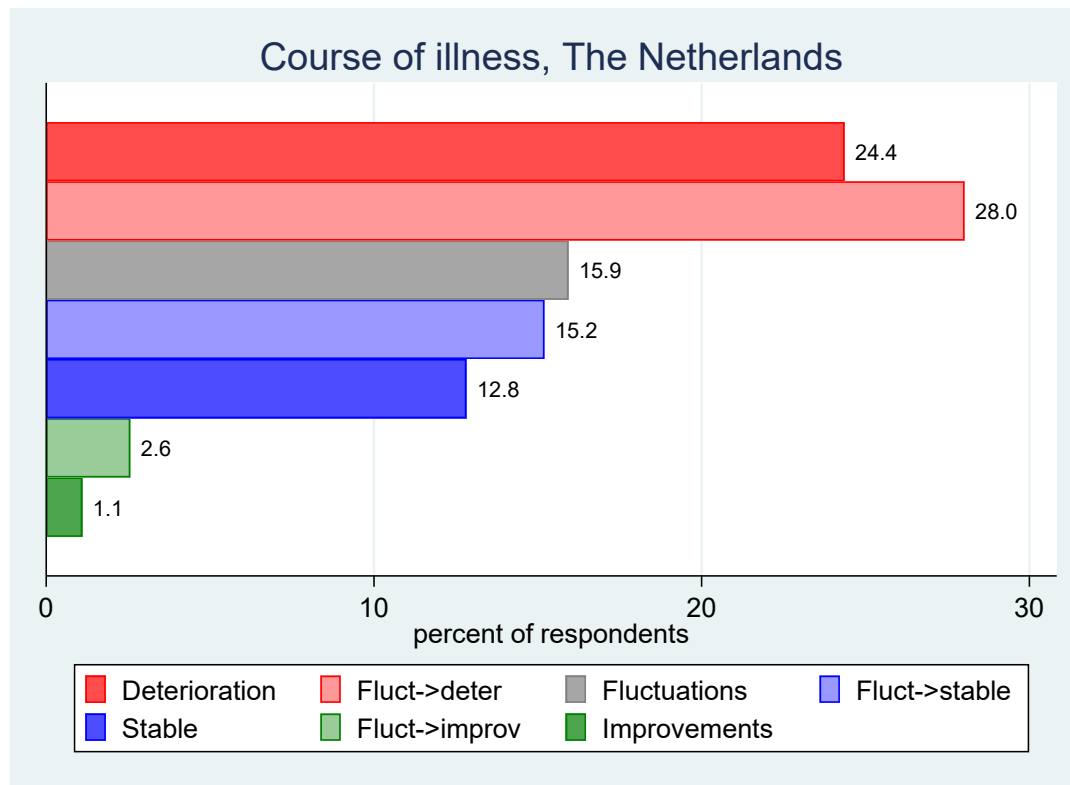
Diag. period (median) by gender & severity, The Netherlands



