

The Complex Regional Pain Syndrome (CRPS) online questionnaire

Welcome to the Complex Regional Pain Syndrome (CRPS) online questionnaire.

Thank you for taking part in this survey. This survey is being run by the University of Bath and the University of Nottingham and is funded by the National Institute for Health Research (NIHR).

This survey will help us to understand how you cope with your CRPS. It will take about 30 minutes to complete.

There are no right or wrong answers – we are simply interested in your experiences.

All information and any comments made will remain anonymous, and will be kept in accordance with the Data Protection Act of 1998. If you don't want to answer a question, you can leave it out and move on to the next.

By clicking 'Continue' you are indicating your consent to completing this survey.

Note that once you have clicked on the 'Continue' button at the bottom of each page you cannot return to review or amend that page.

CONTINUE

Some information about you

Please answer all of the following questions in this section

1. Please provide a unique password (e.g., mickeymouse12345). This will allow us to compare your responses over time. It can also be used to identify your responses should you wish to withdraw your data from this study.
2. Age (years):
3. Gender:
4. Ethnic background:
5. How long have you been diagnosed with CRPS (years and months):
6. How long did you have CRPS symptoms before diagnosis (years and months):
7. Marital status: single, partner, living with partner, married, divorced, widowed, separated

Your CRPS

8. In the box below, please tell us where your CRPS pain is:

| |
|--|
| |
|--|

9. On an **average day**, how much pain are you in? 0 would be no pain at all and 10 would be the worst pain imaginable. Please **click** the appropriate number.

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

10. Based on all the things that you do to cope or deal with your pain, on an **average day**, how much control do you feel you have over it? Please **click** the appropriate number.

| | | | | | | |
|---------------|---|---|-----------------|---|---|---------------------|
| No control | | | Some control | | | Complete control |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

11. Based on all the things you do to cope or deal with your pain, on an **average day**, how much are you able to decrease it? Please **click** the appropriate number.

| | | | | | | |
|--------------------------------|---|---|-----------------------------------|---|---|----------------------------------|
| Can't decrease it at all | | | Can decrease it somewhat | | | Can completely decrease it |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

12. Now we would like you to think of your **present** pain. You will be shown a list of words describing pain. For each description, please choose an option (from none to severe) to tell us how severe your current pain is. If none apply to you, click the 'none' option for each box.

| | |
|-------------------|--|
| Throbbing | |
| Shooting | |
| Stabbing | |
| Sharp | |
| Cramping | |
| Gnawing | |
| Hot-Burning | |
| Aching | |
| Heavy | |
| Tender | |
| Splitting | |
| Tiring-Exhausting | |
| Sickening | |
| Fearful | |
| Punishing-Cruel | |

13. In this section we are interested in the way that your pain is affected by other factors. Consider each of the items and decide whether they increase or decrease your pain. If the factor does not affect you click the 'not applicable' response.

| | <i>Increase</i> | <i>Decrease</i> | <i>Not applicable</i> |
|--------------------------------|-----------------|-----------------|-----------------------|
| Alcohol | | | |
| Stimulants e.g. coffee/tea | | | |
| Eating | | | |
| Heat | | | |
| Cold | | | |
| Damp | | | |
| Weather changes | | | |
| Massage of affected area | | | |
| Pressure | | | |
| No movement | | | |
| Movement | | | |
| Sleep/rest | | | |
| Lying down | | | |
| Distraction e.g. TV or reading | | | |
| Urination or defecation | | | |
| Tension | | | |
| Going to work | | | |
| Intercourse | | | |
| Mild exercise | | | |
| Fatigue | | | |

14. These next set of questions are interested in establishing how strong your pain is. For each of the statements on the left hand side, **click** the description which is the most appropriate description.

| | Mild | Discomforting | Distressing | Horrible | Excruciating |
|-----------------------------------|------|---------------|-------------|----------|--------------|
| Your pain right now | | | | | |
| Your pain at its worst | | | | | |
| Your pain at its best | | | | | |
| The worse toothache you've had | | | | | |
| The worst headache you've had | | | | | |
| The worse stomach ache you're had | | | | | |

Impact of CRPS

In this section we are interested in how you CRPS is impacting on you **right now**.

