#### Supplementary material

S1. Survey questions

#### Demographic information

What is your age in years? ▼ Under 16 ... 100 or older

What is your gender? ▼ Male, Female, Other

#### Pain-related characteristics

Have you been experiencing pain on most days for three months or more?

**O**YES

O NO

On average, for how many **hours** per day do you normally feel pain? Please answer using **numbers**. For example, half an hour would be ".5", and two hours would be "2". Hours per day

For approximately how long have you been experiencing pain? Please answer in **years** and **months**. For example, 6 months would be "0" years and "6" months. Years

Months

Where in your body have you felt pain **over the last week**. You can select as many responses as you like so please select all that apply.

Left arm and/or hand

C Left leg and/or foot

| J | Right | arm | and/ | or | hand |  |
|---|-------|-----|------|----|------|--|
|---|-------|-----|------|----|------|--|

ORight leg and/or foot

Back

O Stomach/abdomen

O Chest

O Groin/genitals

O Neck

O Head

Other (Please specify. You can specify more than one thing if you wish)

For each of the body parts that you have selected, please rate your **average** level of pain that you have experienced in that body part **over the last week**.

No pain Worst pain imaginable 0 1 2 3 4 5 6 7 8 9 10

Please rate your average level of pain that you have experienced in your body OVERALL over the last week (that is, averaged across all your painful body parts).

| No | o pa | in |   |   | Wo | orst pain imaginable |   |   |   |    |  |  |
|----|------|----|---|---|----|----------------------|---|---|---|----|--|--|
| 0  | 1    | 2  | 3 | 4 | 5  | 6                    | 7 | 8 | 9 | 10 |  |  |
|    | _    | _  | _ | _ | _  | _                    | - | _ | _ | _  |  |  |
| _  | _    | _  | _ | _ |    | _                    | _ | _ | _ |    |  |  |

Have you received a medical diagnosis for your pain condition? Here, a medical diagnosis is a diagnosis that has been determined by a medical practitioner such as a GP, specialist doctor (e.g. rheumatologist or pain specialist), physiotherapist, occupational therapist, or nurse.

 $\bigcirc$  yes  $\bigcirc$  NO

Please select all medical diagnoses that you have received for your pain condition.

Complex Regional Pain Syndrome (also known as Reflex Sympathetic Dystrophy, Causalgia, or Sudeck's syndrome)

O Rheumatoid Arthritis

Osteoarthritis

O Plantar fasciitis

) Fibromyalgia

O Hypermobility

O Back pain

Migraine

| O Cluster Headache  |
|---|
| O Multiple Sclerosis  |
| O Neuralgia   |
| O Stomach ulcer   |
| OEndometriosis  |
| O Irritable Bowel Disease   |
| O Crohn's Disease   |
| Other (Please specify. You can specify more than one thing if you wish)   |
| O I have not received any diagnosis for my pain condition   |
| You answered that you have received a medical diagnosis of <i>[diagnosis that was selected]</i> . Which medical practitioner diagnosed you with this condition (if you recall). Please select ALL that apply. |
| ◯ GP  |
| O Specialist doctor (e.g. rheumatologist or pain specialist)  |
| O Physiotherapist   |
| Occupational therapist  |
| O Nurse   |
| Other (Please specify)  |
| O Don't know/can't remember   |
| Was there an event or injury that triggered the onset of your pain condition(s)?  |
| <b>O</b> YES  |
| O NO  |
| What was the event or injury that triggered the onset of your pain condition(s)?  |

O Sprain

O Fracture

O Dislocation

Surgery

🔵 Childbirth

O Stressful situation such as bereavement, divorce, or loss of job (please specify. You can specify more than one thing if you wish)

Other (Please specify. You can specify more than one thing if you wish)

#### **Bodily changes**

Have you experienced any of the following [since the onset of your pain condition/over the past two years]\*. Please only select those things that have **started to bother you** or have **become worse** since the onset of your pain condition. Select ANY that apply.

\* Respondents only saw one of the two options based on whether they reported to have chronic pain or not.

Blurred vision

O Needing to change your glasses or contact lens prescription more often

O Peripheral vision loss

O Sensitivity to bright lights

UHearing loss

O Tinnitus (Ringing in the ears)

O Sensitivity to loud noises

O Losing hair on your head

O Losing hair on parts of your body other than your head

Extra hair growth on any part of your body

Skin rashes

Being more susceptible to sunburn

Changes in the texture of your skin

Changes in skin colour

Swelling (edema) in any body part

O Changes in the nails of your hands (e.g. growing faster or slower, or being more brittle)

Changes in your toenails (e.g. growing faster or slower, or being more brittle)

O Allergic reactions on the skin

O Increased susceptibility to illness (for example, becoming more frequently ill, or taking longer to recover from illness)

O Finding your skin takes longer to heal when cut or bruised

O Needing to urinate more often, or finding it difficult from stopping yourself urinate when you 'need to go'

O Needing to urinate less often, or finding it difficult to urinate

O Loose bowels, diarrhoea, or needing to defecate more often

Constipation

- Having a "sensitive stomach"
- O Nausea

O Increase in weight

O Decrease in weight

Allergic reactions to food and drink

O Decreased alcohol tolerance

- Increased alcohol tolerance
- Weakness in any part of your body
- Tremor in any part of your body
- O Problems with balance
- Falling more frequently
- O Difficulties walking
- O Sweating more
- O Sweating less
- O Dizziness
- O Hay fever

O Loss of sexual desire

O Increased sexual desire

 $\bigcirc$  Feeling unusually cold, or finding it difficult to get warm when you are cold

Feeling unusually hot, or finding it difficult to cool down when you are hot

O Please specify anything else that you have experienced. Even if you have experienced a change to your body or its sensations that you think is odd, unusual, or sounds "a bit crazy", we are interested in hearing about it. You can specify more than one thing if you wish. In the next question you will have an opportunity to explain more about the changes and how they make you feel if you wish. Here, please just list any additional changes if there are any.

#### Sensory sensitivity

Do any of the following give you pain? Please select ANY that apply.\*

Do any of the following give you discomfort? Please select ANY that apply.\*

Do any of the following give you distress? Please select ANY that apply.\*

Do any of the following make your pain worse? Please select ANY that apply.\*

\* The list of items below was used for each of the previous four questions:

| Caffeine  |
|---|
| Alcohol   |
| O Bright lights   |
| O Flashing lights   |
| O High-contrast images, such as black and white stripes spaced close together             |
| O Loud or unpleasant noises   |
| O The touch of clothing/water/breeze  |
| O Particular foods. If yes, please specify  |
| O Particular smells. If yes, please specify   |
| O Cold weather. if yes, then please specify from what temperature your pain starts        |
| O Warm or hot weather. If yes, then please specify from what temperature your pain starts |
| Other (Please specify. You can specify more than one thing if you wish)                   |

# Patient Health Questionnaire (PHQ-9)

|   | Not at all | Several days | More than half days | Nearly every<br>day |
|---|------------|--------------|---------------------|---------------------|
| Little interest or pleasure in doing things   | 0          | $\bigcirc$   | $\bigcirc$          | 0                   |
| Feeling down, depressed, or hopeless  | 0          | 0            | $\bigcirc$          | 0                   |
| Trouble falling/staying asleep, sleeping too much   | 0          | $\bigcirc$   | $\bigcirc$          | $\bigcirc$          |
| Feeling tired or having little energy   | 0          | $\bigcirc$   | 0                   | 0                   |
| Poor appetite or overeating   | 0          | $\bigcirc$   | $\bigcirc$          | 0                   |
| Feeling bad about yourself – or that you<br>are a failure or have let yourself or your<br>family down       | 0          | $\bigcirc$   | 0                   | 0                   |
| Trouble concentrating on things, such as<br>reading the newspaper or watching<br>television                 | 0          | $\bigcirc$   | 0                   | 0                   |
| Moving or speaking so slowly that other people could have noticed   | 0          | $\bigcirc$   | 0                   | 0                   |
| Or the opposite – being so fidgety or<br>restless that you have been moving<br>around a lot more than usual | 0          | 0            | 0                   | $\bigcirc$          |
| Thoughts that you would be better off<br>dead or of hurting yourself in some way                            | 0          | $\bigcirc$   | $\bigcirc$          | 0                   |

Over the last 2 weeks, how often have you been bothered by any of the following problems?

# Generalized Anxiety Disorder (GAD-7)

|   | Not at all | Several days | More than half days | Nearly every<br>day |
|---|------------|--------------|---------------------|---------------------|
| Feeling nervous, anxious, or on edge              | 0          | 0            | $\bigcirc$          | 0                   |
| Not being able to stop or control worrying        | 0          | $\bigcirc$   | 0                   | 0                   |
| Worrying too much about different things          | 0          | $\bigcirc$   | $\bigcirc$          | $\bigcirc$          |
| Trouble relaxing                                  | 0          | $\bigcirc$   | 0                   | $\bigcirc$          |
| Being so restless that it's hard to sit still     | 0          | $\bigcirc$   | $\bigcirc$          | $\bigcirc$          |
| Becoming easily annoyed or irritable              | 0          | $\bigcirc$   | $\bigcirc$          | $\bigcirc$          |
| Feeling afraid as if something awful might happen | 0          | $\bigcirc$   | $\bigcirc$          | $\bigcirc$          |

Over the last 2 weeks, how often have you been bothered by any of the following problems?

