APPENDIX

Table A. Frequencies for signaling item responses (N=1,060)

Response	Fatigue N (%)	Hand function N (%)	Sleep problems N (%)	Emotions and stress N (%)	Body image N (%)	Pain N (%)	Self-management N (%)	Nutrition and diet N (%)	Exercise N (%)
0	55 (5.2)	76 (7.2)	153 (14.4)	122 (11.5)	182 (17.2)	88 (8.3)	76 (7.2)	48 (4.5)	0 (0.0)
1	57 (5.4)	56 (5.3)	51 (4.8)	72 (6.8)	87 (8.2)	57 (5.4)	59 (5.6)	53 (5.0)	64 (6.0)
2	45 (4.3)	40 (3.8)	43 (4.1)	66 (6.2)	78 (7.4)	55 (5.2)	34 (3.2)	36 (3.4)	40 (3.8)
3	46 (4.3)	53 (5.0)	49 (4.6)	51 (4.8)	66 (6.2)	58 (5.5)	48 (4.5)	49 (4.6)	59 (5.6)
4	30 (2.8)	29 (2.7)	39 (3.7)	36 (3.4)	36 (3.4)	35 (3.3)	32 (3.0)	33 (3.1)	47 (4.4)
5	119 (11.2)	110 (10.4)	124 (11.7)	141 (13.3)	133 (12.6)	132 (12.5)	128 (12.1)	137 (12.9)	167 (15.8)
6	50 (4.7)	48 (4.5)	40 (3.8)	56 (5.3)	47 (4.4)	60 (5.7)	69 (6.5)	53 (5.0)	54 (5.1)
7	89 (8.4)	92 (8.7)	77 (7.3)	88 (8.3)	64 (6.0)	88 (8.3)	90 (8.5)	82 (7.7)	78 (7.4)
8	132 (12.5)	105 (9.9)	101 (9.5)	87 (8.2)	82 (7.7)	113 (10.7)	118 (11.1)	116 (10.9)	118 (11.1)
9	69 (6.5)	83 (7.8)	69 (6.5)	66 (6.2)	56 (5.3)	75 (7.1)	72 (6.8)	74 (7.0)	69 (6.5)
10	368 (34.7)	368 (34.7)	314 (29.6)	275 (25.9)	229 (21.6)	299 (28.2)	334 (31.5)	379 (35.8)	364 (34.3)

Table B1. Multiple linear regression of the relationship between sociodemographic and disease variables with signalling question on fatigue (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	0.01 (0.00 to 0.02)	0.05	0.031
Male sex	0.64 (0.24 to 1.03)	0.06	0.002
Disease duration	-0.01 (-0.02 to 0.01)	-0.02	0.442
Diffuse disease	-0.31 (-0.58 to -0.04)	-0.05	0.023
Education in years	0.00 (-0.03 to 0.04)	<0.01	0.867
Married or living as married	0.18 (-0.10 to 0.47)	0.03	0.208
Self-efficacy	0.14 (0.07 to 0.22)	0.10	<0.001
Total R^2	0.04		
Step 2:			
Mean of remaining signalling items	0.80 (0.75 to 0.85)	0.65	<0.001
Total R^2	0.53		
R^2 change	0.49		<0.001
Step 3:			
PROMIS-29 Fatigue	0.09 (0.08 to 0.11)	0.30	<0.001
Total R^2	0.58		
R^2 change	0.05		<0.001

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized
regression coefficient
All B and β values are for the Step 3 model.

Table B2. Multiple linear regression of the relationship between sociodemographic and

disease variables with signalling question on hand function and mobility (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	0.01 (-0.01 to 0.02)	0.02	0.407
Male sex	0.19 (-0.27 to 0.65)	0.02	0.425
Disease duration	-0.01 (-0.02 to 0.01)	-0.01	0.578
Diffuse disease	0.17 (-0.16 to 0.49)	0.02	0.311
Education in years	0.00 (-0.04 to 0.04)	<-0.01	0.986
Married or living as married	0.22 (-0.11 to 0.56)	0.03	0.190
Self-efficacy	0.16 (0.09 to 0.24)	0.11	<0.001
Total R^2	0.03		
Step 2:			
Mean of remaining signalling items	0.80 (0.75 to 0.86)	0.63	<0.001
Total R^2	0.44		
R^2 change	0.41		<0.001
Step 3:			
Cochin Hand function	0.04 (0.03 to 0.05)	0.21	<0.001
Total R^2	0.47		
R^2 change	0.03		<0.001

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized
regression coefficient
All B and β values are for the Step 3 model.

