

Appendix 1 France (n=111).

Symptoms	n	Frequency ≥ Rank	sometimes n (%)	Impact ≥ Rank	moderate n (%)	Impact ≥ moderate and frequency ≥ sometimes (%)
Fatigue	111	1	107 (96)	1	99 (91)	94
Raynaud's phenomenon	110	2	94 (85)	3	85 (78)	91
Joint pain	111	3	93 (84)	2	86 (79)	95
Tender joints	108	4	83 (77)	6	73 (68)	88
Difficulty sleeping	110	5	84 (76)	5	74 (68)	89
Stiffness of hands	107	6	81 (76)	4	76 (71)	94
Erectile dysfunction	4	7	3 (75)	20	2 (50)	67
Muscle pain	107	8	79 (74)	7	72 (67)	91
Dry mouth	107	9	79 (74)	19	54 (50)	69
Shortness of breath	107	10	78 (73)	NA	NA	NA
Heartburn	110	11	78 (71)	10	68 (62)	87
Difficulty holding objects	108	12	76 (70)	9	67 (63)	89
Difficulty climbing stairs	109	13	75 (69)	11	64 (60)	88
Skin tightening	110	14	75 (68)	13	63 (58)	85
Vaginal dryness	103	15	70 (68)	15	50 (54)*	83
Swollen joints	106	16	72 (68)	8	69 (65)	96
Dilated hand vessels	106	17	70 (66)	14	58 (56)	85
Difficulty making fist	107	18	67 (63)	12	63 (59)	94
Dry eyes	109	19	68 (62)	16	56 (52)	84
Itching	108	20	66 (61)	30	35 (33)	55
Difficulty concentrating	109	21	66 (61)	18	55 (51)	85
Numbness	111	22	67 (60)	22	51 (46)	77
Difficulty remembering	107	23	63 (59)	27	44 (42)	71
Difficulty walking	109	24	61 (56)	17	56 (51)	92
Skin color change	110	25	60 (55)	35	23 (21)	39
Diarrhoea	107	26	58 (54)	23	49 (46)	86
Difficulty opening hand	108	27	58 (54)	21	50 (47)	89
Skin pain	105	28	56 (53)	28	40 (38)	73
Difficulty swallowing	107	29	57 (53)	26	44 (42)	79
Constipation	110	30	57 (52)	25	46 (42)	81
Side effects	108	31	53 (49)	24	45 (42)	87
Persistent coughing	109	32	53 (49)	NA	NA	NA
Dilated face vessels	107	33	52 (49)	34	27 (25)	52
Nausea	108	34	48 (44)	32	34 (31)	71
Difficulty in/out car	110	35	46 (42)	29	39 (36)	87
Difficulty dressing	110	36	45 (41)	33	34 (31)	76
Difficulty opening mouth	110	37	43 (39)	31	36 (33)	84
Finger ulcers	110	38	40 (36)	38	12 (13)*	46
Weight loss	110	39	29 (26)	37	23 (21)	79
Open sores	110	40	24 (22)	36	23 (21)	96

* >5% missing; NA: not administered in the French version of the survey due to technical failure.

Appendix 2 The Netherlands (n=229).

Symptoms	n	Frequency ≥	sometimes	Impact ≥	moderate	Impact ≥ moderate and
		Rank	n (%)	Rank	n (%)	frequency ≥ sometimes (%)
Fatigue	226	1	214 (95)	1	180 (80)	84
Raynaud's phenomenon	227	2	205 (90)	2	160 (71)	79
Stiffness of hands	226	3	187 (83)	3	153 (68)	82
Joint pain	228	4	182 (80)	4	134 (59)	74
Erectile dysfunction	28	5	21 (75)	7	14 (50)	67
Skin tightening	229	6	171 (75)	12	108 (47)	63
Difficulty holding objects	227	7	164 (72)	5	124 (55)	76
Tender joints	226	8	161 (71)	13	106 (47)	66
Muscle pain	227	9	160 (70)	9	112 (49)	70
Dry mouth	226	10	157 (69)	18	78 (35)	50
Difficulty sleeping	226	11	155 (69)	11	109 (48)	70
Difficulty climbing stairs	227	12	154 (68)	10	111 (49)	73
Difficulty making fist	227	13	151 (67)	14	98 (43)	65
Shortness of breath	226	14	148 (65)	8	112 (50)	76
Dry eyes	226	15	139 (62)	23	70 (31)	50
Difficulty walking	227	16	139 (61)	6	115 (51)	83
Heartburn	226	17	134 (59)	24	70 (31)	52
Skin color change	228	18	134 (59)	35	46 (20)	34
Skin pain	229	19	132 (58)	19	78 (35)	60
Diarrhoea	225	20	127 (56)	22	71 (32)	56
Difficulty swallowing	227	21	127 (56)	15	83 (37)	65
Difficulty concentrating	226	22	125 (55)	16	83 (36)	66
Dilated hand vessels	228	23	125 (55)	32	49 (21)	39
Vaginal dryness	180	24	95 (53)	25	55 (31)	58
Numbness	225	25	116 (52)	30	54 (24)	47
Difficulty opening hand	227	26	116 (51)	20	77 (34)	66
Difficulty in/out car	227	27	115 (51)	26	66 (29)	58
Difficulty remembering	226	28	110 (49)	27	64 (28)	58
Itching	229	29	111 (48)	39	28 (12)	25
Swollen joints	227	30	110 (48)	17	81 (36)	74
Nausea	227	31	104 (46)	31	54 (24)	52
Difficulty opening mouth	226	32	99 (44)	29	59 (26)	60
Constipation	224	33	95 (42)	36	44 (20)	47
Dilated face vessels	229	34	96 (42)	40	22 (10)	23
Side effects	225	35	93 (41)	28	60 (27)	65
Finger ulcers	227	36	85 (37)	21	73 (32)	86
Persistent coughing	225	37	84 (37)	37	42 (19)	50
Difficulty dressing	227	38	72 (32)	34	48 (21)	67
Open sores	229	39	70 (31)	33	49 (21)	70
Weight loss	227	40	64 (28)	38	30 (13)	47