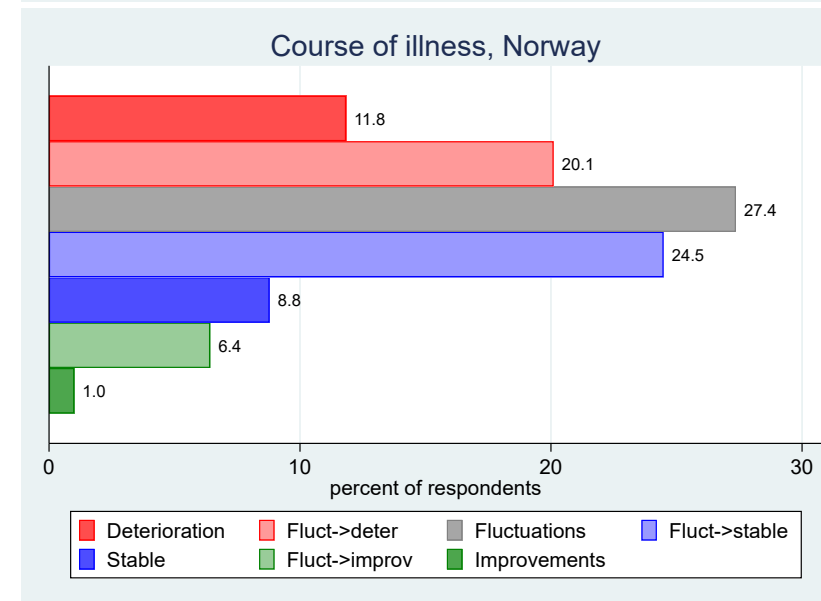
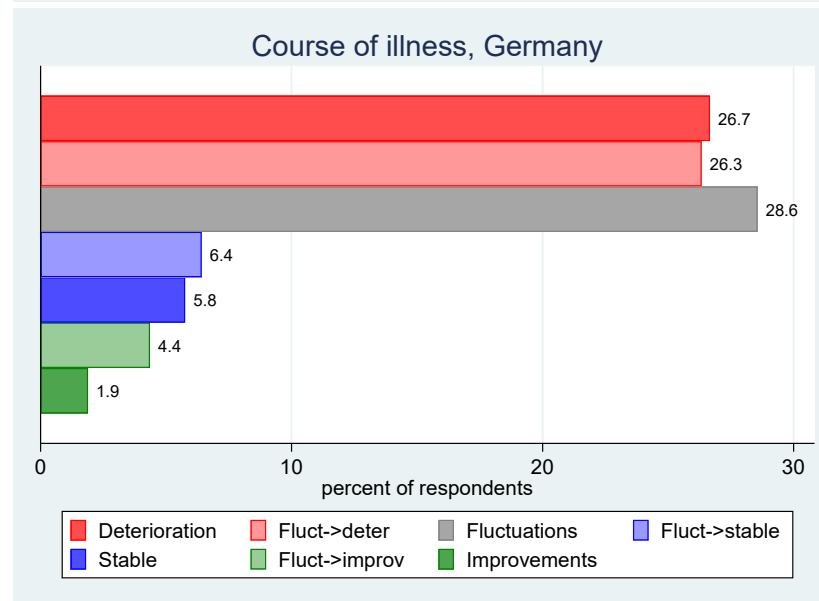
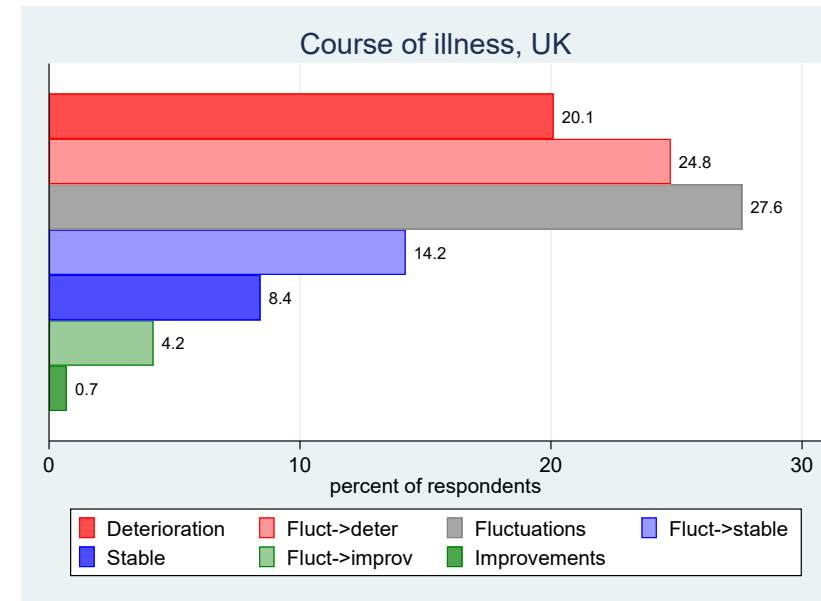
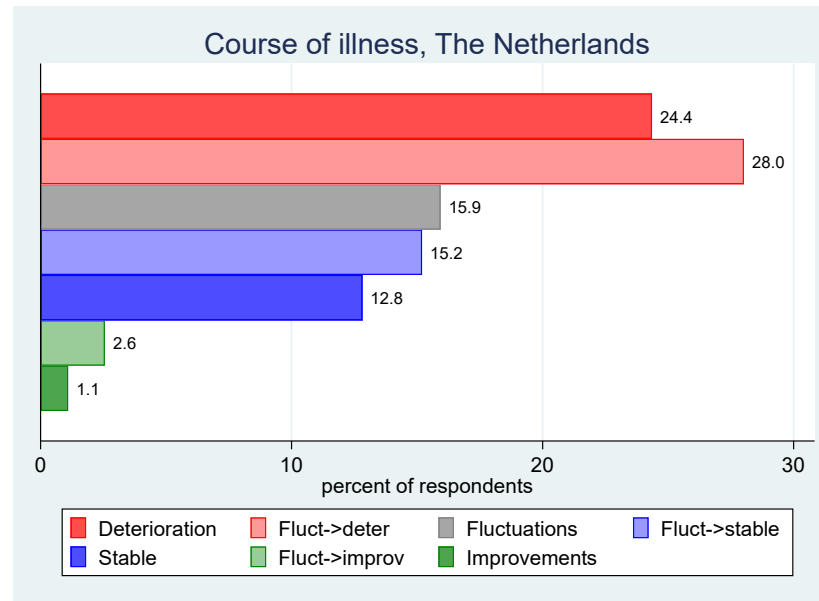
...change over time



