

Supplemental Tables

Supplemental Table S1: Health Behaviors

	Total	AAV	IgG4-RD	Scleroderma
N	132	41	61	30
Smoking status n (%)				
Current	2 (1.5)	1 (2.4)	0 (0.0)	1 (3.3)
Former	51 (38.6)	15 (36.6)	20 (32.8)	16 (53.3)
Never	79 (59.8)	25 (61.0)	41 (67.2)	13 (43.3)
Vaping status n (%)				
Current	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Former	3 (2.3)	1 (2.4)	2 (3.3)	0 (0.0)
Never	128 (97.0)	40 (97.6)	58 (95.1)	30 (100)
Sleep Quality n (%)				
Very good	19 (14.4)	4 (9.8)	10 (16.4)	5 (16.7)
Fairly good	47 (35.6)	14 (34.1)	21 (34.4)	12 (40.0)
Neutral	37 (28.0)	12 (29.3)	17 (27.9)	8 (26.7)
Fairly bad	23 (17.4)	8 (19.5)	10 (16.4)	5 (16.7)
Very bad	6 (4.5)	3 (7.3)	3 (4.9)	0 (0.0)
Health Behaviors				
Vigorous physical activity (days, median, IQR)	0.0 [0.0, 2.0]	1.0 [0.0, 3.5]	0.0 [0.0, 2.0]	0.0 [0.0, 1.0]
Moderate physical activity (days, median, IQR)	2.0 [0.0, 4.0]	3.0 [0.5, 5.0]	2.0 [0.0, 4.0]	1.0 [0.0, 4.0]
Time spent walking (days, median, IQR)	4.0 [2.0, 7.0]	4.0 [2.0, 6.0]	4.0 [2.5, 7.0]	4.0 [1.0, 7.0]
Time spent sitting (hours, median, IQR)	8.0 [5.0, 12.0]	8.0 [5.0, 10.0]	8.0 [6.0, 11.8]	9.0 [5.0, 16.0]
Time spent sleeping (hours, median, IQR)	7.0 [6.0, 8.0]	6.0 [6.0, 7.8]	7.0 [6.2, 7.5]	7.0 [6.0, 8.0]

MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder (GAD-7); SIP: Sickness Impact Profile

Supplemental Table S2a: Uncertainty and Mental Health in AAV Stratified According to Disease Activity

	In remission	Not in remission	I don't know	
N	21	13	7	
MUIS n (%)				
Median, IQR	53.0 [43.0, 56.0]	56.0 [51.0, 74.0]	66.0 [59.0, 67.0]	0.02
Q1 (22-44)	7 (33.3)	1 (7.7)	4 (57.1)	
Q2 (44-66)	13 (61.9)	8 (61.5)	3 (42.9)	
Q3 (66-88)	1 (4.8)	3 (23.1)	0 (0.0)	
Q4 (88-110)	0 (0.0)	1 (7.7)	0 (0.0)	
PHQ-8 n (%)				
Median, IQR	2.0 [2.0, 7.0]	8.0 [5.0, 19.0]	4.0 [1.0, 5.0]	0.01
Minimal (0-4)	13 (61.9)	3 (23.1)	5 (71.4)	
Mild (5-9)	5 (23.8)	4 (30.8)	1 (14.3)	
Moderate (10-14)	2 (9.5)	2 (15.4)	0 (0.0)	
Moderately Severe (15-19)	1 (4.8)	1 (7.7)	0 (0.0)	
Severe (20-24)	0 (0.0)	3 (23.1)	0 (0.0)	
< 10	18 (85.7)	7 (53.8)	6 (85.7)	
>= 10	3 (14.3)	6 (46.2)	1 (14.3)	
GAD-7 n (%)				
Median, IQR	2.0 [0.0, 6.0]	7.0 [4.0, 10.0]	5.0 [2.0, 6.0]	0.07
Minimal (0-4)	13 (61.9)	5 (38.5)	2 (28.6)	
Mild (5-9)	8 (38.1)	4 (30.8)	4 (57.1)	
Moderate (10-14)	0 (0.0)	3 (23.1)	1 (14.3)	
Severe (15-21)	0 (0.0)	1 (7.7)	0 (0.0)	
SIP n (%)				
Median, IQR	1.0 [0.0, 2.0]	5.0 [1.0, 10.0]	6.0 [0.0, 8.0]	0.06
Q1 (0-5)	18 (85.7)	7 (53.8)	2 (28.6)	
Q2 (6-11)	3 (14.3)	5 (38.5)	4 (57.1)	
Q3 (12-16)	0 (0.0)	1 (7.7)	1 (14.3)	
Q4 (17-22)	0 (0.0)	0 (0.0)	0 (0.0)	

MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder (GAD-7); SIP: Sickness Impact Profile

Supplemental Table S2b: Uncertainty and Mental Health in Scleroderma Stratified According to Disease Activity

	In remission	Not in remission	I don't know	P-Value
N	3	16	11	
MUIS n (%)				
Median, IQR	59.0 [52.0, 66.0]	59.0 [54.5, 66.0]	59.0 [55.0, 66.0]	1.0
Q1 (22-44)	0 (0.0)	1 (6.3)	10 (90.9)	
Q2 (44-66)	3 (100.0)	11 (68.8)	1 (9.1)	
Q3 (66-88)	0 (0.0)	4 (25.0)	0 (0.0)	
Q4 (88-110)	0 (0.0)	0 (0.0)	0 (0.0)	
PHQ-8 n (%)				
Median, IQR	1.0 [1.0, 7.0]	3.0 [2.0, 8.0]	2.0 [1.0, 4.0]	0.2
Minimal (0-4)	2 (66.7)	9 (56.3)	8 (72.7)	
Mild (5-9)	1 (33.3)	5 (31.3)	2 (18.2)	
Moderate (10-14)	0 (0.0)	1 (6.3)	0 (0.0)	
Moderately Severe (15-19)	0 (0.0)	1 (6.3)	0 (0.0)	
Severe (20-24)	0 (0.0)	0 (0.0)	0 (0.0)	
< 10	3 (100.0)	14 (87.5)	10 (90.9)	
≥ 10	0 (0.0)	2 (12.5)	0 (0.0)	
GAD-7 n (%)				
Median, IQR	2.0, [0.0, 7.0]	2.0 [0.0, 3.5]	1.0 [0.0, 9.0]	1.0
Minimal (0-4)	2 (66.7)	13 (81.3)	7 (63.6)	
Mild (5-9)	1 (33.3)	3 (18.8)	3 (27.3)	
Moderate (10-14)	0 (0.0)	0 (0.0)	1 (9.1)	
Severe (15-21)	0 (0.0)	0 (0.0)	0 (0.0)	
SIP n (%)				
Median, IQR	0.0 [0.0, 1.0]	1.0 [0.0, 4.0]	4.0 [0.0, 7.0]	0.3
Q1 (0-5)	3 (100.0)	13 (81.3)	8 (72.7)	
Q2 (6-11)	0 (0.0)	3 (18.8)	3 (27.3)	
Q3 (12-16)	0 (0.0)	0 (0.0)	0 (0.0)	
Q4 (17-22)	0 (0.0)	0 (0.0)	0 (0.0)	

MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder (GAD-7); SIP: Sickness Impact Profile

Supplemental Table S2c: Uncertainty and Mental Health in IgG4-RD Stratified According to Disease Activity