Appendix 3 Spain (n=61).

Symptoms	n	Frequency ≥	sometimes	Impact ≥	moderate	Impact ≥ moderate and frequency ≥ sometimes
		Rank	n (%)	Rank	n (%)	(%)
Shortness of breath	49	1	42 (86)	17	16 (44)*	55
Raynaud's phenomenon	51	2	43 (84)	4	32 (65)	78
Joint pain	42	3	34 (81)	3	29 (69)	85
Skin color change	45	4	35 (78)	22	18 (41)	53
Persistent coughing	51	5	39 (76)	29	12 (34)*	52
Muscle pain	42	6	32 (76)	1	30 (71)	94
Fatigue	50	7	38 (76)	8	29 (58)	76
Difficulty concentrating	51	8	38 (75)	15	23 (47)	64
Heartburn	45	9	33 (73)	2	32 (71)	97
Skin tightening	44	10	32 (73)	6	26 (59)	81
Difficulty sleeping	49	11	39 (80)	10	30 (58)	81
Itching	43	12	30 (70)	5	26 (60)	87
Swollen joints	43	13	30 (70)	7	25 (58)	83
Numbness	51	14	35 (69)	14	23 (47)	70
Difficulty climbing stairs	45	15	28 (62)	12	24 (53)	86
Difficulty remembering	50	16	31 (62)	19	21 (44)	72
Vaginal dryness	42	17	26 (62)	28	13 (35)*	57
Difficulty walking	45	18	27 (60)	9	26 (58)	96
Stiffness of hands	44	19	26 (59)	11	25 (57)	96
Finger ulcers	50	20	28 (56)	13	26 (53)	96
Difficulty swallowing	45	21	25 (56)	24	18 (40)	72
Difficulty dressing	45	22	25 (56)	23	18 (41)	75
Dry mouth	44	23	24 (55)	30	14 (33)	64
Constipation	50	24	27 (54)	34	16 (33)	62
Dry eyes	45	25	24 (53)	16	21 (47)	88
Diarrhoea	51	26	27 (53)	33	16 (33)	64
Difficulty holding objects	45	27	23 (51)	18	20 (44)	87
Erectile dysfunction	12	28	6 (50)	21	5 (42)	83
Difficulty in/out car	45	29	22 (49)	20	19 (42)	86
Dilated hand vessels	45	30	22 (49)	36	12 (27)	57
Tender joints	43	31	21 (49)	25	17 (40)	81
Dilated face vessels	44	32	20 (45)	35	14 (32)	70
Skin pain	42	33	19 (45)	26	16 (39)	89
Side effects	51	34	22 (43)	31	17 (33)	77
Difficulty making fist	41	35	17 (41)	27	16 (39)	94
Difficulty opening mouth	52	36	21 (40)	37	12 (24)*	67
Difficulty opening hand	45	37	18 (40)	32	15 (33)	83
Open sores	45	38	18 (40)	39	6 (16)*	55
Nausea	50	39	17 (34)	38	8 (17)	53
Weight loss	51	40	16 (31)	40	6 (12)	43

* >5% missing.

Appendix 4 Switzerland (n=50).

