

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

Focus on the Netherlands

Arild Angelsen

prof. NMBU & board member
Norwegian ME Association

&

Trude Schei

assistant secretary general
Norwegian ME Association

&

Nayana Geetha Ravi

MD & advisor
Norwegian ME Association



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

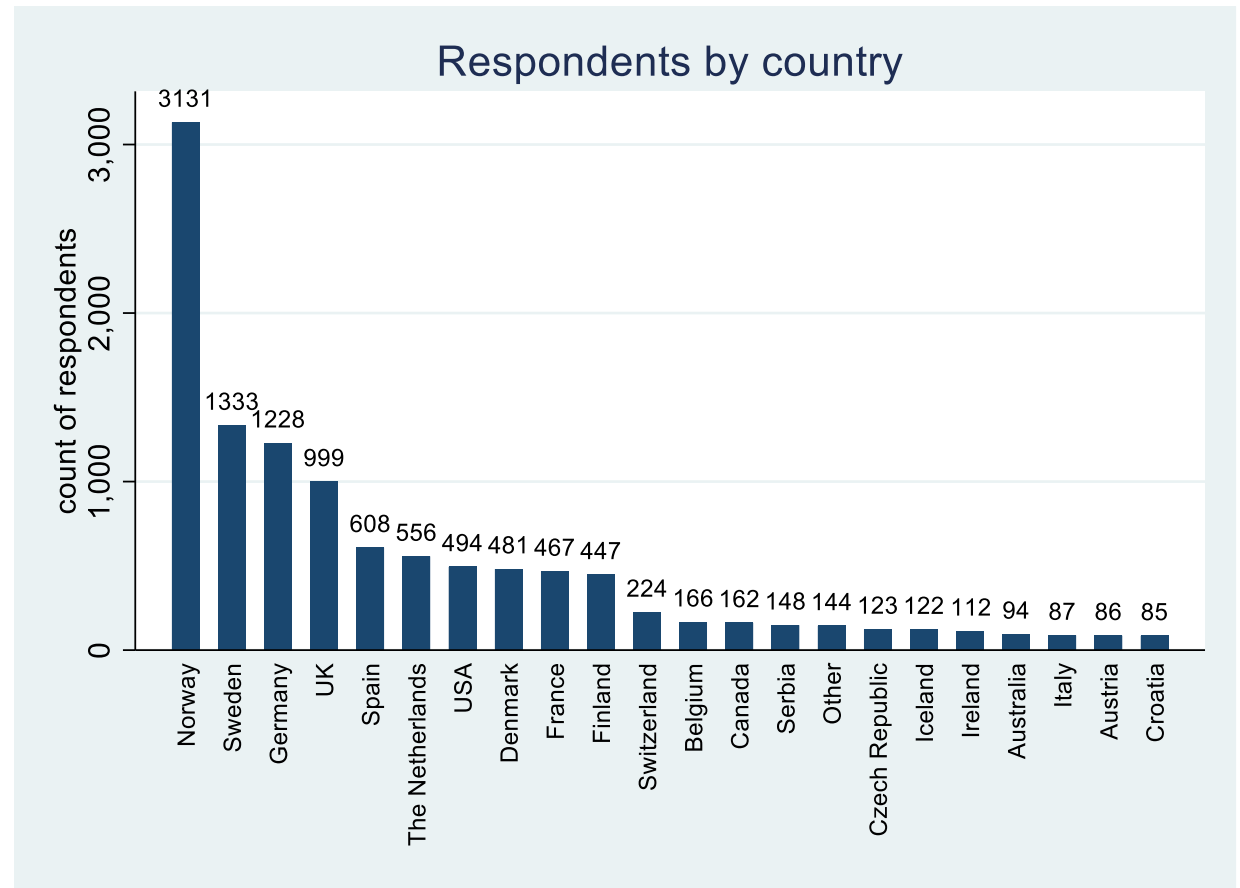