## Patient Health Questionnaire-15 (PHQ-15)

|  | Not b                  | othered at all    | Bothered a lit | tle B             | othered a lot  |
|--|------------------------|-------------------|----------------|-------------------|----------------|
| Stomach pain   |                        | 0                 | 0              |                   | 0              |
| Back pain  |                        | 0                 | 0              |                   | 0              |
| Pain in your arms, leg<br>or joints (knees, hip<br>etc.) |                        | 0                 | 0              |                   | 0              |
| Menstrual cramps o<br>other problems with y<br>periods   |                        | 0                 | 0              |                   | 0              |
| Headaches  |                        | 0                 | 0              |                   | 0              |
| Chest pain   |                        | 0                 | 0              |                   | 0              |
| Dizziness  |                        | 0                 | 0              |                   | 0              |
| Fainting spells  |                        | 0                 | 0              |                   | 0              |
| Feeling your heart por<br>or race                        | und                    | $\bigcirc$        | 0              |                   | 0              |
| Shortness of breath                                      | L                      | $\bigcirc$        | $\bigcirc$     |                   | 0              |
| Constipation, loose<br>bowels, or diarrhoe               |                        | 0                 | $\bigcirc$     |                   | 0              |
| Nausea, gas, or indigestion                              |                        | $\bigcirc$        | $\bigcirc$     |                   | 0              |
| Feeling tired or havin<br>low energy                     | ng                     | $\bigcirc$        | 0              |                   | $\bigcirc$     |
| Trouble sleeping   |                        | $\bigcirc$        | 0              |                   | 0              |
| 1  | Not bothered<br>at all | Bothered a little | Bothered a lot | Prefer not to say | Not applicable |

During the past 4 weeks, how much have you been bothered by any of the following problems?

|  | at all | little | Bothered a lot | say | Not applicable |
|--|--------|--------|----------------|-----|----------------|
| Pain or problems<br>during sexual<br>intercourse | 0      | 0      | 0              | 0   | 0              |

#### S2. 'Other' pain-related medical diagnoses

**Supplementary Table 1.** Numbers and percentages of people who reported one or more pain-related medical diagnoses in the 'other' box, that were grouped in the categories listed below. We categorized the diagnoses based on the coding system for medical research categorisation, outlined by UK Clinical Research Collaboration (<u>https://hrcsonline.net/health-categories/</u>). Note that these also include spontaneously reported *non pain-related* medical diagnoses, even though this was not asked for.

|                                    | CRPS                      | Fibromyalgia      | CRPS+            | Pain controls     |
|------------------------------------|---------------------------|-------------------|------------------|-------------------|
|                                    | ( <i>N</i> = <b>390</b> ) | ( <i>N</i> = 452) | Fibromyalgia     | ( <i>N</i> = 311) |
|                                    |                           |                   | ( <i>N</i> = 88) |                   |
| Musculoskeletal                    | 41 (10.5%)                | 76 (16.8%)        | 10 (11.3%)       | 59 (19.0%)        |
| Neurological                       | 11 (2.8%)                 | 27 (6.0%)         | 8 (9.0%)         | 37 (11.9%)        |
| Inflammatory and immune system     | 8 (2.1%)                  | 23 (5.1%)         | 5 (5.6%)         | 8 (2.6%)          |
| Oral and gastrointestinal          | 6 (1.5%)                  | 14 (3.1%)         | 5 (5.6%)         | 6 (1.9%)          |
| Blood                              | 4 (1.0%)                  | 1 (0.2%)          | 2 (2.3%)         | 1 (0.3%)          |
| Injuries and accidents             | 3 (0.8%)                  | 4 (0.9%)          | 2 (2.3%)         | 14 (4.5%)         |
| Reproductive health and childbirth | 2 (0.5%)                  | 8 (1.8%)          | 2 (2.3%)         | 4 (1.3%)          |
| Renal and urogenital               | 2 (0.5%)                  | 3 (0.7%)          | 2 (2.3%)         | 1 (0.3%)          |
| Metabolic and endocrine            | 1 (0.3%)                  | 7 (1.5%)          | 1 (1.1%)         | 2 (0.6%)          |
| Cardiovascular                     | 1 (0.3%)                  | 4 (0.9%)          | 3 (3.4%)         | 1 (0.3%)          |
| Skin                               | 1 (0.3%)                  | 2 (0.4%)          | 0                | 4 (1.3%)          |
| Mental health                      | 1 (0.3%)                  | 2 (0.4%)          | 0                | 2 (0.6%)          |
| Respiratory                        | 0                         | 3 (0.7%)          | 2 (2.3%)         | 2 (0.6%)          |
| Cancer and neoplasms               | 0                         | 1 (0.2%)          | 0                | 4 (1.3%)          |
| Congenital disorders               | 0                         | 1 (0.2%)          | 0                | 0                 |
| Eye                                | 0                         | 1 (0.2%)          | 0                | 0                 |
| Infection                          | 0                         | 0                 | 2 (2.3%)         | 1 (0.3%)          |
| Ear                                | 0                         | 0                 | 1 (1.1%)         | 0                 |
| Stroke                             | 0                         | 0                 | 0                | 0                 |
| Disputed actiology and other       | 5 (1.3%)                  | 33 (7.3%)         | 1 (1.1%)         | 17 (5.5%)         |

#### S3. Events/injuries that triggered the pain condition

Fracture and surgery were reported more often by respondents with CRPS than respondents without CRPS, followed by sprain and dislocation (Supplementary Table 2). A stressful situation was reported more often by respondents with fibromyalgia than by respondents without fibromyalgia, followed by infection and childbirth. In general, respondents with CRPS+fibromyalgia tended to report the same inciting events as reported by respondents with only one of these conditions.

**Supplementary Table 2.** Numbers and percentages of events/injuries that triggered the pain condition. Note that respondents could report multiple events/injuries, thus percentages do not sum to 100.

|                     | CRPS                       | Fibromyalgia                | CRPS+                     | Pain controls              | Statistics                     |
|---------------------|----------------------------|-----------------------------|---------------------------|----------------------------|--------------------------------|
|                     | (N = <b>390</b> )          | ( <i>N</i> = 452)           | Fibromyalgia              | ( <i>N</i> = 311)          |                                |
|                     |                            |                             | (N = <b>88</b> )          |                            |                                |
| None                | 27 (6.9%) <sup>2,4</sup>   | 227 (50.2%) <sup>1,3</sup>  | 10 (11.4%) <sup>2,4</sup> | 154 (49.5%) <sup>1,3</sup> | $\chi^2(3) = 234.91, p < .001$ |
| Fracture            | 129 (33.1%) <sup>2,4</sup> | 20 (4.4%) <sup>1,3,4</sup>  | 26 (29.5%) <sup>2,4</sup> | 27 (8.7%) <sup>1,2,3</sup> | $\chi^2(3) = 151.90, p < .001$ |
| Surgery             | 126 (32.3%) <sup>2,4</sup> | 32 (7.1%) <sup>1,3</sup>    | 34 (38.6%) <sup>2,4</sup> | 33 (10.6%) <sup>1,3</sup>  | $\chi^2(3) = 126.77, p < .001$ |
| Sprain              | 71 (18.2%) <sup>2,4</sup>  | 19 (4.2%) <sup>1,3</sup>    | 13 (14.8%) <sup>2</sup>   | 23 (7.4%) <sup>1</sup>     | $\chi^2(3) = 49.91, p < .001$  |
| Dislocation         | 29 (7.4%) <sup>2</sup>     | 5 (1.1%) <sup>1,3,4</sup>   | 8 (9.1%) <sup>2</sup>     | 13 (4.2%) <sup>2</sup>     | $\chi^2(3) = 24.67, p < .001$  |
| Stressful situation | 28 (7.2%) <sup>2,3</sup>   | 113 (25.0%) <sup>1,4</sup>  | 15 (17.0%) <sup>1</sup>   | 28 (9.0%) <sup>2</sup>     | $\chi^2(3) = 63.80, p < .001$  |
| Infection           | 13 (3.3%) <sup>2</sup>     | 44 (9.7%) <sup>1,4</sup>    | 6 (6.8%)                  | 10 (3.2%) <sup>2</sup>     | $\chi^2(3) = 20.83, p < .001$  |
| Childbirth          | 3 (0.8%) <sup>2,3</sup>    | 26 (5.8%) <sup>1</sup>      | $7 (8.0\%)^1$             | 10 (3.2%)                  | $\chi^2(3) = 19.39, p < .001$  |
| Other               | 116 (29.7%) <sup>2</sup>   | 95 (21.0%) <sup>1,3,4</sup> | 31 (35.2%) <sup>2</sup>   | 92 (29.6%) <sup>2</sup>    | $\chi^2(3) = 13.79, p = .003$  |

Group mean differed significantly from <sup>1</sup>CRPS, <sup>2</sup>fibromyalgia, <sup>3</sup>CRPS+fibromyalgia, <sup>4</sup>pain controls, and <sup>5</sup>painfree controls.

#### S4. Body parts in which respondents reported experiencing pain in

Most respondents with CRPS reported the leg and/or foot as being most painful, followed by the arm and/or hand (Supplementary Table 3). However, respondents with CRPS also often reported experiencing pain in parts of their body other than their limbs, especially the back, neck, and head. Respondents with fibromyalgia most frequently reported the back, neck, and head as being most painful, and the majority reported some pain in these body areas. Respondents with CRPS+fibromyalgia reported the leg and/or foot as being most painful, followed by the arm and/or hand, although they did experience pain in many other body parts as well, which was comparable with the fibromyalgia only group. More pain controls reported the back as being most painful, and approximately two-thirds of respondents in this group reported some pain in this area. The overall pain intensity for the most painful body part differed between groups, F(4) = 69.11, p < .001. Respondents with fibromyalgia (with or without CRPS) reported the highest pain intensity. Respondents with only CRPS reported higher pain intensity than pain controls.