### 3. Course of illness and factors



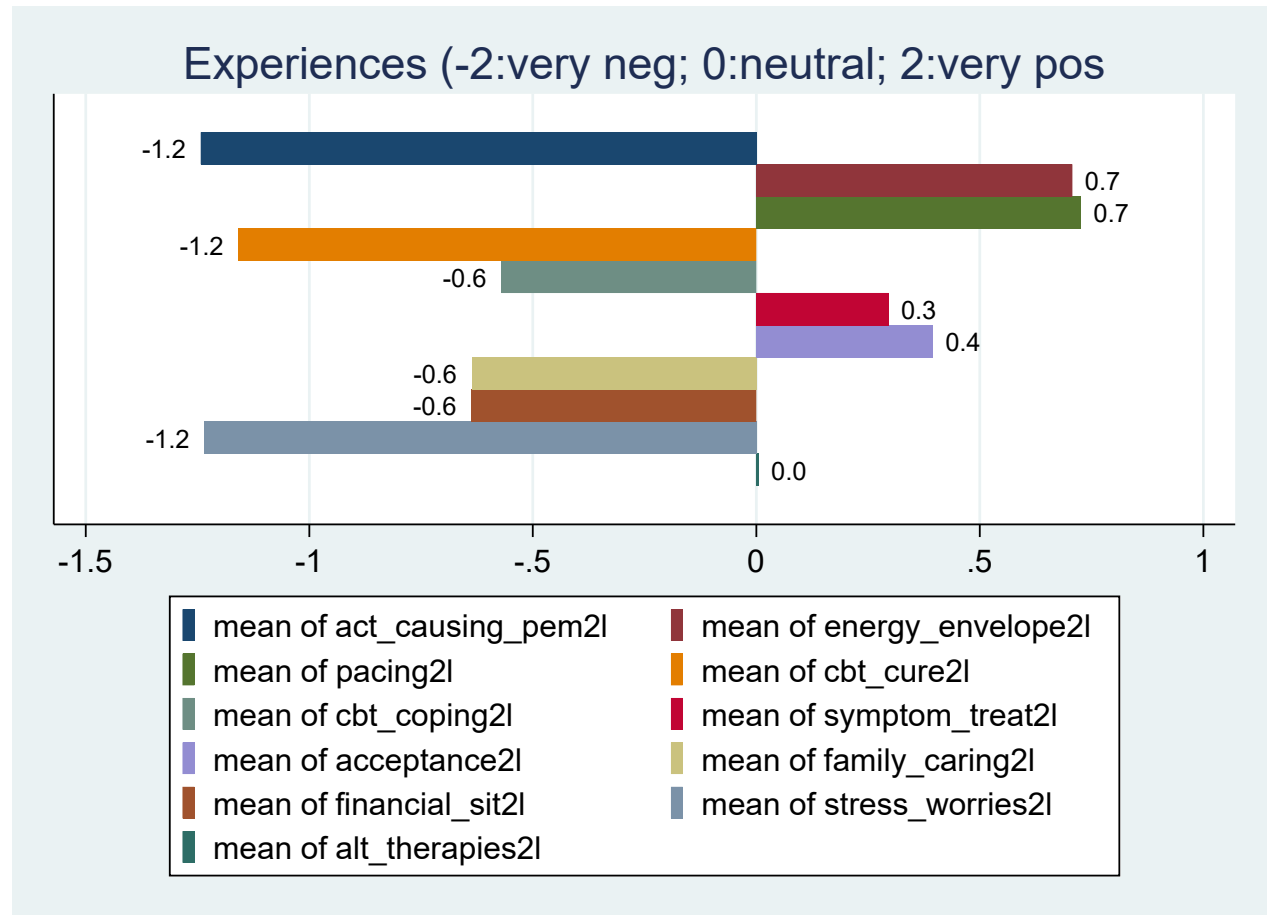
# Comparison of some countries





