

Supplementary Appendix 1. Inflammatory Bowel Disease Disability Index

Please read aloud these instructions to the patient.

The first question is about the overall health of the patient, including both physical and mental health.

(Answers: 1=very good, 2=good, 3=moderate, 4=bad, 5=very bad)

Overall health

1. In general, how would you rate your health today?

Please read aloud this instructions to the patient.

Now I would like to review different functions of your body and activities of daily life. When answering these questions, I would like you to think about the last week, taking both good and bad days into account. When I ask about difficulty/problem, I would like to consider: how much difficulty/problem you have had, on an average, in the past week, while doing the activity in the way that you usually do it. By difficulty, I mean that you require increased effort, that you have discomfort or pain, or that the activity is slower or that there are other changes in the way you do the activity. Please answer this question taking into account any assistance you have available.

(Read and show scale to respondent)

(Answers: 1=none, 2=mild, 3=moderate, 4=severe, 5=extreme)

Sleep and energy

2. Overall in the last week, how much a problem did you have with sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning? (b134)
3. In the last week, how much of a problem did you have due to not feeling rested and refreshed during the day (e.g., feeling tired, not having energy)? (b130)

Affect

4. Overall in the last week, how much of a problem did you have with feeling sad, low or depressed? (b152)
5. Overall in the last week, how much of a problem did you have with worry or anxiety? (b152)

Body image

6. Overall in the last week, how much of a problem did you have with the way your body or body parts looked? (b1801)

Pain

7. Overall in the last week, how much stomach or abdomen aches or pains did you have? (b28011)

(Answers: 1=none, 2=mild, 3=moderate, 4=severe, 5=extreme or cannot do)

Regulating defecation

8. Overall in the last week, how much difficulty did you have coordinating and managing defecation including choosing and getting to an appropriate place for defecation and cleaning oneself after defecation? (d5301)

Looking after one's health

9. Overall in the last week, how much difficulty did you have looking after your health, including maintaining a balanced diet? (d570)

Interpersonal activities

10. Overall in the last week, how much difficulty did you have with personal relationships? (d7)

11. Overall in the last week, how much difficulty did you have with participation in the community? (d920)

Work and education

12. Overall in the last week, how much difficulty did you have with work or household activities? (d840-d859)

13. Overall in the last week, how much difficulty did you have with school or studying activities? (d810-d899)

(b525) Number of liquid or very stool in the last week _____

(b515) Body mass index (BMI) _____ kg/m²

(b515) Do you feel that you have lost weight in the last week? Yes No

(s540) Blood in stool (weekly average): None Little A lot

(s770) Is arthritis or arthralgia present? Yes No

Please rate the extent to which the following aspects of the patient's environment positively or negatively influenced disease activity, body functions, and activities of daily life, which you have reviewed with the patient.

Answers: NA=not applicable, 1=no positive effect, 2=mild positive effect, 3=moderate positive effect, 4=severe positive effect, 5=extreme positive effect

+14. Overall in the last week, did the medication the patient take alleviate her/his problems and difficulties? (e1100)

+15. Overall in the last week, did the food the patient take alleviate her/his problems and difficulties? (e1101)

+16. Overall in the last week, did the patient's family alleviate her/his problems and difficulties? (e310)

+17. Overall in the last week, did health professionals alleviate the patient's problems and difficulties? (e355)

Answers: NA=not applicable, 1=no positive effect, 2=mild positive effect, 3=moderate positive effect, 4=severe positive effect, 5=extreme positive effect

- 14. Overall in the last week, did the medication the patient take worsen her/his problems and difficulties? (e1100)
- 15. Overall in the last week, did the food the patient take worsen her/his problems and difficulties? (e1101)
- 16. Overall in the last week, did the patient's family worsen her/his problems and difficulties? (e310)
- 17. Overall in the last week, did health professionals worsen the patient's problems and difficulties? (e355)

Answer: 1=no, 2=yes

Social security and health services, systems and policies

- 18. Does the patient benefit from the support he or she needs from the social security system? (e570)
- 19. Does the patient receive the health care he or she need? (e580)

The inflammatory bowel disease disability index scoring key Question 1

- Very good = 0 score
- Good = -1 score
- Moderate = -2 score
- Bad = -3 score
- Very bad = -4 score

Questions 2-13

- None = 0 score
- Mild = -1 score
- Moderate = -2 score
- Severe = -3 score
- Extreme = -4 score

B525: number of liquid/very soft stools in last week

- 0 = +1 score
- 1-4 = -1 score
- 5-8 = -2 score
- 9-12 = -3 score
- >12 = -4 score

BMI

- $b15 = -2$ score
- $15.1-19.9 = -1$ score
- $20-24.9 = 0$ score
- $25-29.9 = -1$ score
- $N30 = -2$ score

B515: do you feel that you've lost weight in the last week?

- Yes = -1 score
- No = $+1$ score

S540: blood in stool?

- None = $+1$ score
- Little = -1 score
- A lot = -2 score

S770: is arthritis or arthralgia present?

- Yes = -1 score
- No = $+1$ score

Questions 14-18

Positive/alleviating effects

- NA = $+4$ score
- No positive effect = 0 score
- Mild positive effect = $+1$ score
- Moderate positive effect = $+2$ score
- Severe positive effect = $+3$ score
- Extreme positive effect = $+4$ score

Negative/worsening effects

- NA = 0 score
- No negative effect = 0 score
- Mild negative effect = -1 score
- Moderate negative effect = -2 score
- Severe negative effect = -3 score
- Extreme negative effect = -4 score

Questions 18-19

- No = -1 score
- Yes = $+1$ score