**Supplementary Table 3.** Numbers and percentages of the body parts where respondents reported any pain in the past week, and the average pain intensity reported across any painful body part, the most painful body parts over the past week, and the average pain intensity reported for the most painful body part. Note that respondents could report multiple body parts, thus percentages do not sum to 100.

|                       | CRPS ( <i>N</i> = 390) |             |              | Fibromyalgia | ibromyalgia (N = 452) CF |             |              |             | CRPS+Fibromyalgia (N = 88) |             |            |             | Pain controls $(N = 311)$ |             |            |             |
|-----------------------|------------------------|-------------|--------------|--------------|--------------------------|-------------|--------------|-------------|----------------------------|-------------|------------|-------------|---------------------------|-------------|------------|-------------|
|                       | Experienced            | Intensity   | Most painful | Intensity    | Experienced              | Intensity   | Most painful | Intensity   | Experienc                  | Intensity   | Most       | Intensity   | Experienced               | Intensity   | Most       | Intensity   |
|                       | pain                   |             |              | most         | pain                     |             |              | most        | ed pain                    |             | painful    | most        | pain                      |             | painful    | most        |
|                       |                        |             |              | painful      |                          |             |              | painful     |                            |             |            | painful     |                           |             |            | painful     |
| Left leg and/or foot  | 193 (49.5%)            | 7.05 (2.05) | 100 (25.6%)  | 7.87 (1.76)  | 359 (79.4%)              | 6.15 (2.00) | 43 (9.5%)    | 8.20 (1.67) | 72 (81.8%)                 | 7.24 (2.18) | 29 (33.0%) | 8.51 (1.56) | 124 (39.9%)               | 4.96 (2.04) | 32 (10.3%) | 6.48 (1.79) |
| Right leg and/or foot | 210 (53.8%)            | 7.04 (2.04) | 124 (31.8%)  | 7.68 (1.82)  | 370 (81.9%)              | 6.23 (1.98) | 47 (10.4%)   | 8.43 (1.46) | 58 (65.9%)                 | 7.46 (1.84) | 20 (22.7%) | 8.81 (1.38) | 141 (45.3%)               | 5.09 (2.11) | 43 (13.8%) | 6.27 (2.10) |

| Overall pain intensity | -           | 6.63 (2.14) | -          | 7.49 (1.88) | -           | 7.02 (1.55) | -           | 8.18 (1.42) | -          | 7.44 (1.60) | -          | 8.44 (1.43) | -           | 5.18 (2.18) | -          | 6.28 (2.02) |
|------------------------|-------------|-------------|------------|-------------|-------------|-------------|-------------|-------------|------------|-------------|------------|-------------|-------------|-------------|------------|-------------|
| Other                  | 60 (15.4%)  | 6.96 (2.24) | 27 (6.9%)  | 8.36 (1.47) | 138 (30.5%) | 7.73 (1.73) | 72 (15.9%)  | 8.33 (1.50) | 26 (29.5%) | 7.15 (2.10) | 7 (8.0%)   | 9.34 (1.19) | 66 (21.2%)  | 5.79 (2.50) | 38 (12.2%) | 6.59 (2.49) |
| Head                   | 107 (27.4%) | 5.93 (2.31) | 18 (4.6%)  | 7.79 (1.94) | 357 (79.0%) | 6.31 (2.17) | 76 (16.8%)  | 8.47 (1.49) | 49 (55.7%) | 5.96 (2.43) | 6 (6.8%)   | 9.70 (0.40) | 97 (31.2%)  | 5.75 (2.14) | 40 (12.9%) | 7.09 (1.82) |
| Neck                   | 131 (33.6%) | 5.96 (2.23) | 24 (6.2%)  | 8.01 (1.81) | 401 (88.7%) | 6.61 (2.14) | 118 (26.1%) | 8.39 (1.33) | 63 (71.6%) | 6.21 (2.46) | 10 (11.4%) | 9.07 (1.09) | 133 (42.8%) | 5.09 (2.22) | 35 (11.3%) | 6.26 (2.11) |
| Groin/genitals         | 44 (11.3%)  | 5.64 (2.17) | 6 (1.5%)   | 7.22 (1.71) | 117 (25.9%) | 5.66 (2.40) | 9 (2.0%)    | 8.29 (1.96) | 17 (19.3%) | 6.28 (2.32) | 3 (3.4%)   | 9.83 (0.29) | 30 (9.6%)   | 4.78 (2.14) | 4 (1.3%)   | 6.90 (0.89) |
| Chest                  | 56 (14.4%)  | 5.30 (2.32) | 7 (1.8%)   | 7.29 (2.55) | 219 (48.5%) | 5.53 (2.31) | 20 (4.4%)   | 8.60 (1.26) | 29 (33.0%) | 5.65 (2.34) | 2 (2.3%)   | 9.25 (0.35) | 45 (14.5%)  | 4.27 (2.02) | 5 (1.6%)   | 6.62 (1.39) |
| Stomach/abdomen        | 78 (20.0%)  | 5.46 (2.35) | 12 (3.1%)  | 9.06 (0.97) | 260 (57.5%) | 5.77 (2.20) | 31 (6.9%)   | 8.37 (1.29) | 42 (47.7%) | 6.30 (2.16) | 7 (8.0%)   | 8.99 (1.24) | 85 (27.3%)  | 5.39 (2.09) | 32 (10.3%) | 6.77 (1.81) |
| Back                   | 176 (45.1%) | 6.36 (2.32) | 37 (9.5%)  | 8.46 (1.73) | 415 (91.8%) | 7.12 (2.02) | 152 (33.6%) | 8.33 (1.61) | 75 (85.2%) | 6.85 (2.18) | 14 (15.9%) | 9.01 (1.08) | 203 (65.3%) | 5.38 (2.14) | 87 (28.0%) | 6.13 (2.12) |
| Right arm and/or hand  | 151 (38.7%) | 6.40 (2.07) | 62 (15.9%) | 7.12 (2.08) | 359 (79.4%) | 5.91 (2.04) | 34 (7.5%)   | 8.43 (1.46) | 58 (65.9%) | 6.11 (2.47) | 12 (13.6%) | 9.27 (0.74) | 96 (30.9%)  | 4.49 (2.09) | 24 (7.7%)  | 5.92 (1.90) |
| Left arm and/or hand   | 150 (38.5%) | 6.27 (2.22) | 60 (15.4%) | 7.17 (2.35) | 345 (76.3%) | 5.61 (1.94) | 21 (4.6%)   | 7.97 (1.81) | 62 (70.5%) | 6.25 (2.43) | 15 (17.0%) | 8.73 (1.72) | 90 (28.9%)  | 4.64 (2.29) | 14 (4.5%)  | 7.41 (2.36) |

#### S5. Individual bodily changes

From Supplementary Table 4 it is evident that no individual items are unique to any specific pain group, nor are there any that were not reported by any pain-free controls. Respondents with pain reported most bodily changes with greater frequency than respondents without pain, and respondents with CRPS and/or fibromyalgia reported most bodily changes with greater frequency than pain controls. Respondents with CRPS (with or without fibromyalgia) reported with greater frequency than the other groups those individual items that are part of the CRPS diagnostic criteria (e.g., 'swelling [oedema] in any body part'). However, respondents with fibromyalgia (without CRPS) also reported these items more frequently than the two control populations. Individual items that were reported with greater frequency by respondents with fibromyalgia (with or without CRPS) than the other groups include most items categorised under vision and hearing changes, 'increased susceptibility to illness', items related to bowel function ('loose bowels, diarrhoea, or needing to defecate more often', 'constipation'), 'allergic reactions to food and drink', and 'loss of sexual desire'. However, respondents with CRPS (without fibromyalgia) also reported these items more frequently than the two control populations. Individual items that were reported with greater frequency by the CRPS+fibromyalgia group than any other group included 'losing the hair on your head', 'finding your skin takes longer to heal when cut or bruised', 'falling more frequently', 'difficulties walking', and 'hay fever'.

The responses that were provided in the free-text box are depicted per category in Supplementary Figure 2.