	In remission	Not in remission	I don't know	P-Value
N	32	13	16	
MUIS n (%)				
Median, IQR	49.5 [42.0, 53.5]	54.0 [48.0, 63.0]	58.0 [54.5, 63.5]	0.002
Q1 (22-44)	9 (28.1)	2 (15.4)	1 (6.3)	
Q2 (44-66)	23 (71.9)	11 (84.6)	14 (87.5)	
Q3 (66-88)	0 (0.0)	0 (0.0)	1 (6.3)	
Q4 (88-110)	0 (0.0)	0 (0.0)	0 (0.0)	
PHQ-8 n (%)				
Median, IQR	2.0 [0.0, 4.0]	4.0 [1.0, 9.0]	3.0 [0.0, 6.0]	0.09
Minimal (0-4)	27 (84.4)	8 (61.5)	9 (56.3)	
Mild (5-9)	4 (12.5)	4 (30.8)	5 (31.3)	
Moderate (10-14)	0 (0.0)	0 (0.0)	0 (0.0)	
Moderately Severe (15-19)	1 (3.1)	0 (0.0)	1 (6.3)	
Severe (20-24)	0 (0.0)	1 (7.7)	0 (0.0)	
< 10	31 (96.9)	12 (92.3)	14 (87.5)	
≥ 10	1 (3.1)	1 (7.7)	1 (6.3)	
GAD-7 n (%)				
Median, IQR	0.0 [0.0, 2.5]	3.0 [0.0, 6.0]	3.0 [0.0, 6.0]	0.06
Minimal (0-4)	30 (93.8)	7 (53.8)	11 (68.8)	
Mild (5-9)	2 (6.3)	5 (38.5)	4 (25.0)	
Moderate (10-14)	0 (0.0)	0 (0.0)	1 (6.3)	
Severe (15-21)	0 (0.0)	1 (7.7)	0 (0.0)	
SIP n (%)				
Median, IQR	0.0 [0.0, 5.5]	2.0 [0.0, 9.0]	1.5 [0.5, 7.0]	0.2
Q1 (0-5)	24 (75.0)	7 (53.8)	10 (62.5)	
Q2 (6-11)	7 (21.9)	4 (30.8)	5 (31.3)	
Q3 (12-16)	1 (3.1)	2 (15.4)	1 (6.3)	
Q4 (17-22)	0 (0.0)	0 (0.0)	0 (0.0)	

MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder (GAD-7); SIP: Sickness Impact Profile

Supplemental Table S3a: Uncertainty and Mental Health Stratified by Sex

	MALE	FEMALE	P-Value
N	63	69	
MUIS n (%)			
Median, IQR	52.0 [46.0, 58.0]	58.0 [52.0, 63.0]	0.002
Q1 (22-44)	14 (22)	6 (9)	0.096
Q2 (44-66)	41 (65)	51 (74)	
Q3 (66-88)	7 (11)	12 (17)	
Q4 (88-110)	1 (2)	0 (0)	
Missing	0 (0)	0 (0)	
PHQ-8 n (%)			
Median, IQR	2.0 [1.0, 5.0]	3.0 [1.0, 7.0]	0.15
Minimal (0-4)	44 (71)	40 (59)	0.57
Mild (5-9)	13 (21)	18 (26)	
Moderate (10-14)	1 (2)	4 (6)	
Moderately Severe (15-19)	2 (3)	3 (4)	
Severe (20-24)	2 (3)	3 (4)	
Missing	1 (2)	1 (1)	
GAD-7 n (%)			
Median, IQR	2.0 [0.0, 5.0]	3.0 [0.0, 7.0]	0.061
Minimal (0-4)	47 (75)	43 (62)	0.17
Mild (5-9)	15 (24)	19 (28)	
Moderate (10-14)	1 (2)	5 (7)	
Severe (15-21)	0 (0)	2 (3)	
Missing	0 (0)	0 (0)	
SIP n (%)			
Median, IQR	1.0 [0.0, 7.0]	1.0 [0.0, 6.0]	0.98
Q1 (0-5)	41 (65)	51 (74)	0.45
Q2 (6-11)	18 (29)	16 (23)	
Q3 (12-16)	4 (6)	2 (3)	
Q4 (17-22)	0 (0)	0 (0)	
Missing	0 (0)	0 (0)	

AAV: ANCA-Associated Vasculitis; IgG4-RD: IgG4-Related Disease; SSc: Systemic Sclerosis; MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder; SIP: Sickness Impact Profile

*P-value compares the proportion of patients with at least mild depression or anxiety across the three disease groups.

