

Supplementary Materials

Patient Experience with Chronic Refractory Gout and its Impact on Health-Related Quality of Life: Literature Review and Qualitative Analysis

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Supplemental Table 1 Signs and symptoms of chronic refractory gout: bothersome ratings and meaningful change as reported by participants

Sign/symptom	Spontaneous <i>n</i> (%)	Probed <i>n</i> (%)	Total sample (<i>N</i> = 20)	Bothersome rating			Meaningful change, <i>n</i> (%)			
				<i>N</i> rating	Mean (SD)	Median	Severity	Frequency	Duration	Other
Bodily pain	17 (85.0%)	1 (5.0%)	18 (90.0%)	18 (90.0%)	8.7 (1.7)	10.0	7 (35.0%)	3 (15.0%)	–	–
Joint swelling	8 (40.0%)	10 (50.0%)	18 (90.0%)	18 (90.0%)	7.8 (2.7)	8.0	11 (55.0%)	3 (15.0%)	1 (5.0%)	4 (20.0%)
Joint tenderness	4 (20.0%)	14 (70.0%)	18 (90.0%)	18 (90.0%)	8.9 (1.5)	10.0	9 (45.0%)	1 (5.0%)	–	5 (25.0%)
Joint pain	8 (40.0%)	8 (40.0%)	16 (80.0%)	16 (80.0%)	9.1 (1.3)	10.0	7 (35.0%)	7 (35.0%)	1 (5.0%)	–
Tophi	7 (35.0%)	7 (35.0%)	14 (70.0%)	14 (70.0%)	8.4 (2.7)	10.0	10 (50.0%)	3 (15.0%)	1 (5.0%)	–
Joint stiffness	2 (10.0%)	12 (60.0%)	14 (70.0%)	14 (70.0%)	8.4 (1.6)	8.5	3 (15.0%)	3 (15.0%)	1 (5.0%)	4 (20.0%)
Muscle weakness	–	9 (45.0%)	9 (45.0%)	9 (45.0%)	8.4 (2.0)	8.5	4 (20.0%)	2 (10.0%)	1 (5.0%)	–
Joint redness/heat	5 (25.0%)	–	5 (25.0%)	4 (20.0%)	–	–	–	–	–	–
Cramps	1 (5.0%)	–	1 (5.0%)	1 (5.0%)	10.0 (0)	10.0	–	–	–	–
Difficulty breathing	1 (5.0%)	–	1 (5.0%)	1 (5.0%)	10.0 (0)	10.0	1 (5.0%)	1 (5.0%)	–	–
Itching	1 (5.0%)	–	1 (5.0%)	1 (5.0%)	10.0 (0)	10.0	–	–	–	–
Kidney stones	1 (5.0%)	–	1 (5.0%)	1 (5.0%)	10.0 (0)	10.0	–	–	–	–
Loss of finger movement	1 (5.0%)	–	1 (5.0%)	1 (5.0%)	10.0 (0)	10.0	–	–	–	–

SD standard deviation

Supplemental Table 2 Impacts of chronic refractory gout: bothersome ratings and meaningful change as reported by participants

Impact	Spontaneous <i>n</i> (%)	Probed <i>n</i> (%)	Total sample (<i>N</i> = 20)	Bothersome rating		Meaningful change <i>n</i> (%) ^a			
				Mean (SD)	Median	Frequency	Difficulty doing activity	Pain	Other
Daily activities (general)	4 (20.0%)	12 (60.0%)	16 (80.0%)	–	–	–	–	–	–
Ability to do chores	3 (15.0%)	16 (80.0%)	19 (95.0%)	7.9 (2.1)	8.0	–	2 (10.0%)	1 (5.0%)	–
Ability to run errands/shop	3 (15.0%)	16 (80.0%)	19 (95.0%)	8.3 (1.8)	8.0	5 (25.0%)	3 (15.0%)	3 (15.0%)	–
Dressing self	1 (5.0%)	14 (70.0%)	15 (75.0%)	8.8 (1.8)	10.0	3 (15.0%)	4 (20.0%)	–	–
Activities done in free time	3 (15.0%)	12 (60.0%)	15 (75.0%)	8.6 (2.1)	10.0	–	3 (15.0%)	–	–
Ability to get in/out of car	2 (10.0%)	12 (60.0%)	14 (70.0%)	8.6 (1.7)	9.0	–	3 (15.0%)	3 (15.0%)	–
Gripping and twisting objects	3 (15.0%)	9 (45.0%)	12 (60.0%)	9.2 (1.1)	10.0	3 (15.0%)	2 (10.0%)	1 (5.0%)	–
Open previously opened jars	1 (5.0%)	11 (55.0%)	12 (60.0%)	8.9 (1.1)	9.0	2 (10.0%)	1 (5.0%)	2 (10.0%)	–
Cutting own food	0	8 (40.0%)	8 (40.0%)	8.0 (2.7)	10.0	2 (10.0%)	1 (5.0%)	–	–
Lifting full cup to mouth	0	8 (40.0%)	8 (40.0%)	8.1 (2.3)	9.0	2 (10.0%)	2 (10.0%)	–	–
Open a new carton of milk	0	8 (40.0%)	8 (40.0%)	9.3 (0.8)	9.0	–	1 (5.0%)	1 (5.0%)	–
Ability to drive	7 (35.0%)	0	7 (35.0%)	–	–	–	1 (5.0%)	1 (5.0%)	–
Ability to open car doors	0	7 (35.0%)	7 (35.0%)	8.6 (1.5)	9.0	–	2 (10.0%)	–	–
Turning faucets on and off	0	5 (25.0%)	5 (25.0%)	5.3 (2.6)	5.0	1 (5.0%)	2 (10.0%)	–	–
Affects appearance	0	16 (80.0%)	16 (80.0%)	7.4 (3.0)	8.0	–	–	1 (5.0%)	2 (10.0%)
Emotional impacts (general)	4 (20.0%)	15 (75.0%)	19 (95.0%)	–	–	–	–	–	–
Feel worn out	0	16 (80.0%)	16 (80.0%)	–	–	–	–	–	–
Full of pep	0	16 (80.0%)	16 (80.0%)	–	–	–	–	–	–