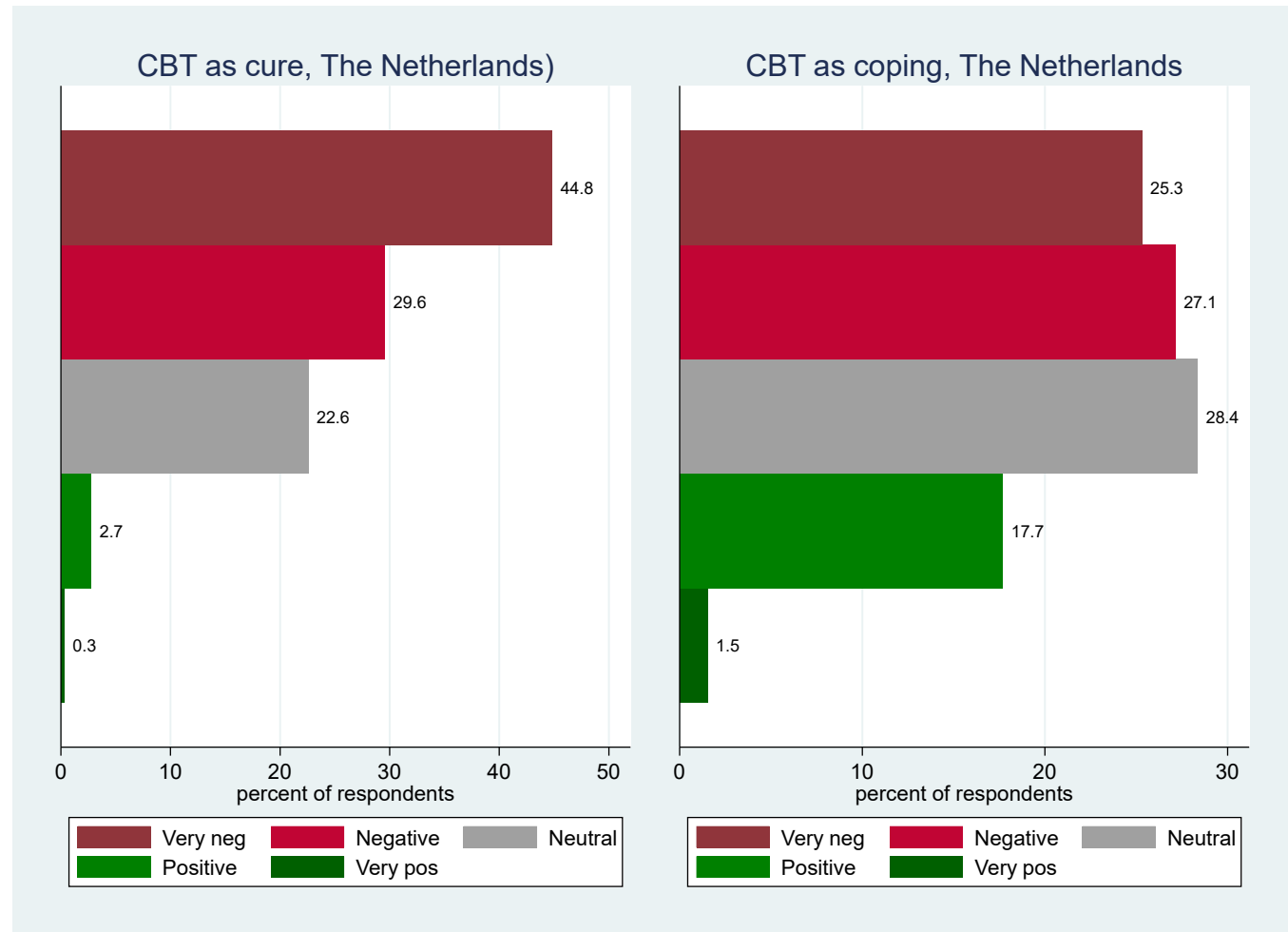
# Factors affecting the course of illness: Pacing and energy envelop on top