1. Pan-European patient survey

- 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



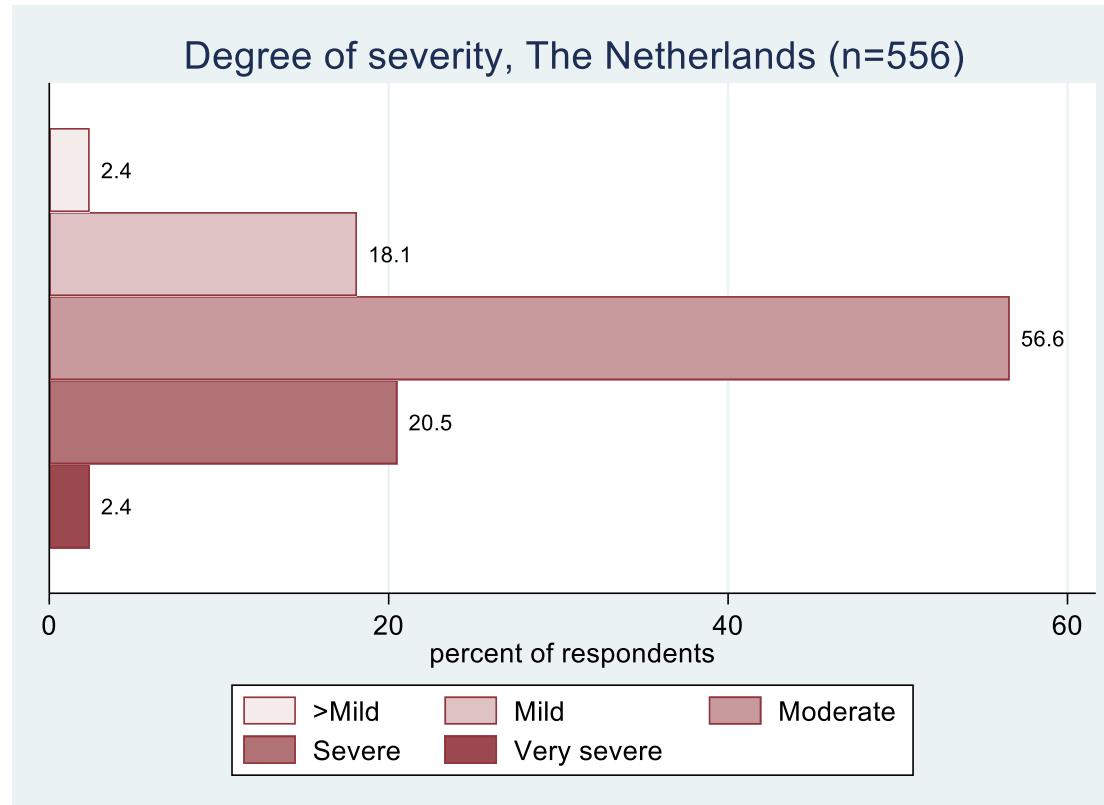
Defining degrees of severity

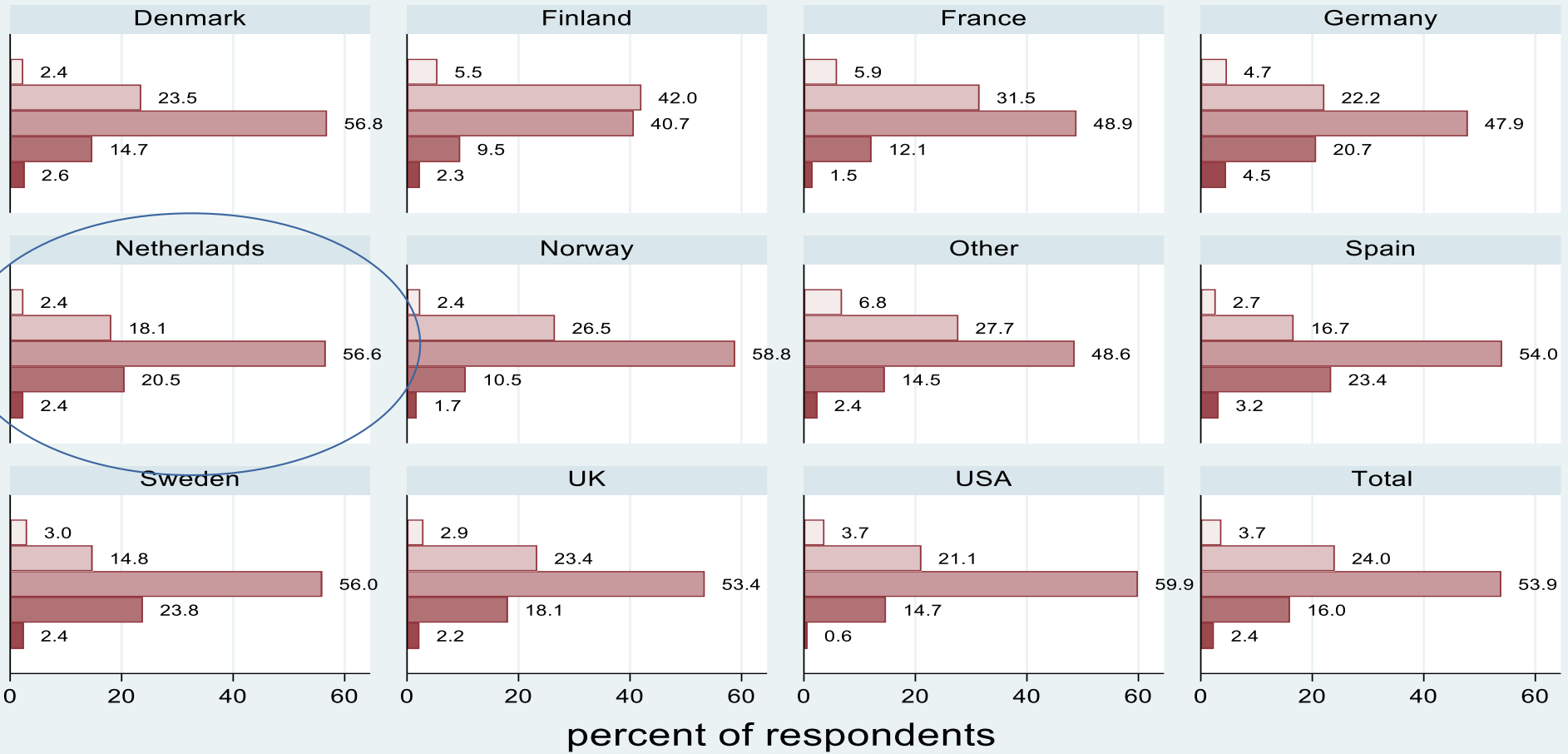
Based on ICC

- **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

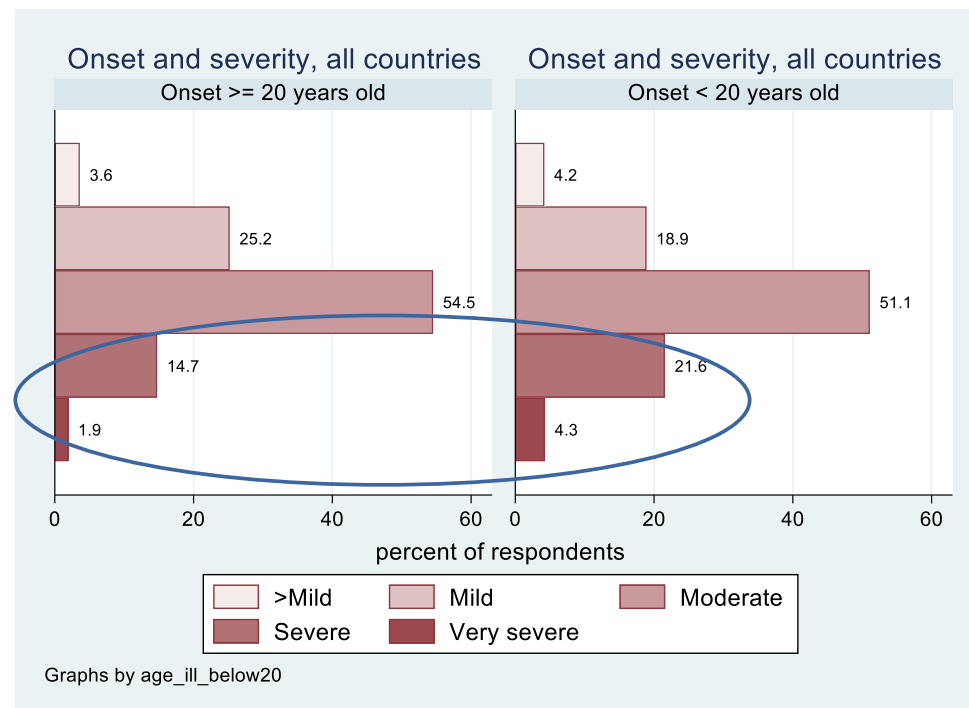
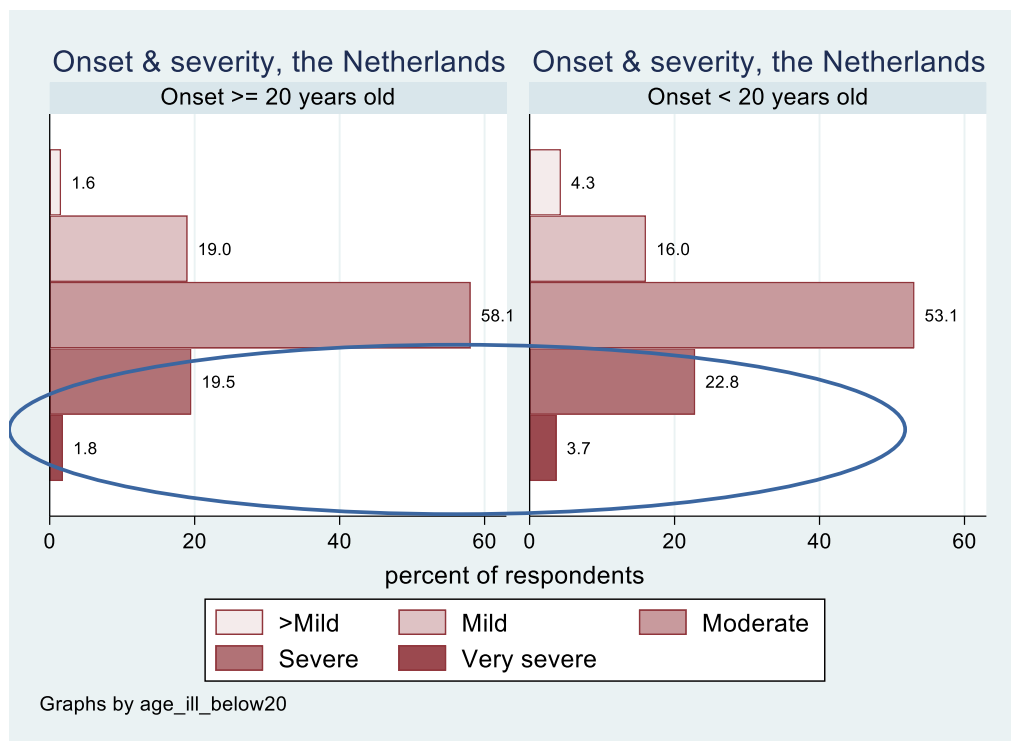