Supplemental Table S3b: Uncertainty and Mental Health Among Female Patients

	Overall	AAV	IgG4-RD	SSc	P-Value
N	69	23	17	29	
MUIS n (%)					
Median, IQR	58.0 [52.0, 63.0]	57.0 [51.0, 62.0]	54.0 [48.0, 63.0]	59.0 [55.0, 65.0]	
Q1 (22-44)	6 (9)	3 (13)	2 (12)	1 (3)	0.42
Q2 (44-66)	51 (74)	16 (70)	14 (82)	21 (72)	
Q3 (66-88)	12 (17)	4 (17)	1 (6)	7 (24)	
Q4 (88-110)	0 (0)	0 (0)	0 (0)	0 (0)	
Missing	0 (0)	0 (0)	0 (0)	0 (0)	
PHQ-8 n (%)					
Median, IQR	3.0 [1.0, 7.0]	5.0 [2.0, 11.0]	3.0 [0.0, 6.0]	3.00 [1.0, 7.0]	
Minimal (0-4)	40 (59)	11 (48)	11 (65)	18 (64)	0.40
Mild (5-9)	18 (26)	5 (22)	5 (29)	8 (29)	
Moderate (10-14)	4 (6)	3 (13)	0 (0)	1 (4)	
Moderately Severe (15-19)	3 (4)	2 (9)	0 (0)	1 (4)	
Severe (20-24)	3 (4)	2 (9)	1 (6)	0 (0)	
Missing	1 (1)	0 (0)	0 (0)	1 (3)	
GAD-7 n (%)					
Median, IQR	3.0 [0.0, 7.0]	6.0 [2.0, 9.0]	1.0 [0.0, 4.0]	2.0 [0.0, 5.0]	
Minimal (0-4)	43 (62)	9 (39)	13 (76)	21 (72)	0.12
Mild (5-9)	19 (28)	10 (43)	2 (12)	7 (24)	
Moderate (10-14)	5 (7)	3 (13)	1 (6)	1 (3)	
Severe (15-21)	2 (3)	1 (4)	1 (6)	0 (0)	
Missing	0 (0)	0 (0)	0 (0)	0 (0)	
SIP n (%)					
Median, IQR	1.0 [0.0, 6.0]	2.0 [0.0, 7.0]	2.0 [0.0, 7.0]	1.0 [0.0, 5.0]	
Q1 (0-5)	51 (74)	15 (65)	12 (71)	24 (83)	0.55
Q2 (6-11)	16 (23)	7 (30)	4 (24)	5 (17)	
Q3 (12-16)	2 (3)	1 (4)	1 (6)	0 (0)	
Q4 (17-22)	0 (0)	0 (0)	0 (0)	0 (0)	
Missing	0 (0)	0 (0)	0 (0)	0 (0)	

AAV: ANCA-Associated Vasculitis; IgG4-RD: IgG4-Related Disease; SSc: Systemic Sclerosis; MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder; SIP: Sickness Impact Profile

*P-value compares the proportion of patients with at least mild depression or anxiety across the three disease groups.

Supplemental Table S3c: Uncertainty and Mental Health Among Male Patients

	Overall	AAV	IgG4-RD	SSc	P-Value
N	63	18	44	1	
MUIS n (%)					
Median, IQR	52.0 [46.0, 58.0]	53.0 [44.0, 66.0]	51.5 [46.5, 56.5]	66.0 [66.0, 66.0]	
Q1 (22-44)	14 (22)	4 (22)	10 (23)	0 (0)	0.019
0.019Q2 (44-66)	41 (65)	9 (50)	32 (73)	0 (0)	
Q3 (66-88)	7 (11)	4 (22)	2 (5)	1 (100)	
Q4 (88-110)	1 (2)	1 (6)	0 (0)	0 (0)	
Missing	0 (0)	0 (0)	0 (0)	0 (0)	
PHQ-8 n (%)					
Median, IQR	2.0 [1.0, 5.0]	3.5 [2.0, 8.0]	2.0 [1.0, 4.0]	2.0 [2.0, 2.0]	
Minimal (0-4)	44 (71)	10 (56)	33 (77)	1 (100)	0.27
Mild (5-9)	13 (21)	5 (28)	8 (19)	0 (0)	
Moderate (10-14)	1 (2)	1 (6)	0 (0)	0 (0)	
Moderately Severe (15-19)	2 (3)	0 (0)	2 (5)	0 (0)	
Severe (20-24)	2 (3)	2 (11)	0 (0)	0 (0)	
Missing	1 (2)	0 (0)	1 (2)	0 (0)	
GAD-7 n (%)					
Median, IQR	2.0 [0.0, 5.0]	2.5 [1.0, 5.0]	1.0 [0.0, 3.0]	0.0 [0.0, 0.0]	
Minimal (0-4)	47 (75)	11 (61)	35 (80)	1 (100)	0.37
Mild (5-9)	15 (24)	6 (33)	9 (20)	0 (0)	
Moderate (10-14)	1 (2)	1 (6)	0 (0)	0 (0)	
Severe (15-21)	0 (0)	0 (0)	0 (0)	0 (0)	
Missing	0 (0)	0 (0)	0 (0)	0 (0)	
SIP n (%)					
Median, IQR	1.0 [0.0, 7.0]	1.5 [0.0, 6.0]	1.0 [0.0, 7.0]	11.0 [11.0, 11.0]	
Q1 (0-5)	41 (65)	12 (67)	29 (66)	0 (0)	0.63
Q2 (6-11)	18 (29)	5 (28)	12 (27)	1 (100)	
Q3 (12-16)	4 (6)	1 (6)	3 (7)	0 (0)	
Q4 (17-22)	0 (0)	0 (0)	0 (0)	0 (0)	
Missing	0 (0)	0 (0)	0 (0)	0 (0)	