**Supplementary Table 4.** Categorization of the predefined bodily changes that respondents could select as answer to the question: '*Have you experienced any of the following* since the onset of your pain condition/over the past two years? Please only select those things that have started to bother you or have become worse since the onset of your pain condition/over the past two years. Select ANY that apply.' Values are not corrected for covariates.

| Bodily change   | CRPS                           | Fibromyalgia                   | CRPS+                         | Pain controls                 | Pain-free                     | Statistics                     |  |
|---|--------------------------------|--------------------------------|-------------------------------|-------------------------------|-------------------------------|--------------------------------|--|
|   | (N = 390)                      | ( <i>N</i> = 452)              | Fibromyalgia                  | ( <i>N</i> = 311)             | controls                      |                                |  |
|   |                                |                                | (N = <b>88</b> )              |                               | ( <i>N</i> = 441)             |                                |  |
| Vision and hearing changes  |                                |                                |                               |                               |                               |                                |  |
| Blurred vision  | 142 (36.4%) <sup>2,3,4,5</sup> | 258 (57.1%) <sup>1,4,5</sup>   | 51 (58.0%) <sup>1,4,5</sup>   | 67 (21.5%) <sup>1,2,3</sup>   | 88 (20.0%) <sup>1,2,3</sup>   | $\chi^2(4) = 183.04, p < .001$ |  |
| Needing to change your glasses or contact lens prescription more often  | 94 (24.1%) <sup>2,3,4,5</sup>  | 172 (38.1%) <sup>1,4,5</sup>   | 35 (39.8%) <sup>1,4,5</sup>   | 47 (15.1%) <sup>1,2,3</sup>   | 75 (17.0%) <sup>1,2,3</sup>   | $\chi^2(4) = 82.38, p < .001$  |  |
| Peripheral vision loss  | 20 (5.1%)                      | 30 (6.6%) <sup>5</sup>         | 6 (6.8%)                      | 8 (2.6%)                      | $7 (1.6\%)^2$                 | $\chi^2(4) = 18.45, p = .001$  |  |
| Sensitivity to bright lights  | 162 (41.5%) <sup>2,3,4,5</sup> | 320 (70.8%) <sup>1,4,5</sup>   | 57 (64.8%) <sup>1,4,5</sup>   | 93 (29.9%) <sup>1,2,3,5</sup> | 71 (16.1%) <sup>1,2,3,4</sup> | $\chi^2(4) = 313.15, p < .001$ |  |
| Hearing loss  | 46 (11.8%) <sup>2</sup>        | 96 (21.2%) <sup>1,4,5</sup>    | 14 (15.9%)                    | 23 (7.4%) <sup>2</sup>        | 31 (7.0%) <sup>2</sup>        | $\chi^2(4) = 52.20, p < .001$  |  |
| Tinnitus (Ringing in the ears)  | 109 (27.9%) <sup>2,5</sup>     | 214 (47.3%) <sup>1,4,5</sup>   | 34 (38.6%) <sup>4,5</sup>     | 68 (21.9%) <sup>2,3,5</sup>   | 43 (9.8%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 168.13, p < .001$ |  |
| Sensitivity to loud noises  | 215 (55.1%) <sup>2,3,4,5</sup> | 320 (70.8%) <sup>1,4,5</sup>   | 65 (73.9%) <sup>1,4,5</sup>   | 96 (30.9%) <sup>1,2,3,5</sup> | 55 (12.5%) <sup>1,2,3,4</sup> | $\chi^2(4) = 381.42, p < .001$ |  |
| Hair, skin, and nail changes  |                                |                                |                               |                               |                               |                                |  |
| Losing hair on your head  | 124 (31.8%) <sup>3,4,5</sup>   | 171 (37.8%) <sup>3,4,5</sup>   | 50 (56.8%) <sup>1,2,4,5</sup> | 63 (20.3%) <sup>1,2,3</sup>   | 84 (19.0%) <sup>1,2,3</sup>   | $\chi^2(4) = 83.96, p < .001$  |  |
| Losing hair on parts of your body other than your head*                 | 67 (17.2%) <sup>4,5</sup>      | 52 (11.5%) <sup>3,4,5</sup>    | 21 (23.9%) <sup>2,4,5</sup>   | 18 (5.8%) <sup>1,2,3</sup>    | 11 (2.5%) <sup>1,2,3</sup>    | $\chi^2(4) = 75.68, p < .001$  |  |
| Extra hair growth on any part of your body*                             | 136 (34.9%) <sup>2,4,5</sup>   | 76 (16.8%) <sup>1,3,4,5</sup>  | 35 (39.8%) <sup>2,4,5</sup>   | 23 (7.4%) <sup>1,2,3</sup>    | 42 (9.5%) <sup>1,2,3</sup>    | $\chi^2(4) = 145.29, p < .001$ |  |
| Skin rashes   | 150 (38.5%) <sup>4,5</sup>     | 212 (46.9%) <sup>4,5</sup>     | 41 (46.6%) <sup>4,5</sup>     | 59 (19.0%) <sup>1,2,3</sup>   | 56 (12.7%) <sup>1,2,3</sup>   | $\chi^2(4) = 164.25, p < .002$ |  |
| Being more susceptible to sunburn                                       | 137 (35.1%) <sup>2,4,5</sup>   | 105 (23.2%) <sup>1,3,4,5</sup> | 37 (42.0%) <sup>2,4,5</sup>   | 34 (10.9%) <sup>1,2,3</sup>   | 38 (8.6%) <sup>1,2,3</sup>    | $\chi^2(4) = 132.13, p < .001$ |  |
| Changes in the texture of your skin*                                    | 250 (64.1%) <sup>2,4,5</sup>   | 153 (33.8%) <sup>1,3,4,5</sup> | 54 (61.4%) <sup>2,4,5</sup>   | 54 (17.4%) <sup>1,2,3,5</sup> | 49 (11.1%) <sup>1,2,3,4</sup> | $\chi^2(4) = 331.21, p < .001$ |  |
| Changes in skin colour*   | 300 (76.9%) <sup>2,4,5</sup>   | 55 (12.2%) <sup>1,3,5</sup>    | 58 (65.9%) <sup>2,4,5</sup>   | 22 (7.1%) <sup>1,3</sup>      | 16 (3.6%) <sup>1,2,3</sup>    | $\chi^2(4) = 799.53, p < .002$ |  |
| Swelling (oedema) in any body part*                                     | 321 (82.3%) <sup>2,4,5</sup>   | 186 (41.2%) <sup>1,3,4,5</sup> | 73 (83.0%) <sup>2,4,5</sup>   | 79 (25.4%) <sup>1,2,3,5</sup> | 24 (5.4%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 602.61, p < .002$ |  |
| Changes in the nails of your hands (e.g., growing faster or slower, or  | 207 (53.1%) <sup>4,5</sup>     | 219 (48.5%) <sup>3,4,5</sup>   | 57 (64.8%) <sup>2,4,5</sup>   | 58 (18.6%) <sup>1,2,3,5</sup> | 50 (11.3%) <sup>1,2,3,4</sup> | $\chi^2(4) = 270.84, p < .00$  |  |
| being more brittle)*  |                                |                                |                               |                               |                               |                                |  |
| Changes in your toenails (e.g., growing faster or slower, or being more | 228 (58.5%) <sup>2,4,5</sup>   | 152 (33.6%) <sup>3,4,5</sup>   | 57 (64.8%) <sup>1,2,4,5</sup> | 41 (13.2%) <sup>1,2,3,5</sup> | 26 (5.9%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 368.09, p < .00$  |  |
| brittle)*   |                                |                                |                               |                               |                               |                                |  |
| Allergic reactions on the skin  | 105 (26.9%)                    | 146 (32.3%)                    | 34 (38.6%)                    | 55 (17.7%)                    | 45 (10.2%)                    | $\chi^2(4) = 83.62, p < .001$  |  |