Symptoms	n	Frequency ≥	sometimes	Impact ≥	moderate	Impact ≥ moderate and
		Rank	n (%)	Rank	n (%)	frequency ≥ sometimes (%)
Erectile dysfunction	1	1	1 (100)	1	1 (100)	100
Fatigue	48	2	41 (85)	5	26 (54)	63
Shortness of breath	44	3	37 (84)	4	17 (55)*	71
Raynaud's phenomenon	47	4	39 (83)	8	21 (50)*	62
Joint pain	46	5	38 (83)	2	28 (65)*	80
Difficulty sleeping	49	6	39 (80)	9	24 (49)	62
Difficulty remembering	48	7	38 (79)	21	19 (40)	51
Skin tightening	43	8	34 (79)	11	20 (49)	63
Muscle pain	42	9	33 (79)	3	22 (55)	71
Difficulty concentrating	48	10	37 (77)	10	23 (49)	64
Difficulty swallowing	43	11	33 (77)	20	17 (40)	53
Vaginal dryness	29	12	22 (76)	19	9 (41)*	60
Heartburn	43	13	32 (74)	6	22 (54)	73
Persistent coughing	45	14	33 (73)	34	5 (21)*	42
Difficulty climbing stairs	44	15	32 (73)	16	20 (45)	63
Stiffness of hands	44	16	32 (73)	18	17 (44)*	63
Itching	42	17	29 (69)	31	11 (28)	41
Dry mouth	42	18	29 (69)	28	13 (31)	46
Tender joints	45	19	31 (69)	12	21 (48)	70
Difficulty walking	44	20	29 (66)	7	23 (52)	79
Dry eyes	44	21	29 (66)	17	19 (44)	68
Constipation	43	22	28 (65)	33	9 (23)*	36
Numbness	46	23	29 (63)	15	20 (45)	74
Difficulty holding objects	43	24	27 (63)	13	20 (47)	74
Difficulty in/out car	44	25	27 (61)	27	14 (32)	52
Diarrhoea	45	26	27 (60)	29	13 (30)	52
Swollen joints	46	27	26 (57)	14	21 (46)	81
Nausea	44	28	24 (55)	32	10 (26)*	56
Skin pain	45	29	24 (53)	23	15 (34)	65
Finger ulcers	38	30	19 (50)	22	13 (36)*	76
Difficulty making fist	45	31	22 (49)	26	14 (32)	67
Dilated hand vessels	43	32	19 (44)	35	8 (20)*	50
Difficulty dressing	44	33	18 (41)	30	12 (28)	71
Difficulty opening hand	44	34	18 (41)	24	15 (34)	83
Side effects	49	35	20 (41)	25	16 (33)	80
Skin colour change	43	36	17 (40)	39	6 (14)	38
Difficulty opening mouth	44	37	17 (39)	38	8 (19)	50
Open sores	44	38	17 (39)	36	8 (20)*	57
Weight loss	38	39	14 (37)	37	7 (19)*	58
Dilated face vessels	42	40	10 (24)	40	2 (5)	20

* >5% missing.

Appendix 5 United Kingdom (n=86).

Symptoms	n	Frequency ≥	sometimes	Impact ≥	moderate	Impact ≥ moderate and frequency ≥ sometimes
		Rank	n (%)	Rank	n (%)	(%)
Erectile dysfunction	9	1	9 (100)	1	9 (89)	89
Raynaud's phenomenon	83	2	81 (98)	3	62 (76)	78
Fatigue	85	3	79 (93)	2	72 (86)	92
Joint pain	83	4	76 (92)	4	61 (74)	81
Stiffness of hands	82	5	75 (91)	5	56 (68)	75
Muscle pain	81	6	70 (86)	7	54 (68)	78
Difficulty holding objects	81	7	69 (85)	9	52 (64)	75
Difficulty sleeping	85	8	71 (84)	6	57 (68)	81
Tender joints	82	9	65 (79)	11	48 (59)	75
Dry mouth	82	10	65 (79)	26	34 (41)	53
Skin tightening	85	11	67 (79)	8	54 (65)	83
Heartburn	84	12	64 (76)	19	42 (51)	67
Shortness of breath	83	13	63 (76)	15	43 (52)	69
Difficulty making fist	83	14	63 (76)	10	51 (61)	81
Difficulty concentrating	84	15	63 (75)	16	44 (52)	70
Dilated hand vessels	85	16	63 (74)	22	38 (45)	61
Skin color change	84	17	61 (73)	28	30 (36)	50
Difficulty remembering	84	18	59 (70)	23	36 (43)	61
Difficulty swallowing	80	19	56 (70)	17	41 (51)	73
Difficulty climbing stairs	75	20	51 (68)	13	40 (53)	78
Dry eyes	82	21	55 (67)	24	35 (43)	64
Itching	84	22	56 (67)	37	22 (27)	41
Diarrhoea	84	23	56 (67)	18	43 (51)	77
Swollen joints	84	24	55 (65)	12	46 (55)	85
Constipation	85	25	54 (64)	20	41 (48)	76
Difficulty walking	81	26	51 (63)	14	43 (53)	84
Difficulty opening hand	82	27	49 (60)	21	39 (48)	80
Difficulty in/out car	82	28	48 (59)	31	29 (35)	60
Vaginal dryness	65	29	38 (58)	27	24 (38)	65
Skin pain	84	30	49 (58)	25	35 (42)	73
Difficulty dressing	83	31	46 (55)	34	25 (30)	56
Numbness	84	32	45 (54)	30	30 (36)	67
Dilated face vessels	85	33	41 (48)	39	17 (20)	43
Nausea	83	34	39 (47)	33	25 (30)	66
Persistent coughing	84	35	38 (45)	35	25 (30)	68
Difficulty opening mouth	85	36	37 (44)	38	22 (26)	61
Side effects	85	37	35 (41)	36	25 (29)	71
Finger ulcers	83	38	31 (37)	29	30 (36)	97
Open sores	83	39	29 (35)	32	26 (31)	90
Weight loss	84	40	21 (25)	40	13 (15)	62