AAV: ANCA-Associated Vasculitis; IgG4-RD: IgG4-Related Disease; SSc: Systemic Sclerosis; MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder; SIP: Sickness Impact Profile

*P-value compares the proportion of patients with at least mild depression or anxiety across the three disease groups.

Supplemental Table S3d: The Association of Uncertainty with Mental Health Among Female Patients

	Correlation coefficient	p-value
Overall		
MUIS and PHQ-8	0.44	< 0.001
MUIS and GAD-7	0.34	0.004
MUIS and SIP	0.34	0.0046
AAV		
MUIS and PHQ-8	0.45	0.031
MUIS and GAD-7	0.42	0.048
MUIS and SIP	0.42	0.045
IgG4-RD		
MUIS and PHQ-8	0.34	0.18
MUIS and GAD-7	0.49	0.046
MUIS and SIP	0.079	0.76
SSc		
MUIS and PHQ-8	0.62	< 0.001
MUIS and GAD-7	0.28	0.15
MUIS and SIP	0.62	< 0.001

AAV: ANCA-Associated Vasculitis; IgG4-RD: IgG4-Related Disease; SSc: Systemic Sclerosis; MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder; SIP: Sickness Impact Profile

Supplemental Table S3e: The Association of Uncertainty with Mental Health Among Male Patients

	Correlation coefficient	p-value
Overall		
MUIS and PHQ-8	0.39	0.002
MUIS and GAD-7	0.25	0.045
MUIS and SIP	0.27	0.033
AAV		
MUIS and PHQ-8	0.68	0.002
MUIS and GAD-7	0.51	0.033
MUIS and SIP	0.73	< 0.001
IgG4-RD		
MUIS and PHQ-8	0.072	0.65
MUIS and GAD-7	0.040	0.80
MUIS and SIP	-0.018	0.91
SSc*		
MUIS and PHQ-8	-	
MUIS and GAD-7	-	
MUIS and SIP	-	

AAV: ANCA-Associated Vasculitis; IgG4-RD: IgG4-Related Disease; SSc: Systemic Sclerosis; MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder; SIP: Sickness Impact Profile; *There were too few male patients in the SSc disease group to assess correlations

Supplemental Table S4: Needs Identified by Patients According to Illness Group

	AAV	IgG4-RD	SSc
N	41	61	30
Managing physical symptoms	18 (43.9)	31 (50.8)	21 (70.0)
Coping with emotional concerns	11 (26.8)	14 (23.0)	7 (23.3)
Managing social concerns/lack of support	4 (9.8)	3 (4.9)	3 (10.0)
Learning strategies to increase self-care	18 (43.9)	21 (34.4)	10 (33.3)
Managing sexual and reproductive concerns	2 (4.9)	2 (3.8)	0 (0.0)
Finding resources	4 (9.8)	6 (9.8)	1 (3.3)
Other	4 (9.8)	5 (8.2)	3 (10.0)
Missing/None	6 (14.6)	13 (21.3)	3 (10.0)