- Pacing and energy envelop most positive
- PEM, CBT as cure, and stress/worries most negative
- Data from Netherlands, similar picture in other countries



# Distinguishing between CBT as cure and CBT as coping

- NICE guidelines
- CBT as cure: ratio positive to negative experiences is **1:25**
- CBT as coping: ratio negative to positive experiences is almost **1:3**
- Essential to make that distinction



# Cure

- Similar pattern
- UK extreme in terms of negative patient experiences



# Coping

- Far from dominantly positive experience
- UK and the Netherlands most negative exp.

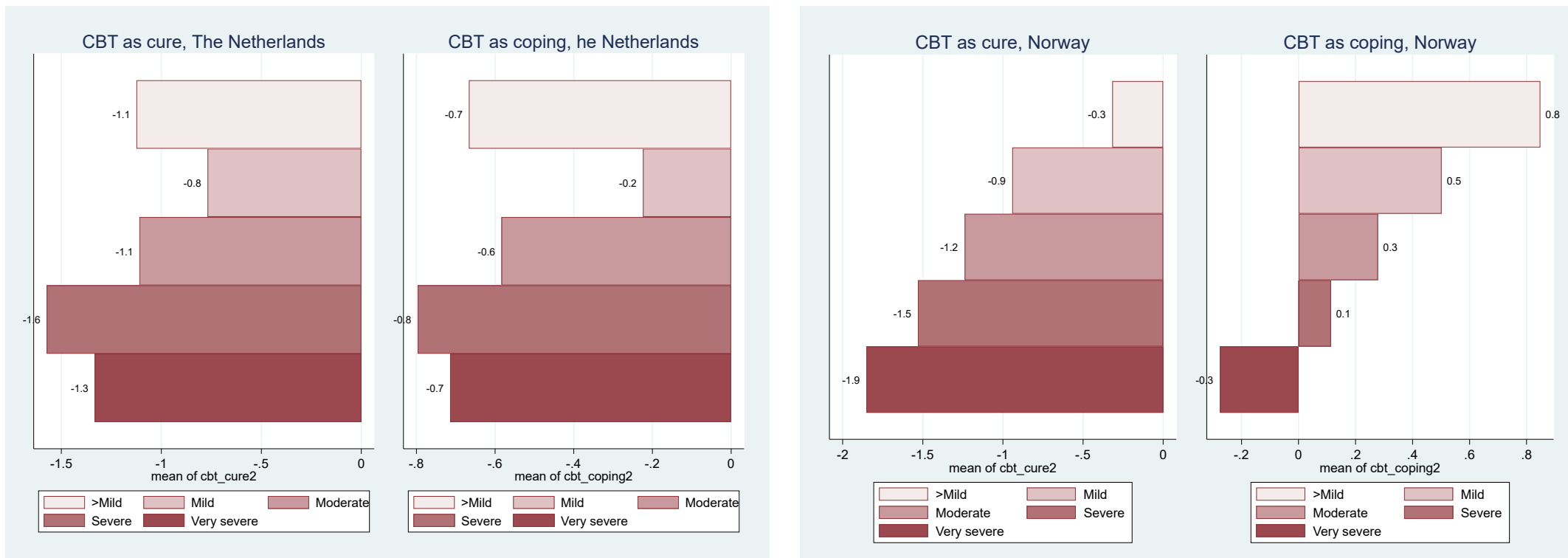
1. Exhausting  
-> PEM?

2. Associated with CBT as cure?



# CBT experience by severity

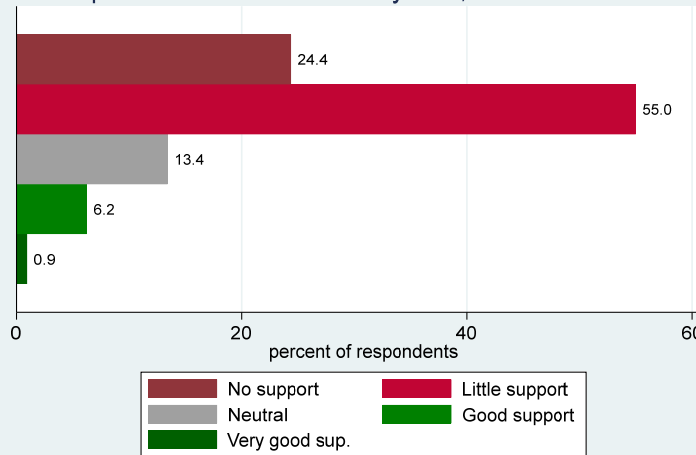
- Score:  
from 'very negative' (-2) to 'neutral' (0) to 'very positive' (2)
- Not as clear pattern in the Netherlands as in Norway