| Infection and healing changes  |                                |                                |                               |                                |                                |                                |
|--|--------------------------------|--------------------------------|-------------------------------|--------------------------------|--------------------------------|--------------------------------|
| Increased susceptibility to illness (for example, becoming more      | 184 (47.2%) <sup>2,3,4,5</sup> | 279 (61.7%) <sup>1,4,5</sup>   | 60 (68.2%) <sup>1,4,5</sup>   | 106 (34.1%) <sup>1,2,3,5</sup> | 60 (13.6%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 256.33, p < .001$ |
| frequently ill, or taking longer to recover from illness)            |                                |                                |                               |                                |                                |                                |
| Finding your skin takes longer to heal when cut or bruised           | 226 (57.9%) <sup>3,4,5</sup>   | 248 (54.9%) <sup>3,4,5</sup>   | 66 (75.0%) <sup>1,2,4,5</sup> | 92 (29.6%) <sup>1,2,3,5</sup>  | 51 (11.6%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 299.81, p < .001$ |
| Urinary/intestinal function  |                                |                                |                               |                                |                                |                                |
| Needing to urinate more often, or finding it difficult from stopping | 141 (36.2%) <sup>2,3,5</sup>   | 277 (61.3%) <sup>1,4,5</sup>   | 57 (64.8%) <sup>1,4,5</sup>   | 95 (30.5%) <sup>2,3,5</sup>    | 81 (18.4%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 209.01, p < .001$ |
| yourself urinate when you 'need to go'                               |                                |                                |                               |                                |                                |                                |
| Needing to urinate less often, or finding it difficult to urinate    | 59 (15.1%) <sup>2,4,5</sup>    | 34 (7.5%) <sup>1,5</sup>       | 12 (13.6%) <sup>4,5</sup>     | 15 (4.8%) <sup>1,3</sup>       | 9 (2.0%) <sup>1,23</sup>       | $\chi^2(4) = 58.37, p < .001$  |
| Loose bowels, diarrhoea, or needing to defecate more often           | 110 (28.2%) <sup>2,3,5</sup>   | 245 (54.2%) <sup>1,4,5</sup>   | 44 (50.0%) <sup>1,4,5</sup>   | 83 (26.7%) <sup>2,3,5</sup>    | 52 (11.8%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 205.7, p < .001$  |
| Constipation   | 156 (40.0%) <sup>2,4,5</sup>   | 263 (58.2%) <sup>1,4,5</sup>   | 46 (52.3%) <sup>4,5</sup>     | 76 (24.4%) <sup>1,2,3,5</sup>  | 41 (9.3%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 267.25, p < .001$ |
| Drinking and eating changes  |                                |                                |                               |                                |                                |                                |
| Having a 'sensitive stomach'   | 149 (38.2%) <sup>2,5</sup>     | 258 (57.1%) <sup>1,4,5</sup>   | 39 (44.3%) <sup>5</sup>       | 111 (35.7%)5                   | 94 (21.3%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 122.94, p < .001$ |
| Nausea   | 157 (40.3%) <sup>2,3,4,5</sup> | 233 (51.5%) <sup>1,4,5</sup>   | 49 (55.7%) <sup>1,4,5</sup>   | 94 (30.2%) <sup>1,2,3,5</sup>  | 42 (9.5%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 206.41, p < .001$ |
| Increase in weight   | 215 (55.1%) <sup>2,4,5</sup>   | 318 (70.4%) <sup>1,4,5</sup>   | 56 (63.6%) <sup>4,5</sup>     | 114 (36.7%) <sup>1,2,3,5</sup> | 111 (25.2%) <sup>1,2,3,4</sup> | $\chi^2(4) = 214.94, p < .001$ |
| Decrease in weight   | 77 (19.7%) <sup>5</sup>        | 57 (12.6%)                     | 19 (21.6%) <sup>5</sup>       | 39 (12.5%)                     | 36 (8.2%) <sup>1,3</sup>       | $\chi^2(4) = 29.16, p < .001$  |
| Allergic reactions to food and drink                                 | 53 (13.6%) <sup>2,5</sup>      | 116 (25.7%) <sup>1,4,5</sup>   | 20 (22.7%) <sup>5</sup>       | 39 (12.5%) <sup>2,5</sup>      | 20 (4.5%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 85.62, p < .001$  |
| Decreased alcohol tolerance  | 78 (20.0%) <sup>2</sup>        | 163 (36.1%) <sup>1,4,5</sup>   | 20 (22.7%)                    | 51 (16.4%) <sup>2</sup>        | $66 (15.0\%)^2$                | $\chi^2(4) = 70.13, p < .001$  |
| Increased alcohol tolerance  | 16 (4.1%)                      | 28 (6.2%)                      | 9 (10.0%)                     | 12 (3.9%)                      | 28 (6.3%)                      | $\chi^2(4) = 7.85, p = .100$   |
| Changes related to movement  |                                |                                |                               |                                |                                |                                |
| Weakness in any part of your body*                                   | 339 (86.9%) <sup>4,5</sup>     | 386 (85.4%) <sup>4,5</sup>     | 79 (89.8%) <sup>4,5</sup>     | 184 (59.2%) <sup>1,2,3,5</sup> | 73 (16.6%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 630.75, p < .001$ |
| Tremor in any part of your body*                                     | 215 (55.1%) <sup>2,3,4,5</sup> | 199 (44.0%) <sup>1,3,4,5</sup> | 62 (70.5%) <sup>1,2,4,5</sup> | 65 (20.9%) <sup>1,2,3,5</sup>  | 22 (5.0%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 341.54, p < .001$ |
| Problems with balance  | 271 (69.5%) <sup>4,5</sup>     | 343 (75.9%) <sup>4,5</sup>     | 64 (72.7%) <sup>4,5</sup>     | 136 (43.7%) <sup>1,2,3,5</sup> | 32 (7.3%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 525.7, p < .001$  |
| Falling more frequently  | 165 (42.3%) <sup>3,4,5</sup>   | 174 (38.5%) <sup>3,4,5</sup>   | 51 (58.0%) <sup>1,2,4,5</sup> | 61 (19.6%) <sup>1,2,3,5</sup>  | 11 (2.5%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 259.44, p < .001$ |
| Difficulties walking   | 279 (71.5%) <sup>3,4,5</sup>   | 314 (69.5%) <sup>3,4,5</sup>   | 75 (85.2%) <sup>1,2,4,5</sup> | 126 (40.5%) <sup>1,2,3,5</sup> | 15 (3.4%) <sup>1,2,3,4</sup>   | $\chi^2(4) =, p < .001$        |
| Changes in biological responses                                      |                                |                                |                               |                                |                                |                                |
| Sweating more*   | 261 (66.9%) <sup>4,5</sup>     | 279 (61.7%) <sup>4,5</sup>     | 63 (71.6%) <sup>4,5</sup>     | 90 (28.9%) <sup>1,2,3,5</sup>  | 76 (17.2%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 320.54, p < .001$ |
| Sweating less*   | 14 (3.6%)                      | 11 (2.4%)                      | 4 (4.5%)                      | 11 (3.5%)                      | 7 (1.6%)                       | $\chi^2(4) = 5.11, p = .276$   |
| Dizziness  | 200 (51.3%) <sup>2,3,4,5</sup> | 308 (68.1%) <sup>1,4,5</sup>   | 62 (70.5%) <sup>1,4,5</sup>   | 116 (37.3%) <sup>1,2,3,5</sup> | 47 (10.7%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 345.55, p < .001$ |

| Hay fever  | 56 (14.4%) <sup>3</sup>        | 93 (20.6%) <sup>3,4,5</sup>    | 31 (35.2%) <sup>1,2,4,5</sup> | 34 (10.9%) <sup>2,3</sup>      | 54 (12.2%) <sup>2,3</sup>     | $\chi^2(4) = 42.74, p < .001$  |
|--|--------------------------------|--------------------------------|-------------------------------|--------------------------------|-------------------------------|--------------------------------|
| Loss of sexual desire  | 202 (51.8%) <sup>2,4,5</sup>   | 281 (62.2%) <sup>1,4,5</sup>   | 56 (63.6%) <sup>4,5</sup>     | 113 (36.3%) <sup>1,2,3,5</sup> | 57 (12.9%) <sup>1,2,3,4</sup> | $\chi^2(4) = 264.6, p < .001$  |
| Increased sexual desire  | 9 (2.3%) <sup>5</sup>          | 9 (2.0%) <sup>5</sup>          | 1 (1.1%)                      | 7 (2.3%) <sup>5</sup>          | 48 (10.9%) <sup>1,2,4</sup>   | $\chi^2(4) = 60.03, p < .001$  |
| Feeling unusually cold, or finding it difficult to get warm when you are | 192 (49.2%) <sup>2,4,5</sup>   | 280 (61.9%) <sup>1,4,5</sup>   | 52 (59.1%) <sup>4,5</sup>     | 97 (31.2%) <sup>1,2,3,5</sup>  | 45 (10.2%) <sup>1,2,3,4</sup> | $\chi^2(4) = 292.00, p < .001$ |
| cold   |                                |                                |                               |                                |                               |                                |
| Feeling unusually hot, or finding it difficult to cool down when you are | 162 (41.5%) <sup>2,3,4,5</sup> | 274 (60.6%) <sup>1,4,5</sup>   | 56 (63.6%) <sup>1,4,5</sup>   | 70 (22.5%) <sup>1,2,3,5</sup>  | 36 (8.2%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 327.83, p < .001$ |
| hot  |                                |                                |                               |                                |                               |                                |
| One part or specific parts of your body feeling unusually cold*          | 252 (64.6%) <sup>2,4,5</sup>   | 145 (32.1%) <sup>1,3,4,5</sup> | 48 (54.5%) <sup>2,4,5</sup>   | 58 (18.6%) <sup>1,2,3,5</sup>  | 38 (8.6%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 346.54, p < .001$ |
| One part or specific parts of your body feeling unusually hot*           | 160 (41.0%) <sup>2,4,5</sup>   | 108 (23.9%) <sup>1,3,4,5</sup> | 43 (48.9%) <sup>2,4,5</sup>   | 35 (11.3%) <sup>1,2,3,5</sup>  | 13 (2.9%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 239.19, p < .001$ |

\* These items are part of the Budapest clinical diagnostic criteria for CRPS [1]

Group mean differed significantly from <sup>1</sup>CRPS, <sup>2</sup>Fibromyalgia, <sup>3</sup>CRPS+fibromyalgia, <sup>4</sup>pain controls, and <sup>5</sup>pain-free controls.

#### S6. Individual pain/discomfort/distress triggers and pain intensifiers

From Supplementary Table 5 and Supplementary Figure 3 it is evident that there are no individual items that were uniquely reported by any one pain group. Nor are there any items that were not reported as triggering pain, discomfort, and distress for at least some pain-free controls, although the frequencies of these reports are lower than for the pain groups. Most items were reported by a higher proportion of respondents with CRPS and/or fibromyalgia compared to the pain control group.

Respondents with fibromyalgia reported more often that caffeine, alcohol, bright lights, flashing lights, high-contrast images, loud or unpleasant noises, particular foods and particular smells triggered pain, discomfort, or distress; or intensified pain compared to respondents with CRPS. Respondents with CRPS reported more often that the touch of clothing/water/breeze triggered pain and distress; and intensified pain compared to respondents with fibromyalgia. Respondents with CRPS+fibromyalgia reported loud or unpleasant noises and warm/hot weather to trigger and intensify pain more often compared to respondents with only one of these conditions.