Graphs by country25

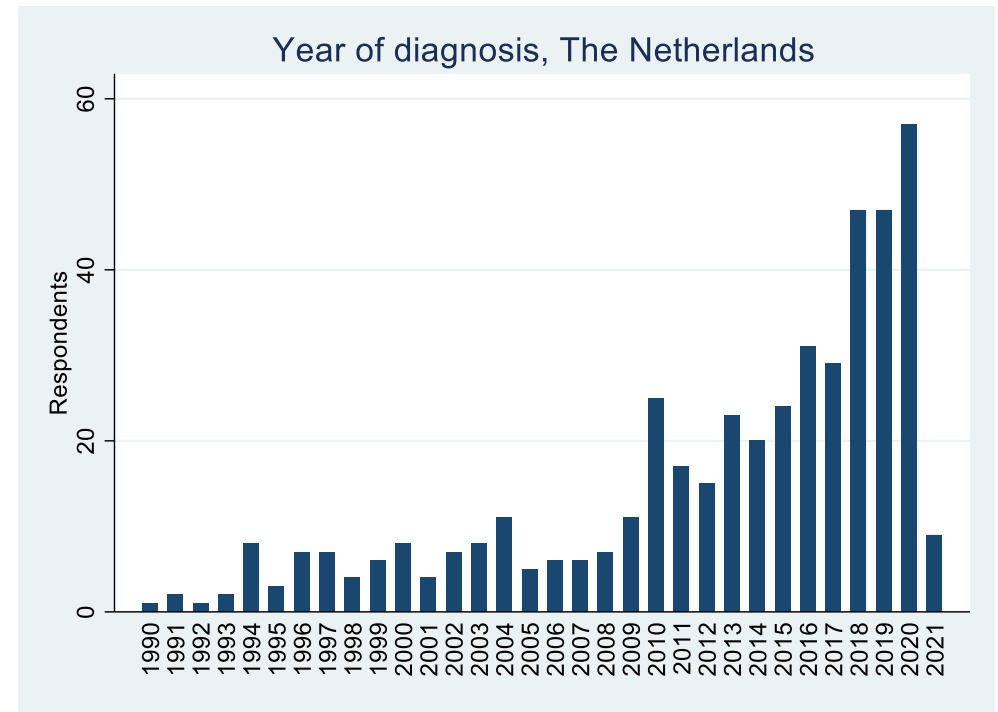
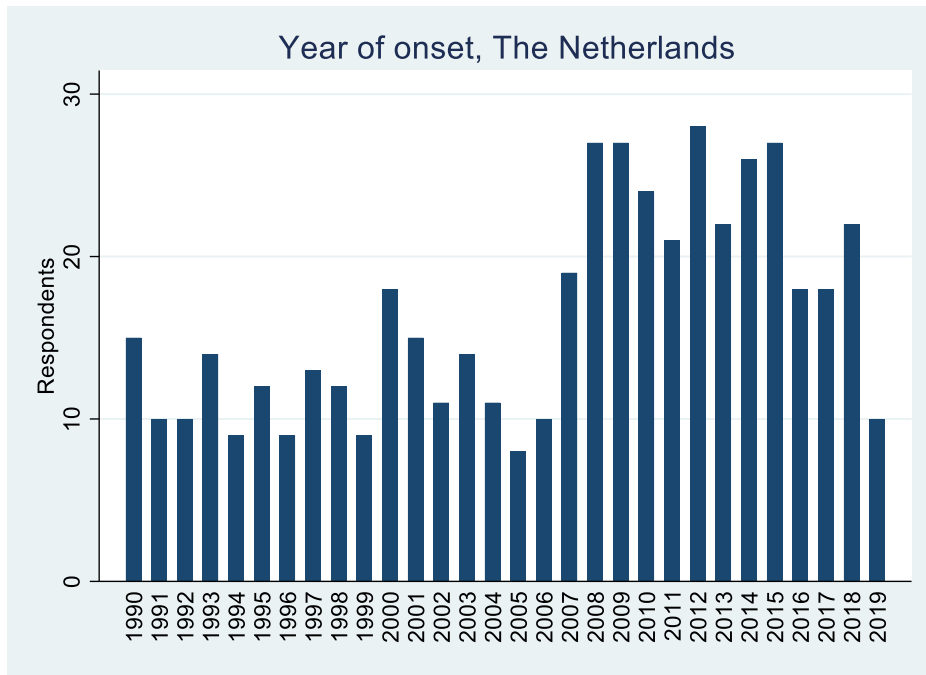
Severity and age at onset (<20 years): A strong link

... as found in other surveys & studies



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

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

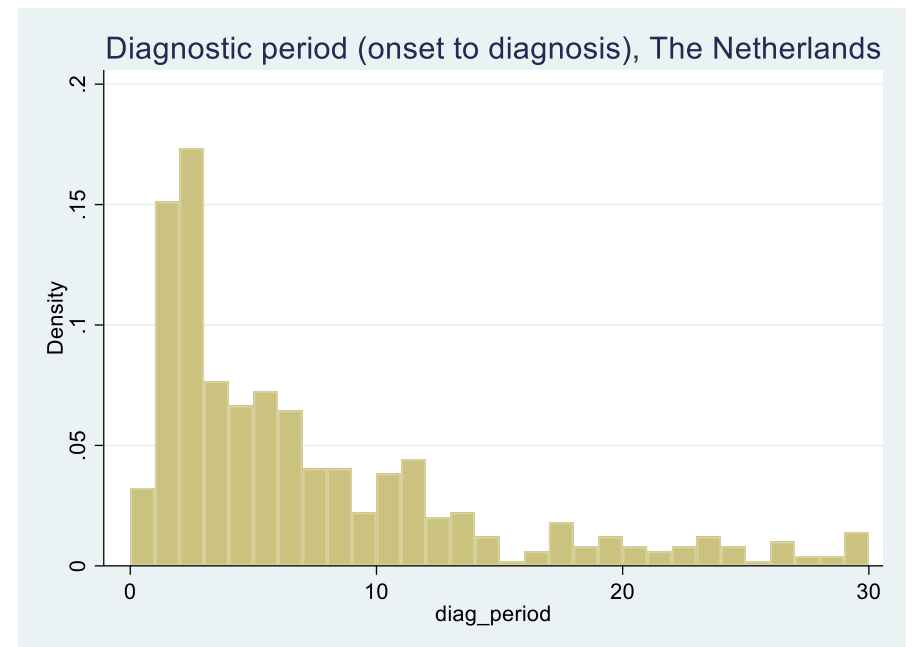


Diagnostic period, the Netherlands

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

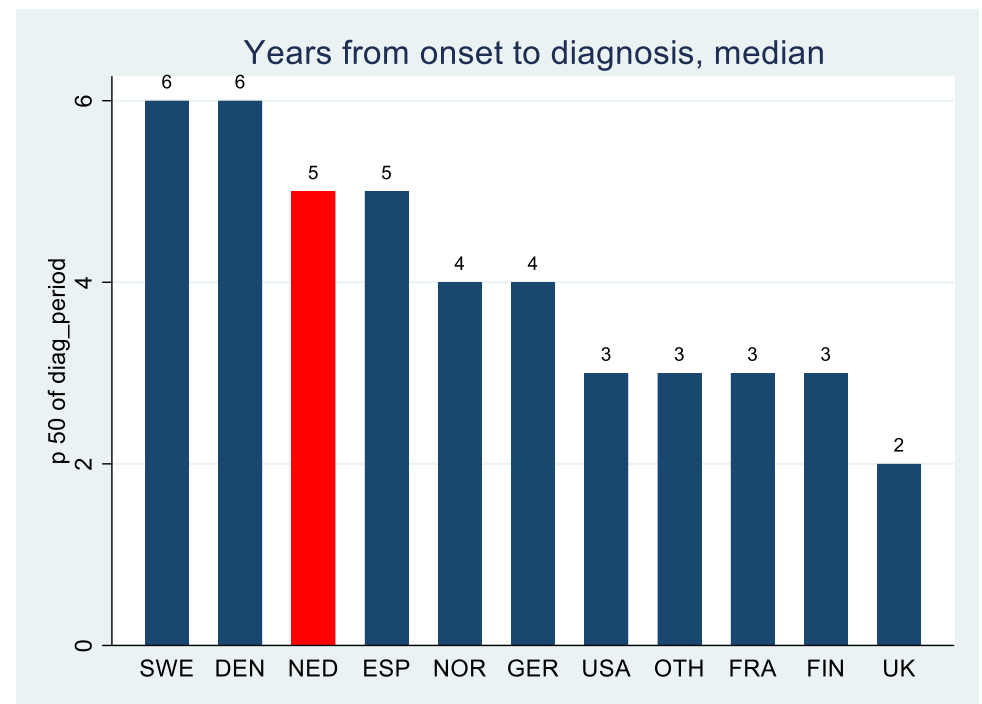
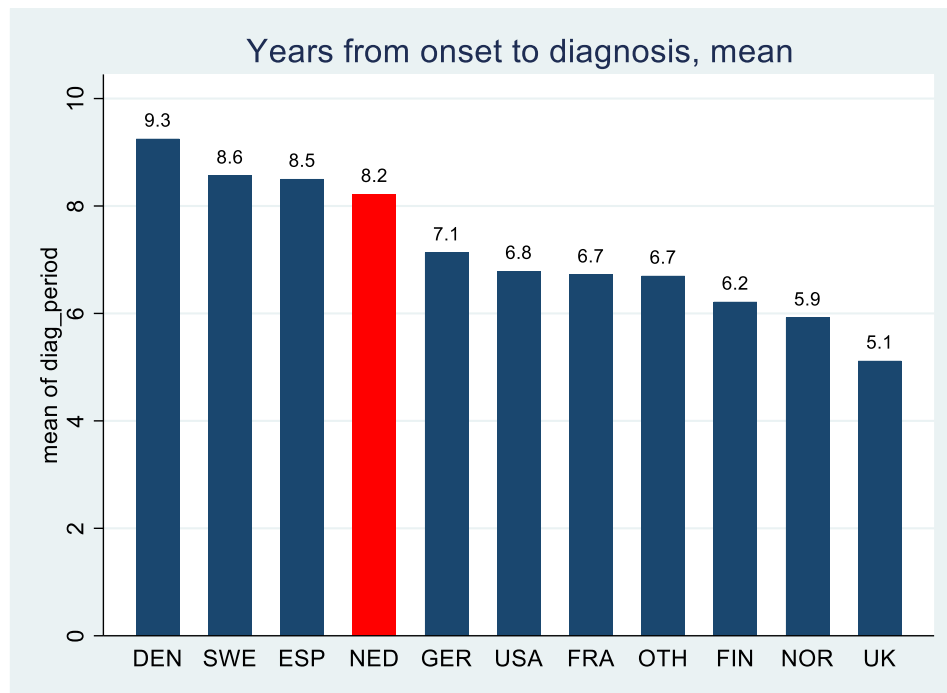
Mean 8.2 years