Feel calm or peaceful	0	15 (75.0%)	15 (75.0%)	–	–	–	–	–	–
Feel happy	0	15 (75.0%)	15 (75.0%)	–	–	–	–	–	–
Feel tired	0	14 (70.0%)	14 (70.0%)	–	–	–	–	–	–
Have a lot of energy	0	14 (70.0%)	14 (70.0%)	–	–	–	–	–	–
Feel down in the dumps	0	12 (60.0%)	12 (60.0%)	–	–	–	–	–	–
Feel very nervous	0	11 (55.0%)	11 (55.0%)	–	–	–	–	–	–
Feel downhearted and blue	0	9 (45.0%)	9 (45.0%)	–	–	–	–	–	–
Feel embarrassed	2 (10.0%)	0	2 (10.0%)	–	–	–	–	–	–
Hygiene									
Ability to shower/wash/dry body	7 (35.0%)	9 (45.0%)	16 (80.0%)	9.1 (1.7)	10.0	2 (10.0%)	6 (30.0%)	2 (10.0%)	–
Ability to go to the bathroom	5 (25.0%)	9 (45.0%)	14 (70.0%)	9.4 (1.4)	10.0	1 (5.0%)	5 (25.0%)	–	–
Ability to take a bath	1 (5.0%)	12 (60.0%)	13 (65.0%)	8.4 (1.9)	9.0	2 (10.0%)	3 (15.0%)	2 (10.0%)	–
Ability to shampoo hair	1 (5.0%)	6 (30.0%)	7 (35.0%)	8.4 (2.1)	9.0	–	1 (5.0%)	–	–
Physical impacts									
Climbing five steps	0	19 (95.0%)	19 (95.0%)	9.0 (1.6)	10.0	–	6 (30.0%)	4 (20.0%)	–
Putting on shoes	14 (70.0%)	5 (25.0%)	19 (95.0%)	9.0 (1.3)	10.0	1 (5.0%)	5 (25.0%)	6 (30.0%)	2 (10.0%)
Walking outdoors on flat ground (general)	14 (70.0%)	5 (25.0%)	19 (95.0%)	9.6 (1.1)	10.0	–	9 (45.0%)	6 (30.0%)	3 (15.0%)
Standing up from a chair	1 (5.0%)	17 (85.0%)	18 (90.0%)	8.9 (1.5)	10.0	2 (10.0%)	7 (35.0%)	4 (20.0%)	1 (5.0%)
Bending down to lift/carry groceries	0	18 (90.0%)	18 (90.0%)	7.7 (2.1)	8.0	2 (10.0%)	4 (20.0%)	–	1 (5.0%)
Getting in/out of bed	4 (20.0%)	14 (70.0%)	18 (90.0%)	8.4 (1.9)	9.0	–	4 (20.0%)	4 (20.0%)	3 (15.0%)
Climbing a flight of stairs ^b	0	20 (100.0%)	20 (100.0%)	8.6 (1.7)	10.0	–	4 (20.0%)	3 (15.0%)	–
Bending down to pick up clothing from the floor	0	15 (75.0%)	15 (75.0%)	8.9 (1.4)	10.0	3 (15.0%)	2 (10.0%)	–	1 (5.0%)
Bending	1 (5.0%)	14 (70.0%)	15 (75.0%)	8.5 (1.7)	9.0	–	5 (25.0%)	2 (10.0%)	–
Climbing several flights of stairs ^c	0	20 (100.0%)	20 (100.0%)	8.6 (1.7)	10.0	–	2 (10.0%)	3 (15.0%)	–