Supplemental Table S5: Communication of Needs Survey with Providers and Interest in Intervention

	Managing physical symptoms	Coping with emotional concerns	Managing social concerns/lack of support	Learning strategies to increase self-care	Managing sexual and reproductive concerns	Finding resources to help with daily concerns	Other	Blank
N	70	32	10	49	4	11	12	20
Discussed with rheumatology provider								
Yes	50 (71.4)	10 (31.3)	3 (30.0)	17 (34.7)	1 (25.0)	4 (36.4)	6 (50.0)	
No	8 (11.4)	15 (46.9)	4 (40.0)	26 (53.1)	3 (75.0)	2 (18.2)	4 (33.3)	
Not sure	9 (12.9)	4 (12.5)	2 (20.0)	4 (8.2)	0 (0.0)	3 (27.3)	2 (16.7)	
Blank	3 (4.3)	3 (9.4)	1 (10.0)	2 (4.1)	4 (0.0)	2 (18.2)	0 (0.0)	
Interested in receiving information								
Yes	43 (61.4)	18 (56.3)	3 (30.0)	33 (67.3)	3 (75.0)	5 (45.5)	6 (50.0)	
No	11 (15.7)	7 (21.9)	4 (40.0)	7 (14.3)	0 (0.0)	2 (18.2)	5 (41.7)	
Not sure	15 (21.4)	6 (18.8)	3 (30.0)	7 (14.3)	1 (25.0)	3 (27.3)	1 (8.3)	
Blank	1 (1.4)	1 (3.1)	0 (0.0)	2 (4.1)	0 (0.0)	1 (9.1)	0 (0.0)	
Interested in receiving information virtually								
Yes	35 (81.4)	14 (77.8)	2 (66.7)	31 (93.9)	3 (100.0)	4 (80.0)	5 (83.3)	
No	0 (0.0)	1 (5.6)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (16.7)	
Not sure	5 (11.6)	2 (11.1)	1 (33.3)	1 (3.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Blank	3 (7.0)	1 (5.6)	0 (0.0)	1 (3.0)	0 (0.0)	1 (20.0)	0 (0.0)	

MUIS: Mishel Uncertainty in Illness Scale; PHQ-8: Patient Health Questionnaire depression scale; GAD-7: General Anxiety Disorder (GAD-7); SIP: Sickness Impact Profile

Supplemental Materials: Survey Measures**(1) Demographics, comorbidities, and self-reported disease activity**

- 1) I would characterize my race/ethnicity as: (Please check all that apply)
- | | |
|---|--|
| <input type="checkbox"/> American Indian or Alaskan | <input type="checkbox"/> Native Hawaiian or Other Pacific Islander |
| <input type="checkbox"/> Asian | <input type="checkbox"/> White |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Other, please specify: _____ |
| <input type="checkbox"/> Hispanic or Latino | <input type="checkbox"/> Prefer not to answer |
- 2) I would characterize my gender as: (Please check one)
- | | |
|---|--|
| <input type="checkbox"/> Male | <input type="checkbox"/> Trans female/Trans woman |
| <input type="checkbox"/> Female | <input type="checkbox"/> Genderqueer/Gender non-conforming |
| <input type="checkbox"/> Trans male/Trans man | <input type="checkbox"/> Different identity |
- 3) What is your relationship status? (Please check one)
- | | |
|---|---|
| <input type="checkbox"/> Single, never married | <input type="checkbox"/> Divorced |
| <input type="checkbox"/> Married | <input type="checkbox"/> Separated or no longer living as married |
| <input type="checkbox"/> Living with partner as married | <input type="checkbox"/> Other, please describe: _____ |
| <input type="checkbox"/> Widowed | |
- 4) Do you have any children?
- Yes (Go to question 4a)
- No (Go to question 5)
- 4a. How many children do you have? _____ (number)
- 5) Are you a caretaker for a family member (e.g. parent, grandparent, grandchildren, spouse, sibling, etc.) or friend?
- Yes (Go to question 5a)
- No (Continue to question 6)
- 5a. For how many people other than your children are you a caretaker? _____ (number)

Understanding your answers to the following questions will help us better address the needs of our patient population.