Median: 5 years

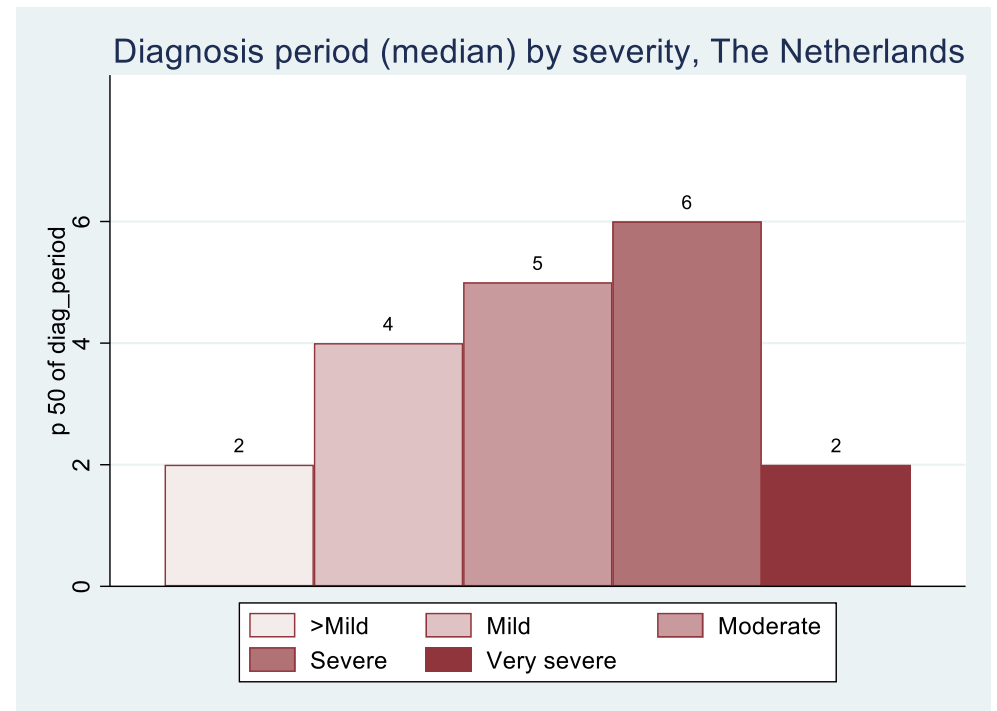
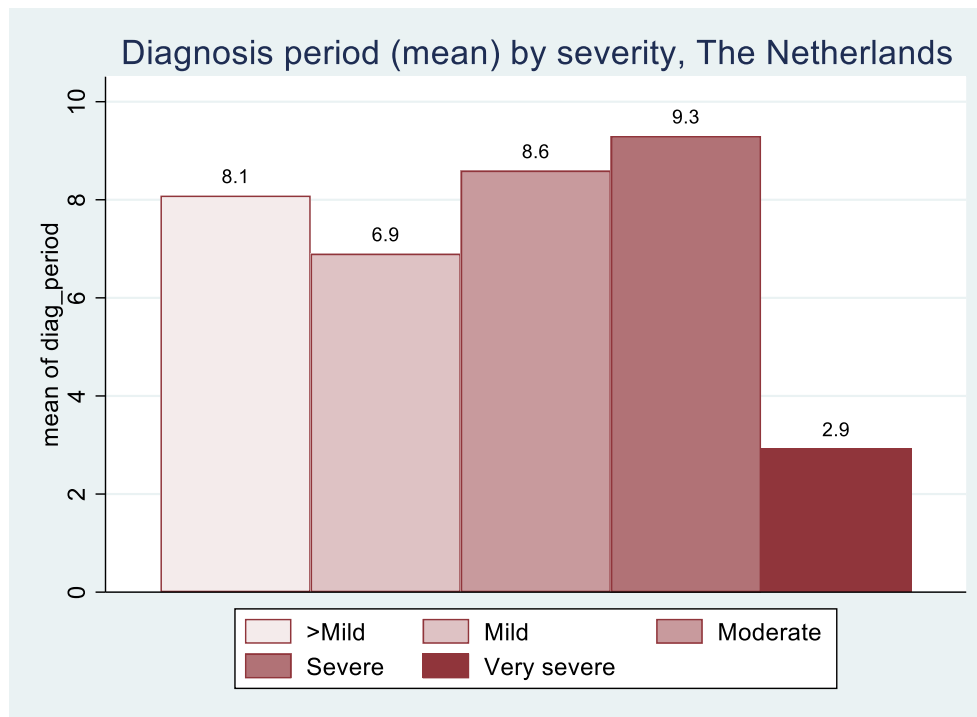