Table B3. Multiple linear regression of the relationship between sociodemographic and disease variables with signalling question on sleep problems (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	0.02 (0.01 to 0.03)	0.08	<0.001
Male sex	0.12 (-0.32 to 0.55)	0.01	0.596
Disease duration	0.00 (-0.02 to 0.02)	<-0.01	0.936
Diffuse disease	-0.26 (-0.56 to 0.03)	-0.04	0.080
Education in years	0.03 (-0.01 to 0.07)	0.03	0.098
Married or living as married	-0.01 (-0.32 to 0.30)	<-0.01	0.949
Self-efficacy	0.21 (0.14 to 0.28)	0.13	<0.001
Total R^2	0.03		
Step 2:			
Mean of remaining signalling items	0.85 (0.80 to 0.91)	0.61	<0.001
Total R^2	0.46		
R^2 change	0.43		<0.001
Step 3:			
PROMIS-29 sleep	0.18 (0.16 to 0.20)	0.43	<0.001
Total R^2	0.61		
R^2 change	0.14		<0.001

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized regression coefficient

All B and β values are for the Step 3 model.

Table B4. Multiple linear regression of the relationship between sociodemographic and

disease variables with signalling question on emotions and stress (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	-0.02 (-0.03 to -0.01)	-0.08	<0.001
Male sex	-0.24 (-0.65 to 0.17)	-0.02	0.257
Disease duration	-0.01 (-0.03 to 0.00)	-0.03	0.096
Diffuse disease	-0.11 (-0.39 to 0.16)	-0.02	0.421
Education in years	0.01 (-0.03 to 0.05)	0.01	0.597
Married or living as married	-0.33 (-0.62 to -0.03)	-0.04	0.032
Self-efficacy	0.05 (-0.02 to 0.13)	0.03	0.131
Total R^2	0.08		
Step 2:			
Mean of remaining signalling items	0.99 (0.93 to 1.04)	0.72	<0.001
Total R^2	0.60		
R^2 change	0.52		<0.001
Step 3:			
PROMIS-29 depression	0.07 (0.05 to 0.08)	0.18	<0.001
Total R^2	0.63		
R^2 change	0.02		<0.001

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized
regression coefficient
All B and β values are for the Step 3 model.

Table B5. Multiple linear regression of the relationship between sociodemographic and disease variables with signalling question on concerns about body image (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	-0.02 (-0.03 to 0.00)	-0.05	0.023
Male sex	-0.38 (-0.85 to 0.09)	-0.03	0.109
Disease duration	-0.01 (-0.03 to 0.01)	-0.02	0.350
Diffuse disease	0.08 (-0.24 to 0.40)	0.01	0.627
Education in years	-0.06 (-0.10 to -0.01)	-0.06	0.009
Married or living as married	0.03 (-0.31 to 0.36)	<0.01	0.879
Self-efficacy	0.16 (0.08 to 0.23)	0.09	<0.001
Total R²	0.07		
Step 2:			
Mean of remaining signalling items	0.91 (0.85 to 0.97)	0.64	<0.001
Total R²	0.49		
R² change	0.43		<0.001
Step 3:			
SAAS score	0.08 (0.06 to 0.09)	0.28	<0.001
Total R²	0.55		
R² change	0.06		<0.001

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized regression coefficient

All B and β values are for the Step 3 model.