The responses that were provided in the free-text box are depicted per category in Supplementary Figure 4. The number of respondents who spontaneously mentioned additional items in the free-text box was lower than 10% per group, limiting how meaningful even qualitative group comparisons can be. **Supplementary Table 5.** Proportion of respondents that choose each of the individual pain, discomfort, and distress triggers; and pain intensifiers.

| Sensory sensitivity  | CRPS  | Fibromyalgia   | CRPS+  | Pain controls   | Pain-free   | Statistics  |  |
|--|---|--|--|---|---|---|--|
|  | ( <i>N</i> = 339)   | (N = 403)  | Fibromyalgia $(N = 275)$   |   | controls  |   |  |
|  |   |  | ( <i>N</i> = 79)   |   | ( <i>N</i> = 393)   |   |  |
| Pain triggers  |   |  |  |   |   |   |  |
| Caffeine   | 7 (2.1%)  | 23 (5.7%) <sup>5</sup>   | 5 (6.3%)   | 10 (3.6%)   | 6 (1.5%) <sup>2</sup>   | $\chi^2(4) = 14.57, p = .006$   |  |
| Alcohol  | 22 (6.5%) <sup>2,5</sup>  | 54 (13.4%) <sup>1,4,5</sup>  | 10 (12.7%) <sup>5</sup>  | 12 (4.4%) <sup>2,5</sup>  | 3 (0.8%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 57.33, p < .001$   |  |
| Bright lights  | 56 (16.5%) <sup>2.5</sup>   | 119 (29.5%) <sup>1,4,5</sup>   | 15 (19.0%) <sup>5</sup>  | 29 (10.5%) <sup>2,5</sup>   | 11 (2.8%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 115.44, p < .001$  |  |
| Flashing lights  | 59 (17.4%) <sup>4,5</sup>   | 94 (23.3%) <sup>4,5</sup>  | 12 (15.2%)5  | 22 (8.0%) <sup>1,2,5</sup>  | 7 (1.8%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 93.77, p < .001$   |  |
| High-contrast images   | 15 (4.4%)   | 29 (7.2%) <sup>5</sup>   | 5 (6.3%)   | 11 (4.0%)   | 6 (1.5%)  | $\chi^2(4) = 15.89, p = .003$   |  |
| Loud or unpleasant noises<br>The touch of clothing/water/breeze<br>Particular foods<br>Particular smells<br>Cold weather<br>Warm or hot weather<br>Other | $101 (29.8\%)^{3,4,5}$ $238 (70.2\%)^{2,4,5}$ $31 (9.1\%)^{2.5}$ $17 (5.0\%)^{5}$ $224 (66.1\%)^{4,5}$ $124 (36.6\%)^{2,3,4,5}$ $71 (20.9\%)^{4,5}$ | $115 (28.5\%)^{3.4.5}$<br>$116 (28.8\%)^{1.3.4.5}$<br>$97 (24.1\%)^{1.4.5}$<br>$32 (7.9\%)^{4.5}$<br>$240 (59.6\%)^{3.4.5}$<br>$102 (25.3\%)^{1.3.4.5}$<br>$58 (14.4\%)^5$ | $\begin{array}{c} 35 \ (44.3\%)^{1.2,4,5} \\ 56 \ (70.9\%)^{2.4,5} \\ 13 \ (16.5\%)^5 \\ 10 \ (12.7\%)^{4,5} \\ 59 \ (74.7\%)^{2.4,5} \\ 39 \ (49.4\%)^{1.2,4,5} \\ 13 \ (16.5\%)^5 \end{array}$ | $\begin{array}{c} 41 \ (14.9\%)^{1.2.3.5} \\ 31 \ (11.3\%)^{1.2.3.5} \\ 27 \ (9.8\%)^{2.5} \\ 4 \ (1.5\%)^{2.3} \\ 79 \ (28.7\%)^{1.2.3.5} \\ 30 \ (10.9\%)^{1.2.3.5} \\ 34 \ (12.4\%)^{1} \end{array}$ | $\begin{array}{c} 13 \ (3.3\%)^{1,2,3,4} \\ 4 \ (1.0\%)^{1,2,3,4} \\ 16 \ (4.1\%)^{1,2,3,4} \\ 3 \ (0.8\%)^{1,2,3} \\ 20 \ (5.1\%)^{1,2,3,4} \\ 4 \ (1.0\%)^{1,2,3,4} \\ 5 \ (1.3\%)^{1,2,3,4} \end{array}$ | $\begin{split} \chi^2(4) &= 138.03, p < .001\\ \chi^2(4) &= 528.39, p < .001\\ \chi^2(4) &= 82.05, p < .001\\ \chi^2(4) &= 82.05, p < .001\\ \chi^2(4) &= 42.84, p < .001\\ \chi^2(4) &= 406.56, p < .002\\ \chi^2(4) &= 209.98, p < .002\\ \chi^2(4) &= 71.38, p < .001 \end{split}$ |  |
| Discomfort triggers  |   |  |  |   |   |   |  |
| Caffeine   | 30 (8.8%)   | 61 (15.1%)   | 9 (11.4%)  | 27 (9.8%)   | 42 (10.7%)  | $\chi^2(4) = 8.66, p = .070$  |  |
| Alcohol  | $41 (12.1\%)^2$   | 82 (20.3%) <sup>1</sup>  | 10 (12.7%)   | 34 (12.4%)  | 66 (16.8%)  | $\chi^2(4) = 13.16, p = .011$   |  |
| Bright lights  | 156 (46.0%) <sup>2,5</sup>  | 286 (71.0%) <sup>1,4,5</sup>   | 45 (57.0%) <sup>4,5</sup>  | 108 (39.3%) <sup>2,3</sup>  | 140 (35.6%) <sup>1,2,3</sup>  | $\chi^2(4) = 119.48, p < .001$  |  |
| Flashing lights  | $131(38.6\%)^2$   | 240 (59.6%) <sup>1,4,5</sup>   | 41 (51.9%) <sup>4,5</sup>  | 84 (30.5%) <sup>2,3</sup>   | 119 (30.3%) <sup>2,3</sup>  | $\chi^2(4) = 92.84, p < .001$   |  |
| High-contrast images   | 98 (28.9%) <sup>2,3,5</sup>   | 198 (49.1%) <sup>1,4,5</sup>   | 37 (46.8%) <sup>1,4,5</sup>  | 60 (21.8%) <sup>2,3</sup>   | 76 (19.3%) <sup>1,2,3</sup>   | $\chi^2(4) = 106.62, p < .001$  |  |
| Loud or unpleasant noises  | 153 (45.1%) <sup>2,5</sup>  | 239 (59.3%) <sup>1,4,5</sup>   | 44 (55.7%) <sup>4,5</sup>  | 97 (35.3%) <sup>2,3</sup>   | 137 (34.9%) <sup>1,2,3</sup>  | $\chi^2(4) = 63.82, p < .001$   |  |
| The touch of clothing/water/breeze   | 144 (42.5%) <sup>4,5</sup>  | 202 (50.1%) <sup>4,5</sup>   | 32 (40.5%) <sup>4,5</sup>  | 43 (15.6%) <sup>1,2,3,5</sup>   | 25 (6.4%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 238.81, p < .001$  |  |
| Particular foods   | 38 (11.2%) <sup>2,3</sup>   | 106 (26.3%) <sup>1,4,5</sup>   | 19 (24.1%) <sup>1</sup>  | 35 (12.7%) <sup>2</sup>   | 55 (14.0%) <sup>2</sup>   | $\chi^2(4) = 41.65, p < .001$   |  |
| Particular smells  | 26 (7.7%) <sup>2,3</sup>  | 109 (27.0%) <sup>1,4,5</sup>   | 16 (20.3%) <sup>1,5</sup>  | 27 (9.8%) <sup>2</sup>  | 24 (6.1%) <sup>2,3</sup>  | $\chi^2(4) = 97.47, p < .001$   |  |
| Cold weather   | 106 (31.3%) <sup>5</sup>  | 160 (39.7%) <sup>4,5</sup>   | 28 (35.4%) <sup>5</sup>  | 74 (26.9%) <sup>2,5</sup>   | 39 (9.9%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 96.30, p < .001$   |  |
| Warm or hot weather  | 97 (28.6%) <sup>2,4,5</sup>   | 157 (39.0%) <sup>1,4,5</sup>   | 29 (36.7%) <sup>4,5</sup>  | 47 (17.1%) <sup>1,2,3</sup>   | 46 (11.7%) <sup>1,2,3</sup>   | $\chi^2(4) = 95.55, p < .001$   |  |
| Other  | 40 (11.8%) <sup>5</sup>   | 53 (13.2%) <sup>5</sup>  | 7 (8.9%) <sup>5</sup>  | 22 (8.0%) <sup>5</sup>  | 8 (2.0%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 36.18, p < .001$   |  |
| Distress triggers  |   |  |  |   |   |   |  |
| Caffeine   | $5(1.5\%)^2$  | $26 (6.5\%)^1$   | 3 (3.8%)   | 13 (4.7%)   | 18 (4.6%)   | $\chi^2(4) = 11.18, p = .025$   |  |