Diagnostic period across countries

- Sweden and Denmark the longest, UK the shortest

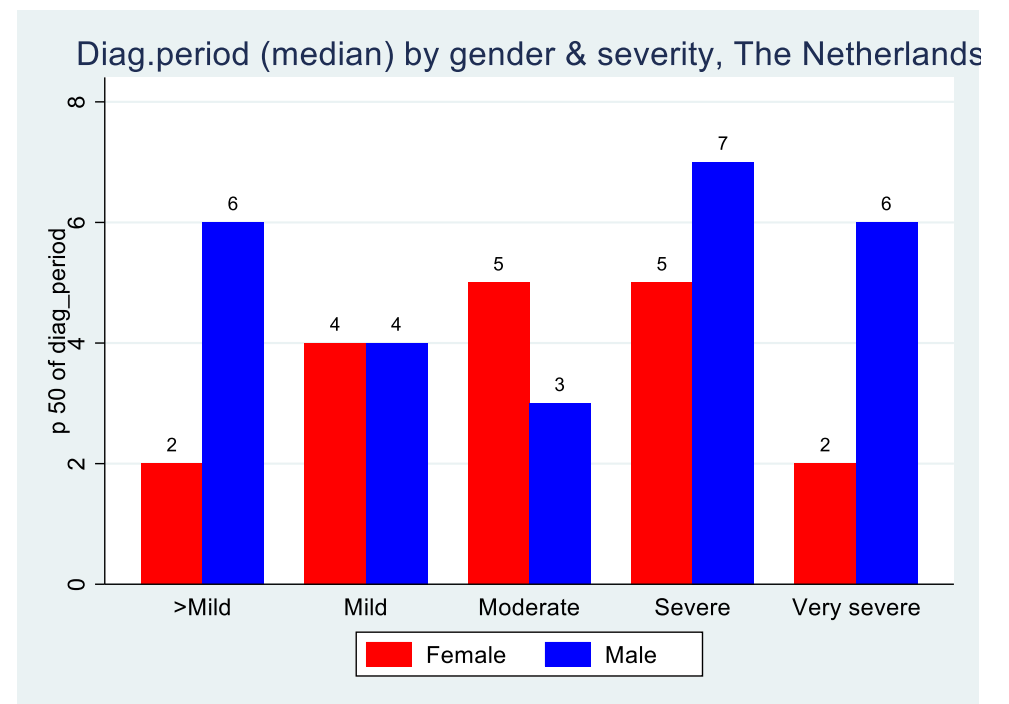
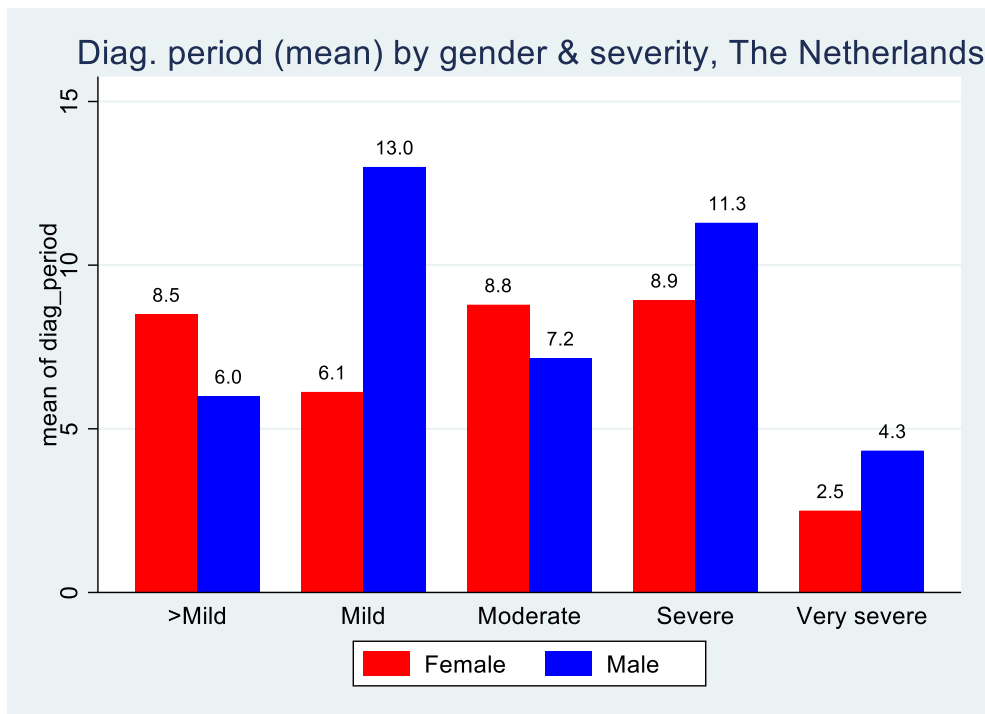


Diagnostic period and severity

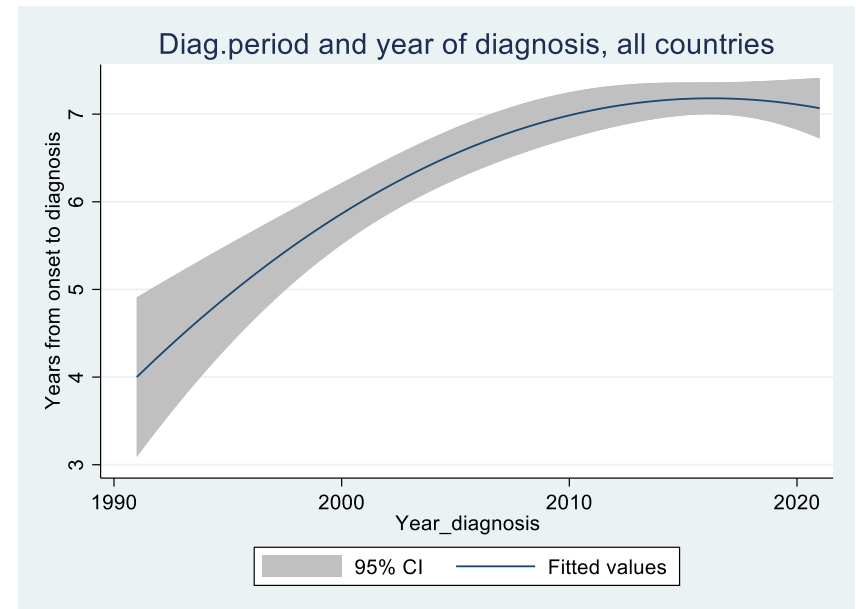
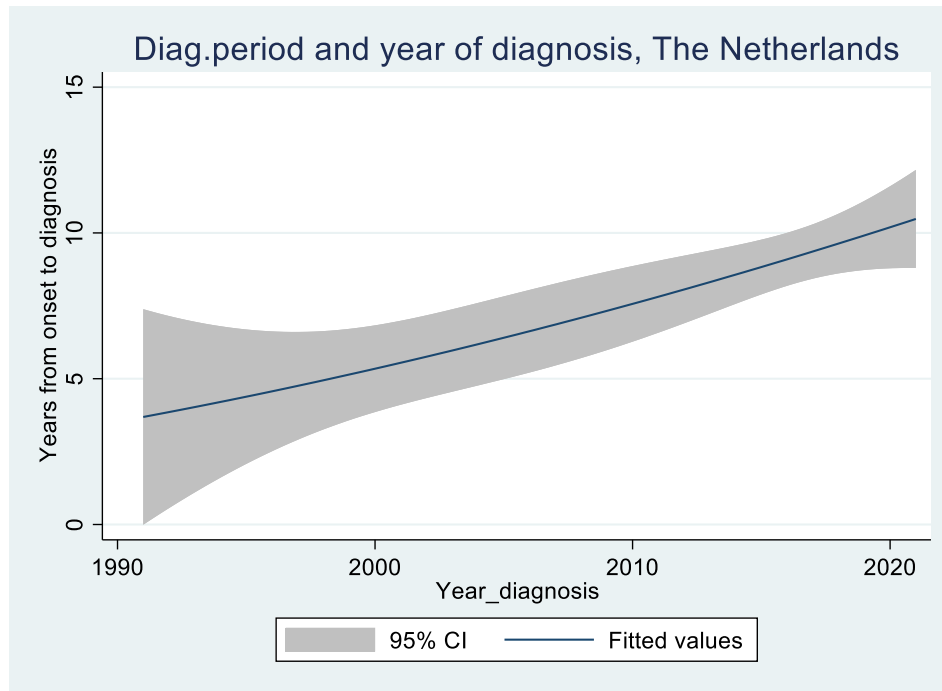