- 6) Which of the following best describes your level of education? (Please check one)
- | | |
|--|--|
| <input type="checkbox"/> 8 th grade or less | <input type="checkbox"/> Completed two-year degree/AA degree/technical school training |
| <input type="checkbox"/> Some high school | <input type="checkbox"/> Completed four-year college/university (BA or BS) |
| <input type="checkbox"/> Completed high school or GED | <input type="checkbox"/> Master's Degree |
| <input type="checkbox"/> Attended some college | <input type="checkbox"/> Doctoral/Medical/Law Degree |
- 7) What is your current employment status? (Please check one)
- | | |
|--|--|
| <input type="checkbox"/> Employed full time | <input type="checkbox"/> Unable to work due to illness or disability |
| <input type="checkbox"/> Employed part time | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Unemployed and looking for work | <input type="checkbox"/> Student |
| <input type="checkbox"/> Unable to work due to caring for home or family | <input type="checkbox"/> Other, please describe: _____ |

- 8) What is your annual household income? (Please check one)
- | | |
|---|---|
| <input type="checkbox"/> Less than \$20,000 | <input type="checkbox"/> \$80,000-99,999 |
| <input type="checkbox"/> \$20,000-39,999 | <input type="checkbox"/> \$100,000 and over |
| <input type="checkbox"/> \$40,000-59,999 | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> \$60,000-79,999 | <input type="checkbox"/> Prefer not to answer |
- 9) How many people are supported on this income? _____ (number)
- 10) What kind of health insurance or health coverage do you have? (Please check one)
- | | |
|--|---|
| <input type="checkbox"/> Employer-sponsored insurance (through a policy offered by a place of employment for you or a family member) | <input type="checkbox"/> Medicaid/state public insurance |
| <input type="checkbox"/> Individual insurance (through a policy purchased by you/your policy holder) | <input type="checkbox"/> Other state, local government, or community programs |
| <input type="checkbox"/> Medicare | <input type="checkbox"/> Military health care (Tricare/VA/Camp-VA) |
| | <input type="checkbox"/> Don't know |
| | <input type="checkbox"/> Other, please describe: _____ |
| | <input type="checkbox"/> No health insurance |
- 11) Do you have a current diagnosis of any of these conditions? (Please check all that apply)
- | | |
|--|--|
| <input type="checkbox"/> Cardiovascular disease (ie. Heart disease, stroke, high blood pressure, high cholesterol) | <input type="checkbox"/> Lung disease (e.g. asthma, COPD, sleep apnea) |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Overweight/Obesity (BMI > 30.0) |
| <input type="checkbox"/> Kidney disease | <input type="checkbox"/> Underweight (BMI <20) |
| <input type="checkbox"/> Liver disease | <input type="checkbox"/> Other, please specify: _____ |
- 12) For which of the following diseases do you primarily see your rheumatologist? (Please check one)
- ANCA-associated vasculitis (including Wegener's granulomatosis, granulomatosis with polyangiitis, microscopic polyangiitis, eosinophilic granulomatosis with polyangiitis, and Churg-Strauss syndrome)
 - Fibromyalgia
 - Giant cell arteritis
 - Gout
 - IgG4-related disease
 - Inflammatory myositis (including dermatomyositis, polymyositis, or inclusion body myositis)
 - Lupus
 - Rheumatoid arthritis, psoriatic arthritis, ankylosing spondyloarthritis, or IBD-associated arthritis
 - Osteoarthritis (wear and tear, degenerative arthritis)
 - Sarcoidosis
 - Scleroderma (or systemic sclerosis)
 - Vasculitis
 - Other, please describe: _____
- 13) How would you describe your disease today?
- In remission (or not active)
 - Not in remission (or active)
 - I do not know

(2) Mishel Uncertainty in Illness Scale

Please read each statement. Take your time and think about what each statement says. Then fill in the button under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would indicate either "Strongly Agree" or "Agree". If you disagree with a statement, then indicate either "Strongly Disagree" or "Disagree". If you are undecided about how you feel, then indicate "Undecided" for that statement.

Please respond to every statement.