| Alcohol                            | 20 (5.9%)                   | 21 (5.2%)                    | 6 (7.6%)                    | 19 (6.9%)                    | 21 (5.3%)                     | $\chi^2(4) = 1.48, p = .830$   |
|------------------------------------|-----------------------------|------------------------------|-----------------------------|------------------------------|-------------------------------|--------------------------------|
| Bright lights                      | 54 (15.9%) <sup>2,5</sup>   | 98 (24.3%) <sup>1,4,5</sup>  | 10 (12.7%)5                 | 34 (12.4%) <sup>2,5</sup>    | 15 (3.8%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 70.50, p < .001$  |
| Flashing lights                    | 58 (17.1%) <sup>1,5</sup>   | 111 (27.5%) <sup>2,4,5</sup> | 19 (24.1%) <sup>5</sup>     | 40 (14.5%) <sup>2,5</sup>    | 23 (5.9%) <sup>1,2,3,4</sup>  | $\chi^2(4) = 70.78, p < .001$  |
| High-contrast images               | 24 (7.1%) <sup>2</sup>      | 69 (17.1%) <sup>1,4,5</sup>  | 9 (11.4%)                   | 16 (5.8%) <sup>2</sup>       | 15 (3.8%) <sup>2</sup>        | $\chi^2(4) = 51.17, p < .001$  |
| Loud or unpleasant noises          | 89 (26.3%) <sup>2,5</sup>   | 164 (40.7%) <sup>1,4,5</sup> | 30 (38.0%) <sup>4,5</sup>   | 55 (20.0%) <sup>2,3,5</sup>  | 45 (11.5%) <sup>1,2,3,4</sup> | $\chi^2(4) = 100.15, p < .001$ |
| The touch of clothing/water/breeze | 78 (23.0%) <sup>2,4,5</sup> | 52 (12.9%) <sup>1,4,5</sup>  | 17 (21.5%) <sup>4,5</sup>   | 16 (5.8%) <sup>1,2,3</sup>   | 10 (2.5%) <sup>1,2,3</sup>    | $\chi^2(4) = 91.54, p < .001$  |
| Particular foods                   | 19 (5.6%)                   | 45 (11.2%) <sup>5</sup>      | 6 (7.6%)                    | 14 (5.1%)                    | $10 (2.5\%)^2$                | $\chi^2(4) = 26.69, p < .001$  |
| Particular smells                  | 20 (5.9%) <sup>2,5</sup>    | 62 (15.4%) <sup>1,4,5</sup>  | 11 (13.9%) <sup>4,5</sup>   | 13 (4.7%) <sup>2,3</sup>     | 7 (1.8%) <sup>1,2,3</sup>     | $\chi^2(4) = 62.94, p < .001$  |
| Cold weather                       | 69 (20.4%) <sup>4,5</sup>   | 77 (19.1%) <sup>4,5</sup>    | 17 (21.5%) <sup>4,5</sup>   | 27 (9.8%) <sup>1,2,3,5</sup> | 7 (1.8%) <sup>1,2,3,4</sup>   | $\chi^2(4) = 79.50, p < .001$  |
| Warm or hot weather                | 59 (17.4%) <sup>4,5</sup>   | 75 (18.6%) <sup>4,5</sup>    | 21 (26.6%) <sup>4,5</sup>   | 18 (6.5%) <sup>1,2,3</sup>   | 12 (3.1%) <sup>1,2,3</sup>    | $\chi^2(4) = 76.91, p < .001$  |
| Other                              | 30 (8.8%) <sup>5</sup>      | 47 (11.7%) <sup>5</sup>      | 7 (8.9%) <sup>5</sup>       | 15 (5.5%)                    | 7 (1.8%) <sup>1,2,3</sup>     | $\chi^2(4) = 32.57, p < .001$  |
| Pain intensifiers                  |                             |                              |                             |                              |                               |                                |
| Caffeine                           | 21 (6.2%)                   | 44 (10.9%)                   | 7 (8.9%)                    | 27 (9.8%)                    |                               | $\chi^2(3) = 5.28, p = .153$   |
| Alcohol                            | 34 (10.0%)                  | 66 (16.4%)                   | 10 (12.7%)                  | 27 (9.8%)                    |                               | $\chi^2(3) = 9.24, p = .026$   |
| Bright lights                      | 122 (36.0%) <sup>2,4</sup>  | 218 (54.1%) <sup>1,4</sup>   | 38 (48.1%) <sup>4</sup>     | 73 (26.5%) <sup>1,2,3</sup>  |                               | $\chi^2(3) = 57.41, p < .001$  |
| Flashing lights                    | 100 (29.5%) <sup>2,4</sup>  | 170 (42.2%) <sup>1,4</sup>   | 30 (38.0%) <sup>4</sup>     | 53 (19.3%) <sup>1,2,3</sup>  |                               | $\chi^2(3) = 41.78, p < .001$  |
| High-contrast images               | 47 (13.9%) <sup>2</sup>     | 93 (23.1%) <sup>1,4</sup>    | 20 (25.3%) <sup>4</sup>     | 24 (8.7%) <sup>2,3</sup>     |                               | $\chi^2(3) = 30.39, p < .001$  |
| Loud or unpleasant noises          | 178 (52.5%) <sup>3,4</sup>  | 229 (56.8%) <sup>3,4</sup>   | 57 (72.2%) <sup>1,2,4</sup> | 87 (31.6%) <sup>1,2,3</sup>  |                               | $\chi^2(3) = 60.93, p < .001$  |
| The touch of clothing/water/breeze | 267 (78.8%) <sup>2,4</sup>  | 175 (43.4%) <sup>1,3,4</sup> | 62 (78.5%) <sup>2,4</sup>   | 44 (16.0%) <sup>1,2,3</sup>  |                               | $\chi^2(3) = 271.93, p < .00$  |
| Particular foods                   | 31 (9.1%) <sup>2</sup>      | 68 (16.9%) <sup>1,4</sup>    | 11 (13.9%)                  | 26 (9.5%) <sup>2</sup>       |                               | $\chi^2(3) = 13.09, p = .004$  |
| Particular smells                  | 18 (5.3%) <sup>2</sup>      | 74 (18.4%) <sup>1,4</sup>    | 11 (13.9%)                  | 16 (5.8%) <sup>2</sup>       |                               | $\chi^2(3) = 42.21, p < .001$  |
| Cold weather                       | 221 (65.2%) <sup>4</sup>    | 228 (56.6%) <sup>4</sup>     | 53 (67.1%) <sup>4</sup>     | 94 (34.2%) <sup>1,2,3</sup>  |                               | $\chi^2(3) = 67.12, p < .001$  |
| Warm or hot weather                | 155 (45.7%) <sup>2,4</sup>  | 134 (33.3%) <sup>1,3,4</sup> | 43 (54.4%) <sup>2,4</sup>   | 40 (14.5%) <sup>1,2,3</sup>  |                               | $\chi^2(3) = 82.01, p = .001$  |
| Other                              | 54 (15.9%)                  | 56 (13.9%)                   | 13 (16.5%)                  | 40 (14.5%)                   |                               | $\chi^2(3) = 0.78, p = .854$   |

Group mean differed significantly from <sup>1</sup>CRPS, <sup>2</sup>Fibromyalgia, <sup>3</sup>CRPS+fibromyalgia, <sup>4</sup>pain controls, and <sup>5</sup>pain-free controls.

### S7. Predictors of somatic sensations, bodily changes and sensory sensitivity

|                                   | CRPS                  |        | Fibromyalgia          |                       |        |                       |
|-----------------------------------|-----------------------|--------|-----------------------|-----------------------|--------|-----------------------|
| <u>Dependent</u> / independent    | F / B (95% CI)        | р      | <b>R</b> <sup>2</sup> | F / B (95% CI)        | р      | <b>R</b> <sup>2</sup> |
| variables                         |                       |        |                       |                       |        |                       |
| Somatic sensations (PHQ-15)       | F(7) = 28.07          | < .001 | .39                   | F(7) = 34.74          | <.001  | .41                   |
| Gender                            | 0.90 (-0.45 to 2.25)  | .190   | .01                   | -0.07 (-1.77 to 1.62) | .931   | 0                     |
| Age                               | -0.02 (-0.05 to 0.02) | .422   | 0                     | -0.03 (-0.06 to 0)    | .069   | 0.0                   |
| PHQ-9                             | 0.25 (0.14 to 0.37)   | <.001* | .06                   | 0.29 (0.19 to 0.39)   | <.001* | 0.0                   |
| GAD-7                             | 0.22 (0.10 to 0.34)   | <.001* | .04                   | 0.19 (0.10 to 0.29)   | <.001* | 0.0                   |
| Pain duration in years            | 0.05 (-0.01 to 0.11)  | .076   | .01                   | -0.02 (-0.06 to 0.02) | .431   | 0                     |
| Hours of pain per day             | 0.04 (-0.03 to 0.11)  | .222   | 0                     | 0.05 (-0.01 to 0.10)  | .111   | 0.0                   |
| Number of medical diagnoses       | 0.57 (0.29 to 0.85)   | <.001* | .05                   | 0.30 (0.09 to 0.50)   | .005*  | 0.0                   |
| Total number of bodily changes    | F(7) = 15.00          | < .001 | .26                   | F(7) = 25.20          | <.001  | .34                   |
| Gender                            | 0.89 (-1.41 to 3.19)  | .446   | 0                     | 2.58 (-0.48 to 5.64)  | .098   | .01                   |
| Age                               | 0.03 (-0.03 to 0.09)  | .362   | 0                     | 0.02 (-0.04 to 0.08)  | .530   | 0                     |
| PHQ-9                             | 0.31 (0.12 to 0.51)   | .002*  | .03                   | 0.43 (0.25 to 0.60)   | <.001* | .01                   |
| GAD-7                             | 0.11 (-0.09 to 0.31)  | .284   | 0                     | 0.07 (-0.11 to 0.24)  | .446   | 0                     |
| Pain duration in years            | 0.09 (-0.01 to 0.18)  | .078   | .01                   | 0.10 (0.03 to 0.17)   | .009*  | .01                   |
| Hours of pain per day             | 0.16 (0.04 to 0.27)   | .007*  | .02                   | 0.12 (0.02 to 0.23)   | .019*  | .02                   |
| Number of medical diagnoses       | 1.33 (0.86 to 1.81)   | <.001* | .09                   | 0.95 (0.58 to 1.32)   | <.001* | .03                   |
| Proportion of                     | F(7) = 7.24           | < .001 | .14                   | F(7) = 9.03           | <.001  | .15                   |
| pain/discomfort/distress triggers |                       |        |                       |                       |        |                       |
| Gender                            | 0.44 (-0.13 to 1.01)  | .126   | .01                   | 0.66 (-0.27 to 1.62)  | .160   | .01                   |
| Age                               | 0 (-0.02 to 0.01)     | .652   | 0                     | -0.01 (-0.03 to 0.01) | .205   | 0                     |
| PHQ-9                             | 0.04 (-0.01 to 0.09)  | .124   | .01                   | 0.05 (-0.01 to 0.10)  | .081   | .01                   |
| GAD-7                             | 0.05 (0 to 0.10)      | .062   | .01                   | 0.02 (-0.03 to 0.08)  | .377   | 0                     |
| Pain duration in years            | 0.02 (0 to 0.04)      | .106   | .01                   | 0.02 (0 to 0.04)      | .059   | .01                   |
| Hours of pain per day             | 0.02 (-0.01 to 0.04)  | .301   | 0                     | 0.04 (0.01 to 0.07)   | .020*  | .02                   |
| Number of medical diagnoses       | 0.20 (0.08 to 0.32)   | .001*  | .04                   | 0.19 (0.08 to 0.31)   | .001*  | .03                   |
| Pain intensifiers                 | F(7) = 5.39           | < .001 | .11                   | F(7) = 6.25           | <.001  | .11                   |
| Gender                            | 0.37 (-0.43 to 1.17)  | .364   | 0                     | 0.97 (-0.29 to 2.22)  | .129   | .01                   |
| Age                               | 0.01 (-0.01 to 0.04)  | .227   | 0                     | 0 (-0.03 to 0.02)     | .729   | 0                     |
| PHQ-9                             | 0.04 (-0.03 to 0.11)  | .227   | 0                     | 0.07 (0 to 0.15)      | .046*  | .01                   |