... by gender

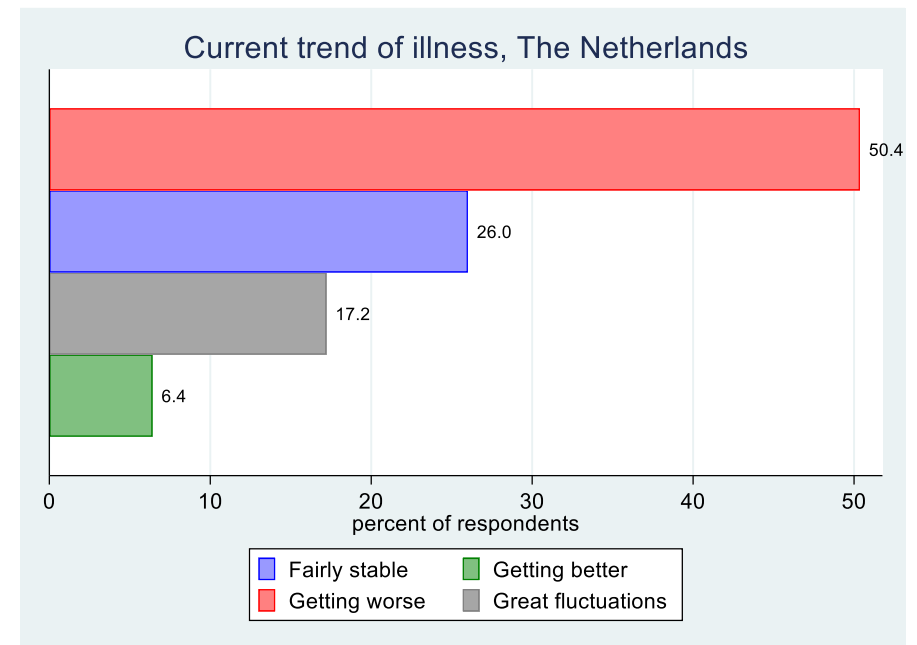
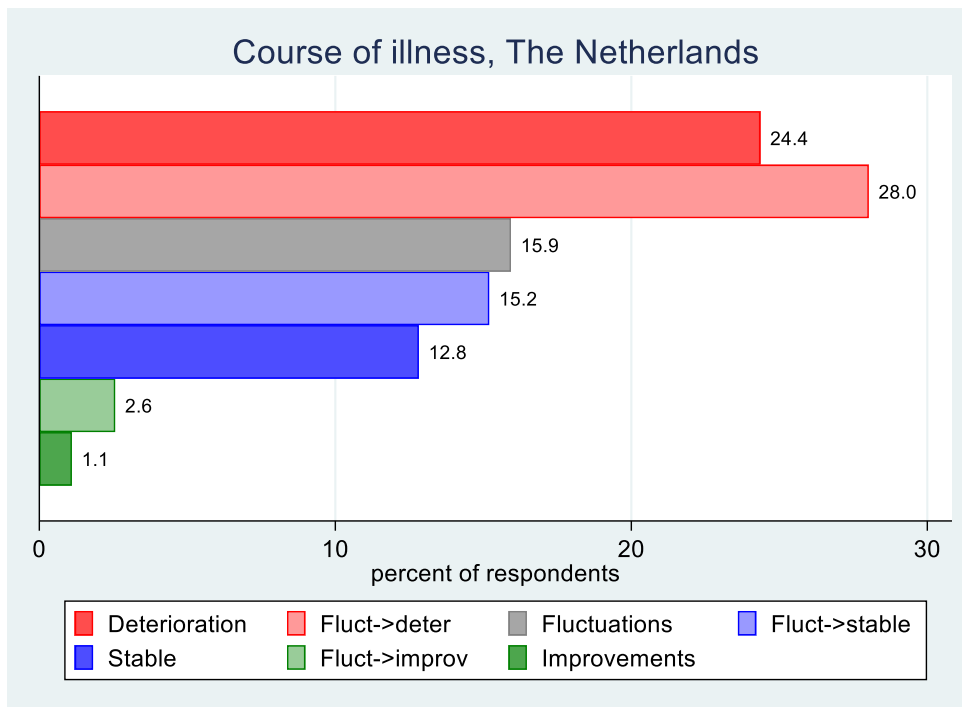
- Unlike other countries, average (mean) diagnostic period is slightly lower for women than for men (8.1 vs 8.8 years)



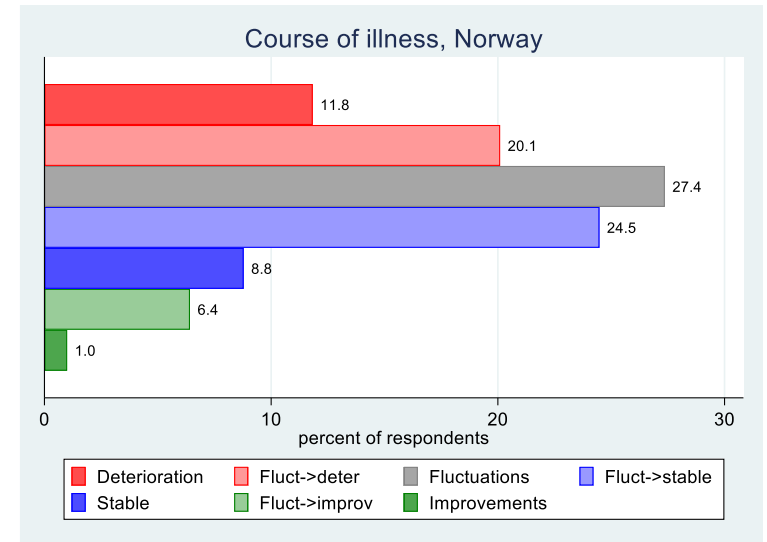
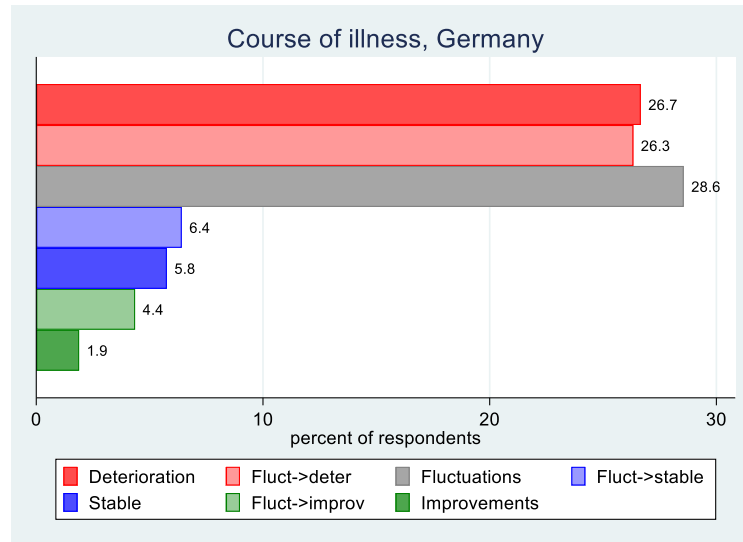
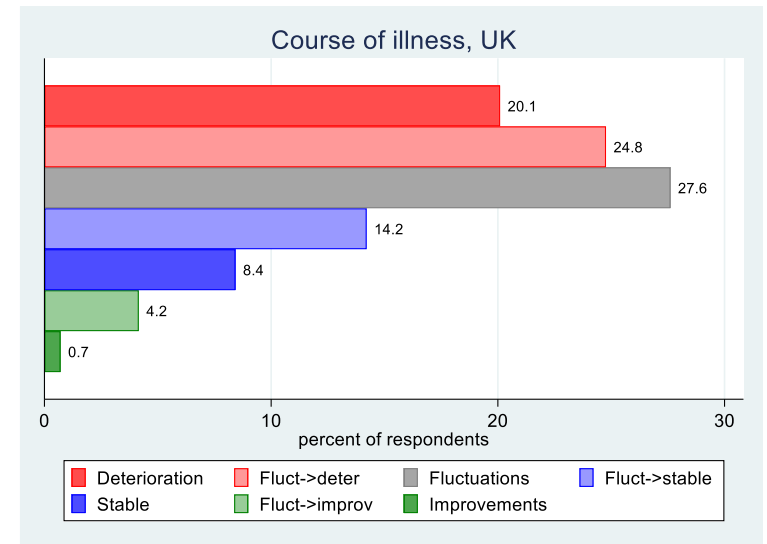
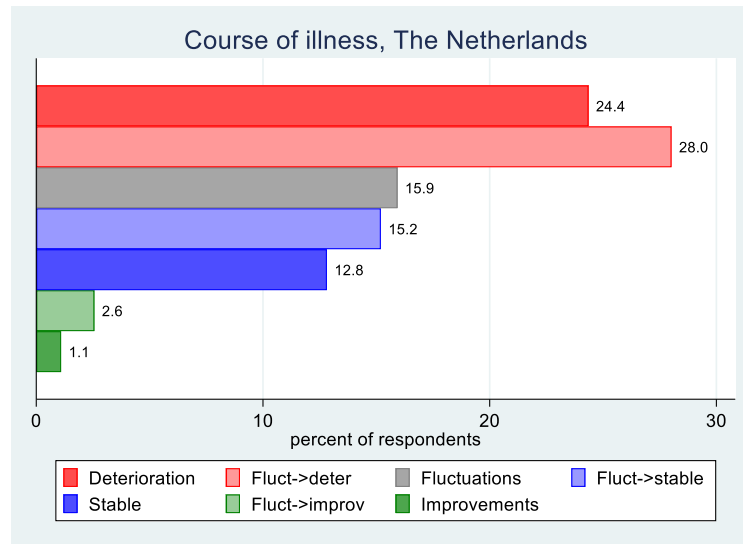
...change over time