In this survey, "my condition" refers to the condition, illness, or disease for which you see your rheumatologist.

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
I do not know what is wrong with me					
I have a lot of questions without answers					
I am unsure if my rheumatology condition is getting better or worse					
It is unclear how bad my symptoms will be					
The explanations that my rheumatology providers give about my condition seem unclear to me					
The purpose of each rheumatology treatment is clear to me					
When I have pain, I know what this means about my rheumatology condition					
I do not know when to expect things like lab tests, biopsies, x-rays, or other tests will be done to me					
The symptoms of my rheumatology condition continue to change unpredictably					
I understand everything explained to me by my rheumatology providers					
My rheumatology providers say things to me that could mean many things					
I can predict how long my rheumatology condition will last					
My rheumatology treatment is too complicated to figure out					
It is difficult to know if the rheumatology treatments I am getting are helping					
I see so many different types of providers; it is unclear who is responsible for what					
Because of the unpredictability of my rheumatology condition, I cannot plan for the future					
The course of my rheumatology condition keeps changing. I have good and bad days.					
It is unclear to me how I will manage my rheumatology condition after I leave my appointments with my rheumatology providers					
I have been given many differing opinions about what is wrong with me					
It is not clear what is going to happen to me in the future because of my rheumatology condition					
I usually know if I am going to have a good or bad day					
The results of my rheumatology tests are always changing					

(3) Health Behavior Questionnaire

This survey asks about health behaviors. Please answer every question to the best of your ability.

14) Have you smoked tobacco, now or in the past? (Please check one)

- Yes, I am a current tobacco smoker
 Yes, I am a former tobacco smoker
 No, I have never smoked tobacco

15) Have you ever used vaping products or e-cigarettes, now or in the past? (Please check one)

- Yes, I am a current user
 Yes, I am a former user
 No, I have never used those products

These questions are about the time you spent being physically active in the last 7 days. They include questions about activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Your answers are important. Please answer each question even if you do not consider yourself to be an active person. In answering the following questions: "vigorous" physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. "moderate" activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal.

16) During the last seven days, on how many days did you do vigorous physical activities, like heavy lifting, digging, aerobics, or fast bicycling?

Think about only those physical activities that you did for at least 10 minutes at a time.
_____ (days)

17) During the last seven days, on how many days did you do moderate physical activities, like carrying light loads, bicycling at a regular pace, or doubles tennis?

Again, think only about those physical activities that you did for at least 10 minutes at a time. Do not include walking.
_____ (days)

18) During the last seven days, on how many days did you walk for at least 10 minutes at a time?

This includes walking at work and at home, walking to travel from place to place, and any other walking that you did solely for recreation, sport, exercise, or leisure. _____ (days)

19) The last question is about the time you spent sitting while at work, at home, while doing course work, and during leisure time. This includes time spent sitting at a desk, visiting friends, reading, traveling on a bus, or sitting or lying down to watch television.

During the last seven days, how much time in total did you usually spend sitting each day?
_____ (hours)

The following questions relate to your usual sleep habits during the PAST MONTH only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month.

20) During the past month, how many hours of actual sleep did you get per night? (This may be different than the number of hours you spent in bed)

_____ (hours)

21) During the past month, how would you rate your sleep quality overall? (Please check one)

- Very good Fairly good Neutral Fairly bad Very bad

(4) Needs Survey

We would like to get a sense of which informational services and topics are most important to you. From the following list, which would you consider to be your major concerns? (Please check all that apply)

	Have you discussed this topic with your rheumatology provider in the past? (Yes/No/Not sure)	Would you be interested in receiving more information on this topic? (Yes/No/Not sure)	Would you be interested in receiving this information virtually? (e.g. using your computer or smartphone) (Yes/No/Not sure)
Managing physical symptoms of your disease			
Coping with emotional concerns related to your disease and its treatment			
Managing social concerns/lack of social support			
Learning strategies to increase self-care activities (e.g. sleep, diet, exercise)			
Managing sexual and reproductive concerns			
Finding resources to help with daily concerns (e.g. finding PCP, childcare, assist with financial costs of healthcare and treatment, etc.)			
Other, please describe:			