**Supplementary Table 6.** Outcomes of the multiple regression model of somatic sensations, bodily changes, pain/discomfort/distress triggers and pain intensifiers for respondents with CRPS and fibromyalgia.

| GAD-7                       | 0.04 (-0.03 to 0.11) | .305  | 0   | -0.05 (-0.12 to 0.02) | .197   | 0   |
|-----------------------------|----------------------|-------|-----|-----------------------|--------|-----|
| Pain duration in years      | 0.04 (0.01 to 0.08)  | .008* | .02 | 0.06 (0.03 to 0.09)   | <.001* | .04 |
| Hours of pain per day       | 0.03 (-0.01 to 0.07) | .091  | .01 | 0.02 (-0.02 to 0.07)  | .280   | 0   |
| Number of medical diagnoses | 0.23 (0.07 to 0.40)  | .006* | .02 | 0.13 (-0.03 to 0.28)  | .105   | .01 |

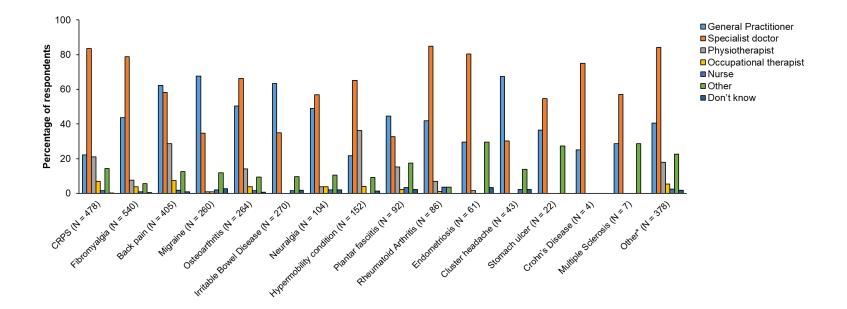
Abbreviations: Patient Health Questionnaire-9, PHQ-9; Patient Health Questionnaire-15, PHQ-15; Generalized

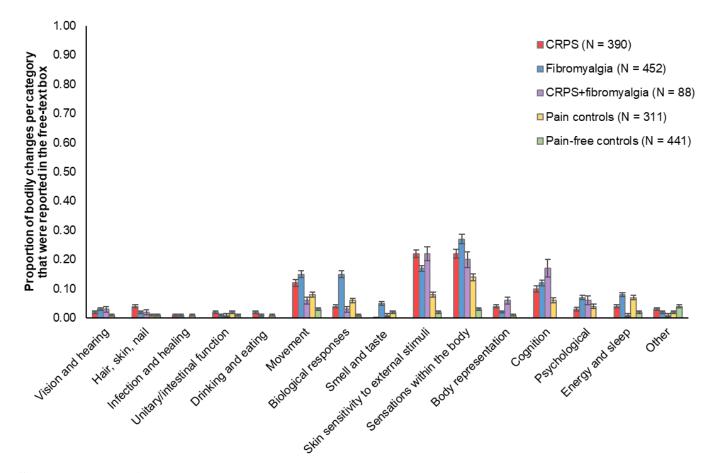
Anxiety Disorder-7, GAD-7.

\* Significant at alpha < .05

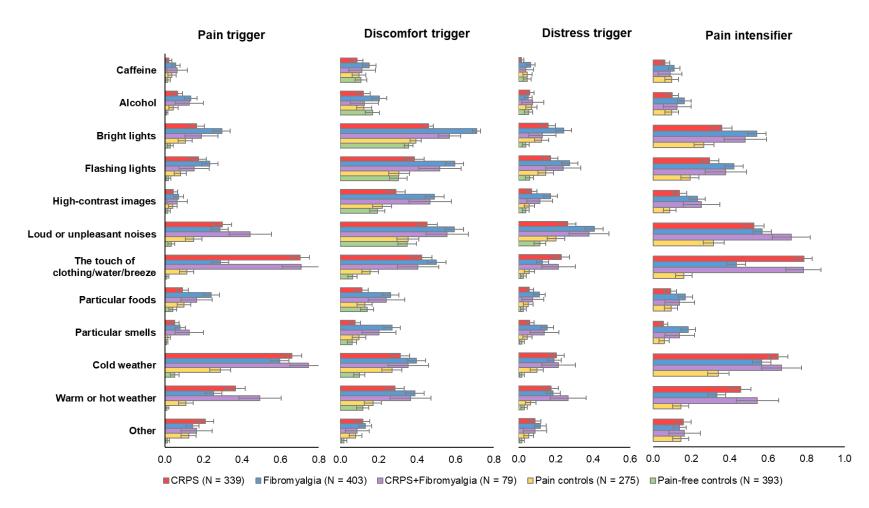
## References

 Harden NR, Bruehl S, Perez RSGM, Birklein F, Marinus J, Maihofner C, Lubenow T, Buvanendran A, Mackey S, Graciosa J, Mogilevski M, Ramsden C, Chont M, Vatine J-J. Validation of proposed diagnostic criteria (the "Budapest Criteria") for Complex Regional Pain Syndrome. Pain 2010;150:268–274. **Supplementary Figure 1**. Percentages of medical practitioners that respondents received their medical diagnosis from, split per medical diagnosis. Note that respondents could report multiple practitioners who had provided the medical diagnosis, thus percentages do not sum to 100. \* 'Other' medical diagnoses indicate the number of respondents who received 1 or more other medical diagnosis.

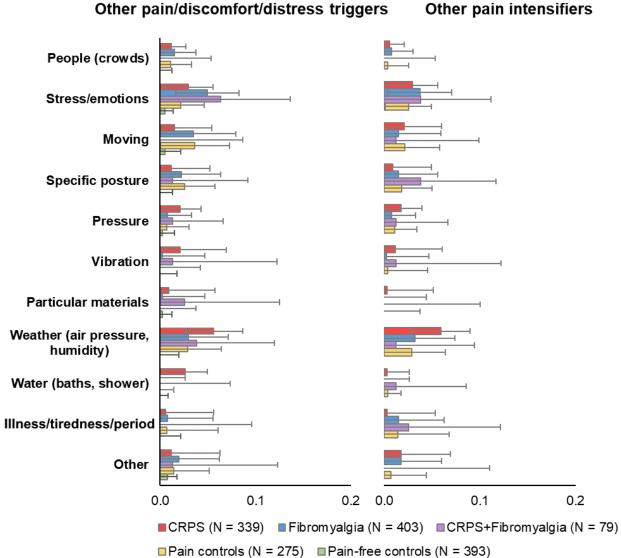




**Supplementary Figure 2.** Proportion of bodily changes provided in the free-text box, depicted per category. Answers in the free-text box were categorized in the existing categories or in new categories. Error bars depict 95% confidence intervals. Note that these means are not corrected for our covariates, nor did we compare groups statistically.



**Supplementary Figure 3.** Proportion of respondents who selected each of the pain, discomfort, distress triggers, and pain intensifiers. Error bars depict 95% confidence intervals. Note that these means are not corrected for our covariates, nor did we compare groups statistically.



#### Other pain intensifiers

**Supplementary Figure 4.** Proportion of pain/discomfort/distress triggers provided in the free-text box, depicted per category. Answers in the free-text box were categorized in the existing categories or in new categories. Error bars depict 95% confidence intervals. Note that these means are not corrected for our covariates, nor did we compare groups statistically.