3. Course of illness and factors

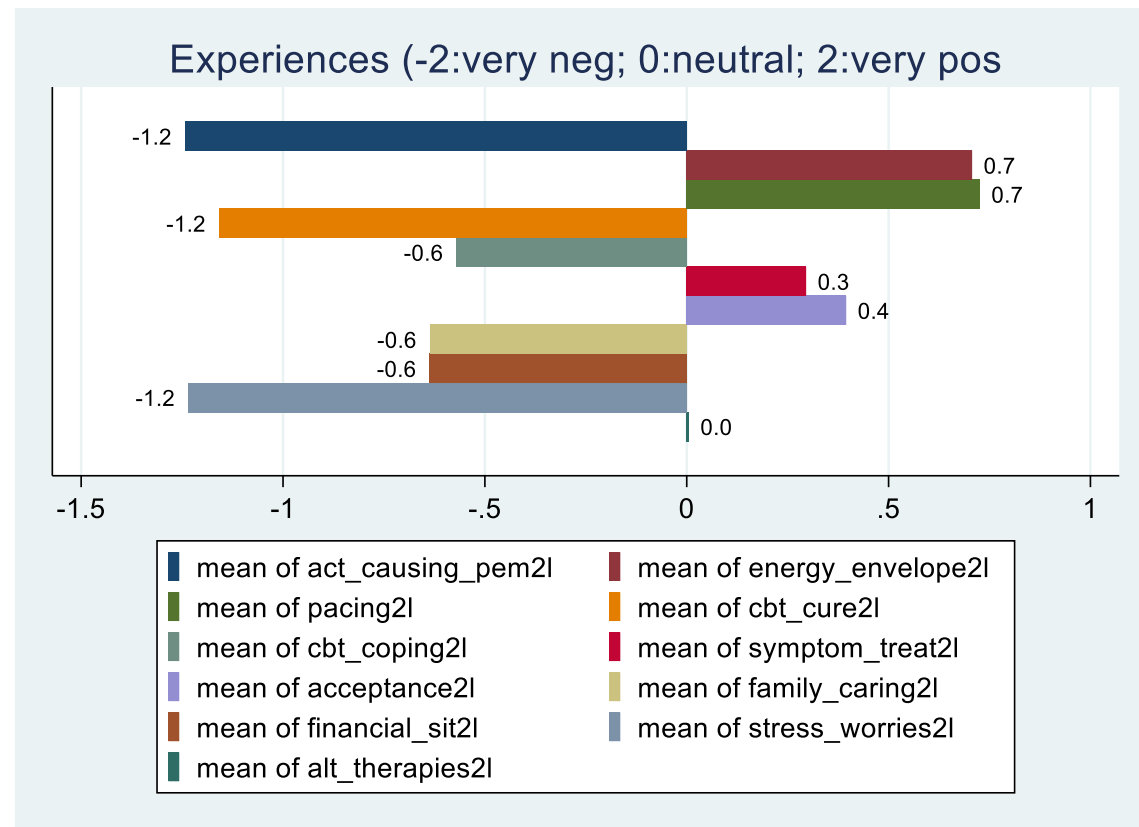


Comparison of some countries



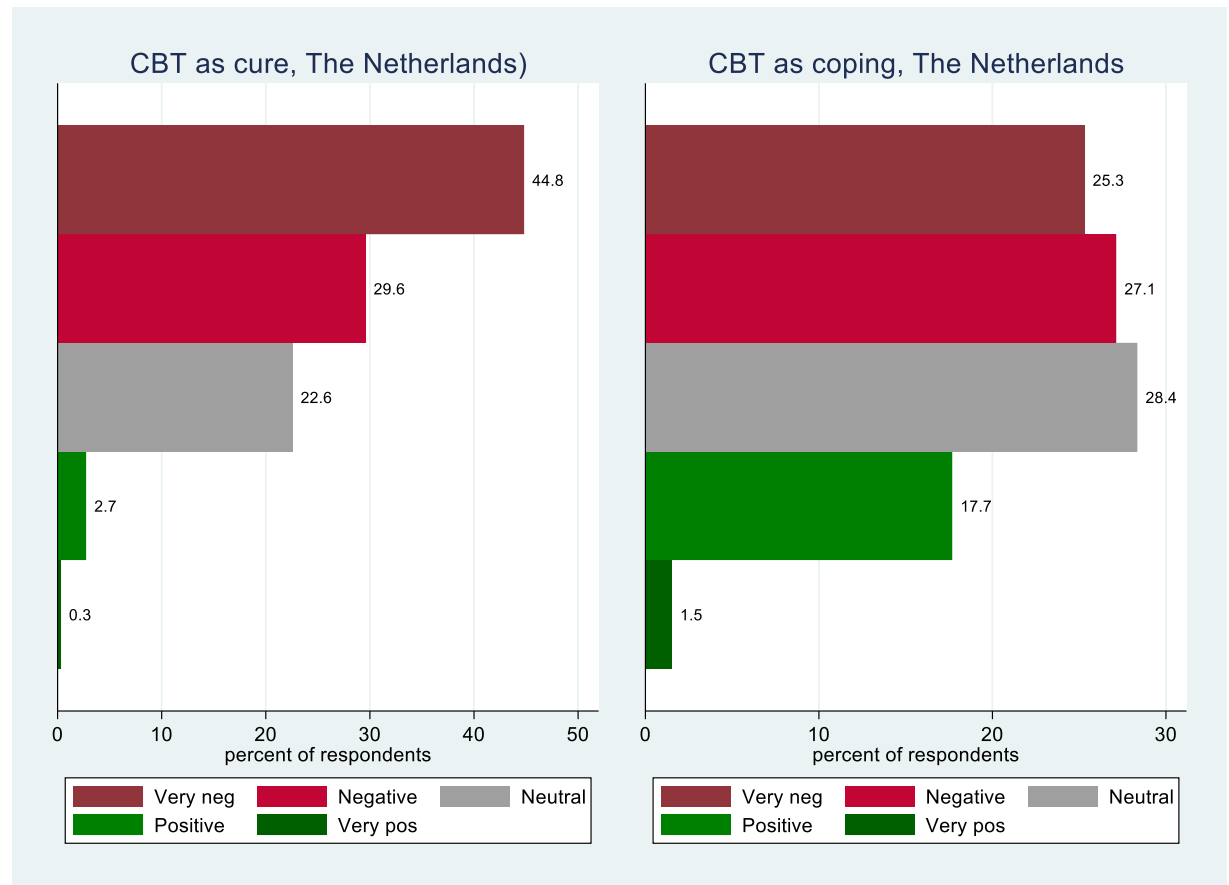
Factors affecting the course of illness: Pacing and energy envelop on top