15. Thinking about how you feel right now please answer the following questions about yourself by indicating the extent of your agreement with each statement by clicking the appropriate response.

| | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|--|-------------------|----------|---------|-------|----------------|
| There is not enough purpose in my life | | | | | |
| To me, the things I do are all worthwhile | | | | | |
| Most of what I do seems trivial & unimportant to me. | | | | | |
| I value my activities a lot | | | | | |
| I don't care very much about the things I do | | | | | |
| I have lots of reasons for living | | | | | |
| In uncertain times, I usually expect the best | | | | | |
| It's easy for me to relax | | | | | |
| If something can go wrong for me, it will. | | | | | |
| I'm always optimistic about my future | | | | | |
| I enjoy my friends a lot | | | | | |
| It's important for me to keep busy | | | | | |
| I hardly ever expect things to go my way | | | | | |
| I don't get upset too easily | | | | | |
| I rarely count on good things happening to me | | | | | |
| Overall I expect more good things to happen to me than bad | | | | | |

Emotions

Emotions play an important part in most illnesses. This section of the questionnaire is designed to measure how you feel. Read each statement and **click** the response that comes closest to how you have been feeling in the **past week**.

16. I feel tense or wound up

| | |
|---|---------------------------------|
| 3 | Most of the time |
| 2 | A lot of the time |
| 1 | From time to time, occasionally |
| 0 | Not at all |

18. I get a sort of frightened feeling as if something awful is about to happen [A]

| | |
|---|-----------------------------------|
| 3 | Very definitely and quite badly |
| 2 | Yes, but not too badly |
| 1 | A little, but it doesn't worry me |
| 0 | Not at all |

20. Worrying thoughts go through my mind

| | |
|---|--------------------------------------|
| 3 | A great deal of the time |
| 2 | A lot of the time |
| 1 | From time to time, but not too often |
| 0 | Only occasionally |

22. I can sit at ease and feel relaxed

| | |
|---|------------|
| 0 | Definitely |
| 1 | Usually |
| 2 | Not often |
| 3 | Not at all |

24. I get a sort of frightened feeling like 'butterflies' in the stomach

| | |
|---|--------------|
| 3 | Not at all |
| 2 | Occasionally |
| 1 | Quite Often |
| 0 | Very Often |

26. I feel restless as if I have to be on the move

17. I still enjoy the things I used to enjoy

| | |
|---|--------------------|
| 0 | Definitely as much |
| 1 | Not quite so much |
| 2 | Only a little |
| 3 | Hardly at all |

19. I can laugh and see the funny side of things

| | |
|---|----------------------------|
| 0 | As much as I always could |
| 1 | Not quite so much now |
| 2 | Definitely not so much now |
| 3 | Not at all |

21. I feel cheerful

| | |
|---|------------|
| 0 | Definitely |
| 1 | Usually |
| 2 | Not often |
| 3 | Not at all |

23. I feel as if I am slowed down

| | |
|---|---------------------|
| 3 | Nearly all the time |
| 2 | Very often |
| 1 | Sometimes |
| 0 | Not at all |

25. I have lost interest in my appearance

| | |
|---|---------------------------------------|
| 3 | Definitely |
| 2 | I don't take as much care as I should |
| 1 | I may not take quite as much care |
| 0 | I take just as much care as ever |

27. I look forward with enjoyment to things

| | |
|---|------------------|
| 3 | Very much indeed |
| 2 | Quite a lot |
| 1 | Not very much |
| 0 | Not at all |

| | |
|---|--------------------------------|
| 0 | As much as I ever did |
| 1 | Rather less than I used to |
| 2 | Definitely less than I used to |
| 3 | Hardly at all |

28. I get sudden feelings of panic

| | |
|---|-------------------|
| 3 | Very often indeed |
| 2 | Quite often |
| 1 | Not very often |
| 0 | Not at all |

**29. I can enjoy a good book or
radio or TV programme**

| | |
|---|-------------|
| 0 | Often |
| 1 | Sometimes |
| 2 | Not often |
| 3 | Very seldom |

Coping (Brief COPE)

30. Each statement describes a different way of coping. Please rate the extent to which you have used that type of coping. We are interested in **how regularly** you use different types of coping, not how effective they are.