Table B6. Multiple linear regression of the relationship between sociodemographic and disease variables with signalling question on pain (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	0.00 (-0.01 to 0.01)	0.01	0.696
Male sex	0.42 (0.04 to 0.81)	0.04	0.032
Disease duration	0.01 (-0.01 to 0.02)	0.01	0.467
Diffuse disease	-0.17 (-0.44 to 0.09)	-0.03	0.193
Education in years	-0.05 (-0.09 to -0.02)	-0.05	0.005
Married or living as married	0.11 (-0.17 to 0.39)	0.02	0.426
Self-efficacy	0.07 (0.00 to 0.14)	0.04	0.047
Total R²			
Step 2:			
Mean of remaining signalling items	0.86 (0.81 to 0.91)	0.67	<0.001
Total R²	0.07		
R² change	0.57		<0.001
Step 3:			
PROMIS-29 Pain	0.12 (0.10 to 0.13)	0.32	<0.001
Total R²	0.64		
R² change	0.07		<0.001

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized
regression coefficient
All B and β values are for the Step 3 model.

Table B7. Multiple linear regression of the relationship between sociodemographic and disease variables with signalling question on self-management (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	0.01 (0.00 to 0.02)	0.03	0.176
Male sex	0.04 (-0.34 to 0.41)	<0.01	0.843
Disease duration	0.00 (-0.02 to 0.01)	-0.01	0.775
Diffuse disease	0.12 (-0.13 to 0.38)	0.02	0.335
Education in years	-0.01 (-0.05 to 0.02)	-0.01	0.466
Married or living as married	0.10 (-0.17 to 0.37)	0.01	0.453
Self-efficacy	-0.04 (-0.10 to 0.01)	-0.03	0.124
Total R^2	0.04		
Step 2:			
Mean of remaining signalling items	1.01 (0.96 to 1.06)	0.80	<0.001
Total R^2	0.64		
R^2 change	0.60		<0.001

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized regression coefficient
All B and β values are for the Step 3 model.

Table B8. Multiple linear regression of the relationship between sociodemographic and disease variables with signalling question on nutrition/diet (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	0.00 (-0.01 to 0.01)	<-0.01	0.949
Male sex	-0.53 (-0.94 to -0.11)	-0.05	0.014
Disease duration	-0.01 (-0.02 to 0.01)	-0.02	0.356
Diffuse disease	-0.07 (-0.35 to 0.21)	-0.01	0.621
Education in years	0.05 (0.01 to 0.09)	0.06	0.011
Married or living as married	-0.08 (-0.38 to 0.22)	-0.01	0.613
Self-efficacy	0.12 (0.06 to 0.19)	0.09	<0.001
Total R²	0.03		
Step 2:			
Mean of remaining signalling items	0.84 (0.79 to 0.89)	0.71	<0.001
Total R²	0.51		
R² change	0.48		<0.001
Step 3:			
Interference of GI symptoms	0.07 (0.02 to 0.12)	0.07	0.004
Total R²	0.51		
R² change	<0.01		<0.001

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized regression coefficient

All B and β values are for the Step 3 model.

Table B9. Multiple linear regression of the relationship between sociodemographic and disease variables with signalling question on exercise (n = 1,060)

	B (95% CI)	β	P
Step 1:			
Age in years	0.00 (-0.01 to 0.01)	0.01	0.725
Male sex	-0.21 (-0.62 to 0.20)	-0.02	0.313
Disease duration	0.00 (-0.02 to 0.02)	<-0.01	0.981
Diffuse disease	0.15 (-0.12 to 0.43)	0.03	0.273
Education in years	0.06 (0.02 to 0.09)	0.07	0.003
Married or living as married	-0.06 (-0.35 to 0.23)	-0.01	0.689
Self-efficacy	0.21 (0.14 to 0.27)	0.16	<0.001
Total R^2	0.02		
Step 2:			
Mean of remaining signalling items	0.74 (0.69 to 0.79)	0.70	<0.001
Total R^2	0.46		
R^2 change	0.44		<0.001
Step 3:			
Activity level	-0.10 (-0.24 to 0.03)	-0.04	0.130
Total R^2	0.46		
R^2 change	<0.01		0.13

B (95% CI): raw regression coefficient and 95% confidence interval; β: standardized regression coefficient
All B and β values are for the Step 3 model.