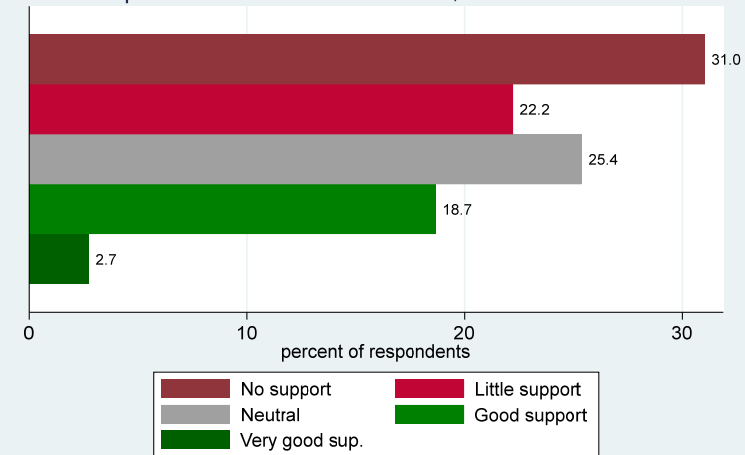
# 4. Support from health services & others

- 0-4 scale:  
0=no support  
1=little support ...  
4=very good support
- Overall, not very satisfied

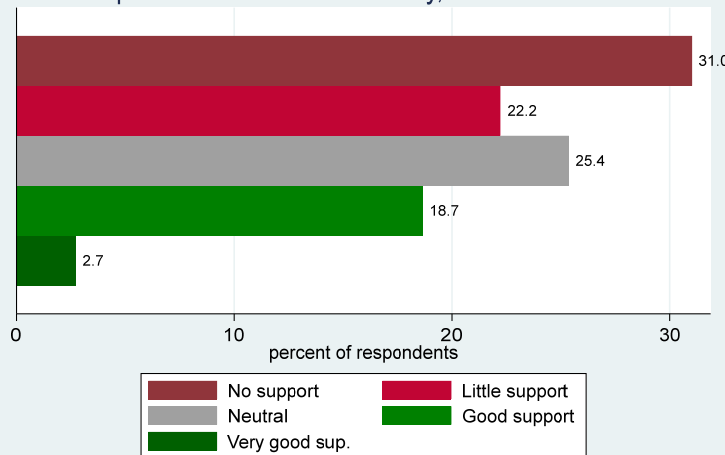
Experience with healthcare system, The Netherlands



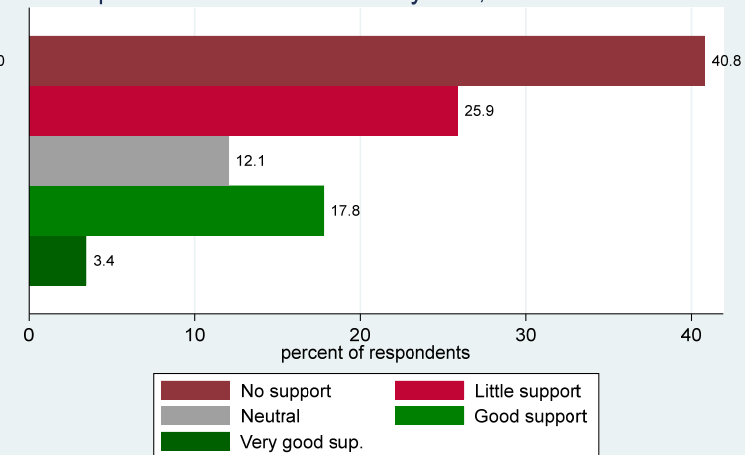
Experience with social services, The Netherlands