- 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

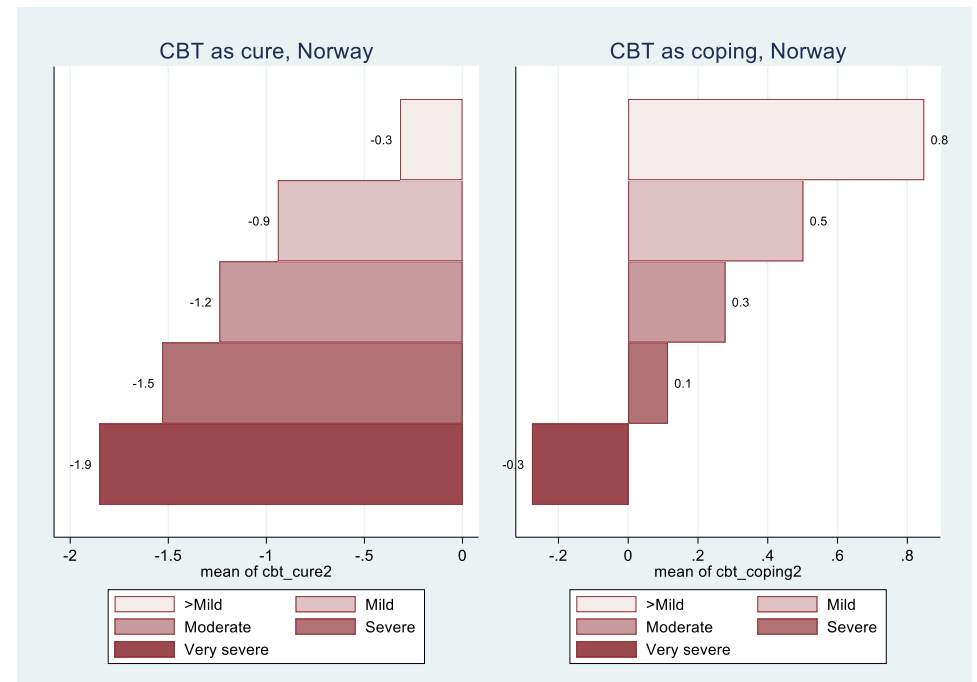
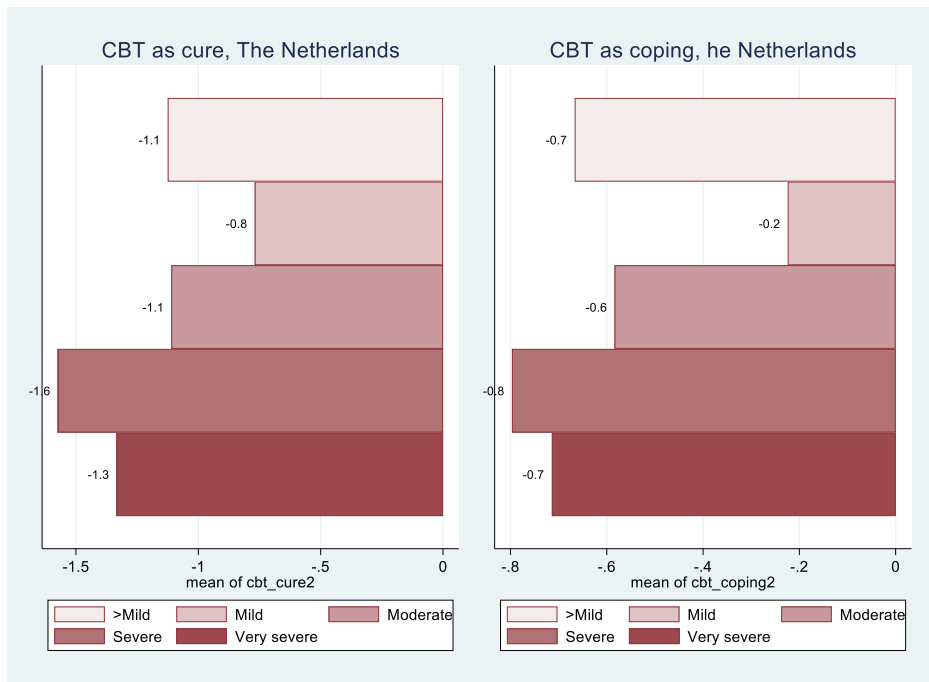
- Far from dominantly positive experience
- UK and the Netherlands most negative exp.

1. Exhausting -> PEM?
2. Associated with CBT as cure?



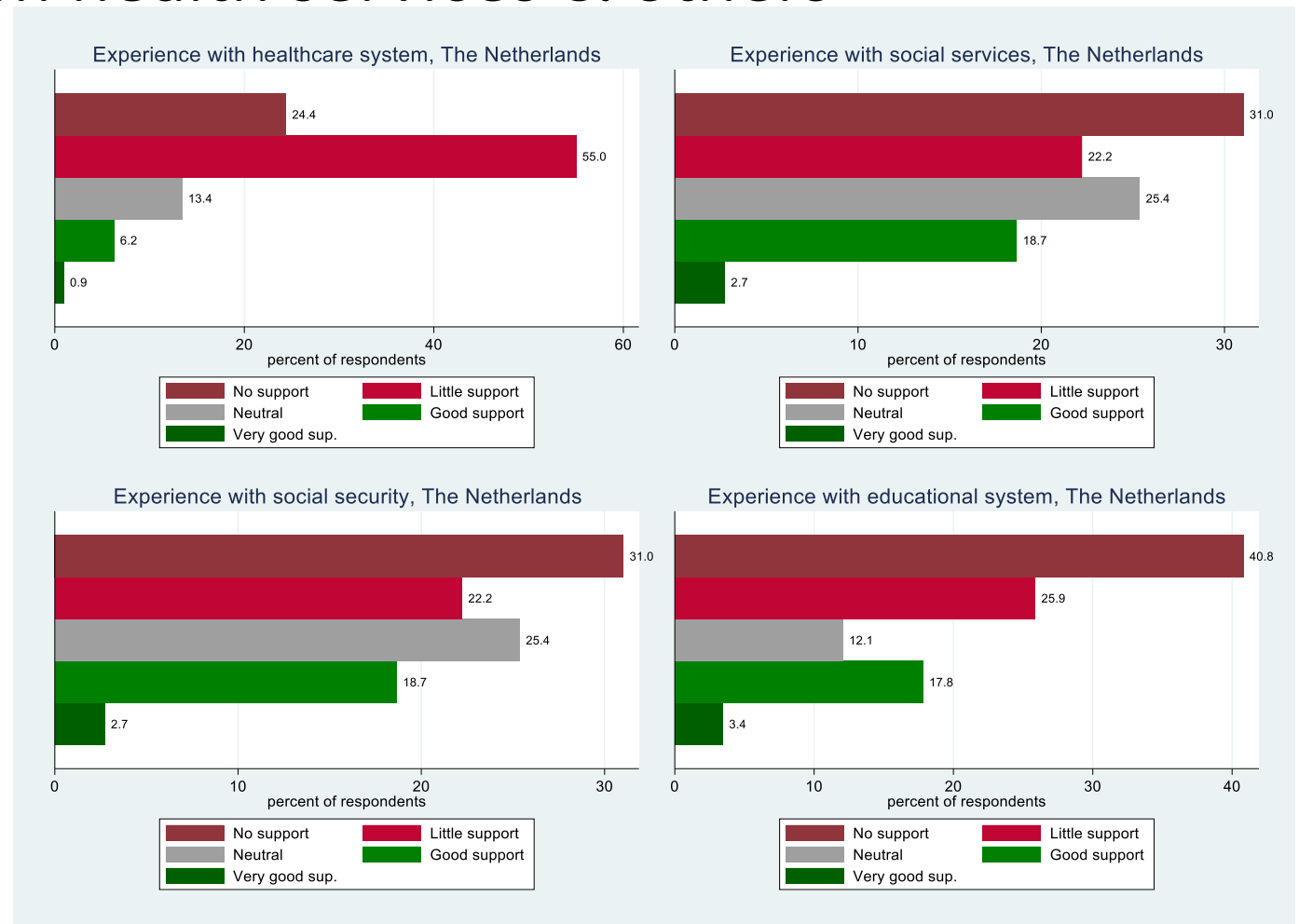
CBT experience by severity

- 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



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