Kneeling	0	12 (60.0%)	12 (60.0%)	8.0 (2.2)	8.0	1 (5.0%)	2 (10.0%)	1 (5.0%)	–
Stooping	0	11 (55.0%)	11 (55.0%)	8.0 (1.9)	8.0	1 (5.0%)	3 (15.0%)	1 (5.0%)	–
Picking up 5lb object from above head	0	11 (55.0%)	11 (55.0%)	8.4 (2.1)	9.5	1 (5.0%)	2 (10.0%)	1 (5.0%)	–
Sex life	1 (5.0%)	7 (35.0%)	8 (40.0%)	9.4 (1.0)	10.0	4 (20.0%)	2 (10.0%)	–	–
Sleep impacts	15 (75.0%)	3 (15.0%)	18 (90.0%)	8.8 (2.1)	10.0	2 (10.0%)	4 (20.0%)	1 (5.0%)	–
Affect social life	3 (15.0%)	14 (70.0%)	17 (85.0%)	8.7 (2.2)	9.0	3 (15.0%)	2 (10.0%)	1 (5.0%)	–

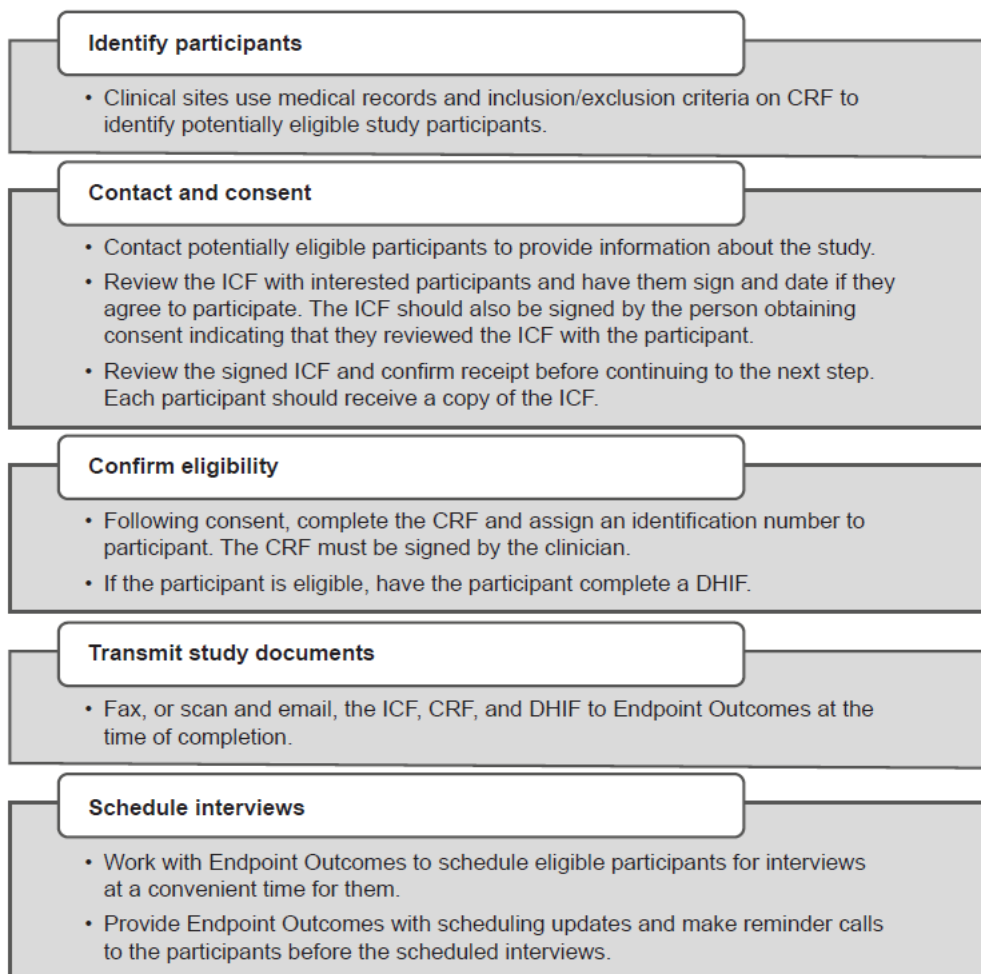
^aSome participants endorsed more than one way in which a meaningful change could occur

^bThe majority of participants ($n = 14$, 70.0%) were asked directly about climbing a flight of stairs. Some participants ($n = 6$, 30.0%) were not asked about climbing a flight of stairs, because it was determined they would be affected given they reported having difficulty climbing five steps

^cThe majority of participants ($n = 13$, 65.0%) were asked directly about climbing several flights of stairs. Some participants ($n = 7$, 35.0%) were not asked about climbing several flights of stairs, because it was determined they would be affected given they reported difficulty climbing five steps

SD standard deviation

Supplementary Figure 1 Recruitment process



CRF case report form; *ICF* informed consent form; *DHIF* demographic and health information form