Experience with social security, The Netherlands

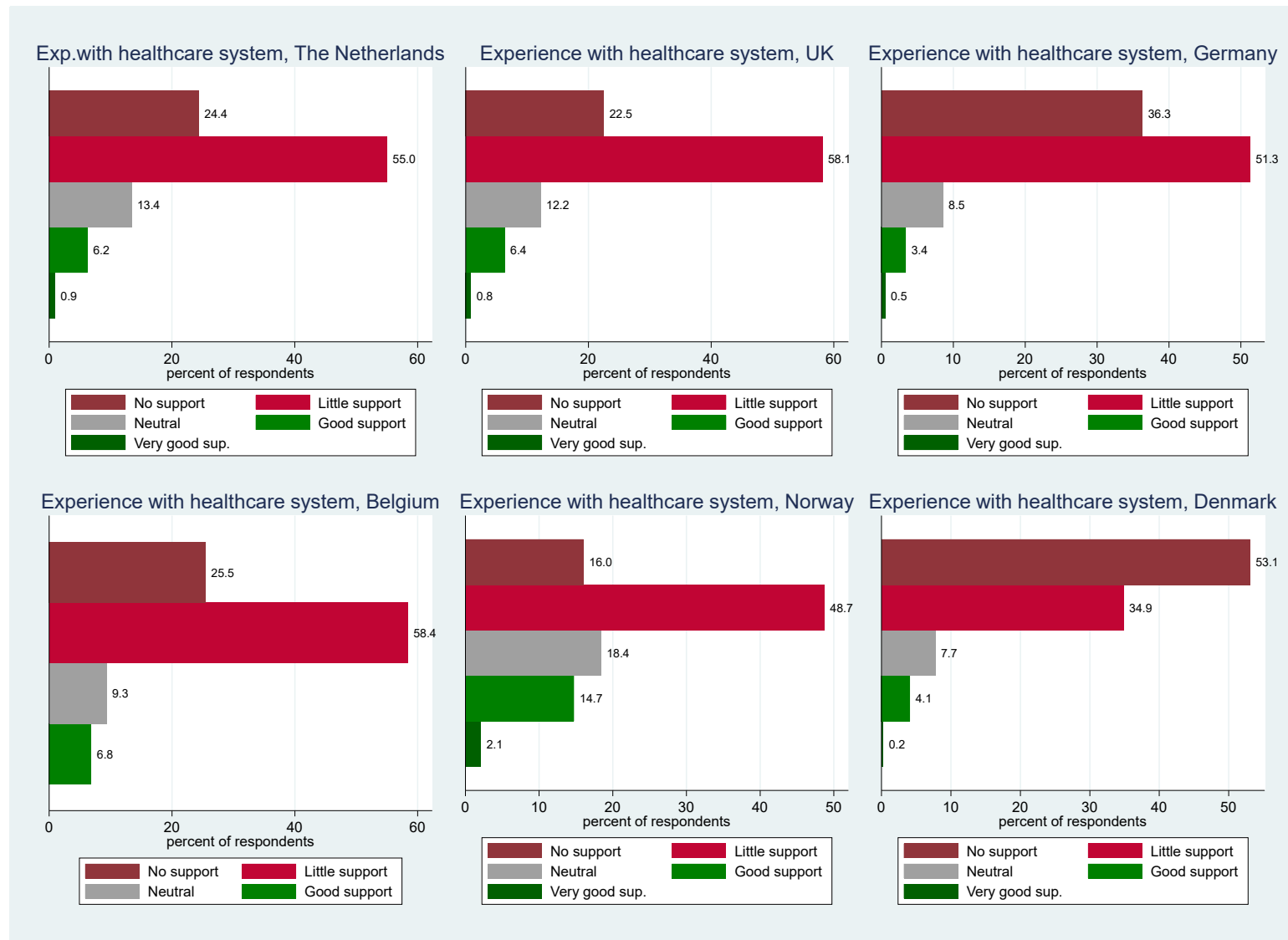


Experience with educational system, The Netherlands



# Healthcare system across countries

- The Netherlands: **7.1%** (very) good support
- The large majority of patients in all countries: Little or no support
- Denmark an extreme case: 53% get no support



# Some conclusions

- Many similarities across countries:
  - Distribution of degrees of severity (moderately ill as the dominant)
  - Young age at onset & severity
  - Factors affecting the course of illness
  - CBT experiences: cure vs. coping
  - Dissatisfaction with health and other public services