| | | Not at all | A little bit | A medium amount | A lot |
|----|--|------------|--------------|-----------------|-------|
| 1 | I've been turning to work or other activities to take my mind off things | | | | |
| 2 | I've been concentrating my efforts on doing something about it | | | | |
| 3 | I've been saying to myself "this isn't real" | | | | |
| 4 | I've been using alcohol or drugs to make myself feel better | | | | |
| 5 | I've been getting emotional support from others | | | | |
| 6 | I've been giving up trying to deal with it | | | | |
| 7 | I've been taking action to try and make the situation better | | | | |
| 8 | I've been refusing to believe that it has happened | | | | |
| 9 | I've been saying things to let my unpleasant feelings escape | | | | |
| 10 | I've been getting help and advice from other people | | | | |
| 11 | I've been using alcohol or drugs to get me through it | | | | |
| 12 | I've been trying to see it in a different light, to make it seem more positive | | | | |
| 13 | I've been criticising myself | | | | |
| 14 | I've been trying to come up with a strategy about what to do | | | | |
| 15 | I've been getting comfort and understanding from someone | | | | |
| 16 | I've been giving up the attempt to cope | | | | |
| 17 | I've been looking for something good in what's happening | | | | |
| 18 | I've been making jokes about it | | | | |

| | | Not at all | A little bit | A medium amount | A lot |
|----|---|------------|--------------|-----------------|-------|
| 19 | I've been doing something to think about it less e.g. watching TV | | | | |
| 20 | I've been accepting the reality of the fact that it has happened | | | | |
| 21 | I've been expressing my negative feelings | | | | |
| 22 | I've been trying to find comfort in my religion or spiritual beliefs | | | | |
| 23 | I've been trying to get advice or help from other people about what to do | | | | |
| 24 | I've been learning to live with it | | | | |
| 25 | I've been thinking hard about what steps to take | | | | |
| 26 | I've been blaming myself for things that happened | | | | |
| 27 | I've been praying or meditating | | | | |
| 28 | I've been making fun of the situation | | | | |

31. Quality of life :

Now we would like you to think of the areas of your life or activities that you engage in and which have been affected by your CRPS in the past month. You will be asked to provide up to five of these areas. We will then ask you to rate the area/activity in turn.

There are three steps to this section, each in a different column. There is an outline of what to do in each column below:

1st column: In the boxes below, please list up to five of these areas of your life or activities that have been affected by CRPS in the past month. Click on the boxes and input the area/activity.

2nd column: Now, using the scoring system in the drop down menu, we would like you to choose a number/statement for each activity that best matches how you felt when you were at your worst in the past month.

3rd column: Lastly, we would like you to tell us which of the areas you have listed above you would like to improve. Imagine that you have 50 points. These points can be used to show which area or areas you would like to improve.

You cannot use more than 50 points in total, but you can spend them in any way you like.

If you want all the areas to improve, you might decide to spread the points equally over each of the boxes, giving 10 points for each activity; alternatively, there might be one particular activity that you wish to focus on, in that case you would spend the whole 50points on one area/activity.

It is up to you how you decide to spend the points.

Please make sure that no more than 50 points in total are used.

| | Areas of your life or activities that you engage in which have been affected by your CRPS in the past month | For each activity, choose a number/statement which reflects how you were affected when you were at your worst in the past month | Spend your50 points |
|-----------------|--|--|----------------------------|
| <u>1</u> | | | |
| <u>2</u> | | | |
| <u>3</u> | | | |
| <u>4</u> | | | |
| <u>5</u> | | | |

32. Your Social Support

In this section we would like to learn about the social support that you use.

Below is a list of different kinds of support. Please tell us how often you use each kind of support listed by clicking the appropriate button. If you do not use a particular kind of support, click 'none of the time'.

| | | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|----|--|-------------------------|-----------------------------|-------------------------|-------------------------|------------------------|
| 1 | Someone you can count on to listen to you when you need to talk | | | | | |
| 2 | Someone to give you information to help you understand a situation | | | | | |
| 3 | Someone to give you good advice about a crisis | | | | | |
| 4 | Someone to confide in or talk to about yourself or your problems | | | | | |
| 5 | Someone whose advice you really want | | | | | |
| 6 | Someone to share your most private worries and fears with | | | | | |
| 7 | Someone to turn to for suggestions about how to deal with a personal problem | | | | | |
| 8 | Someone who understands your problems | | | | | |
| 9 | Someone to help you if you were confined to bed | | | | | |
| 10 | Someone to take you to the doctor if you needed it | | | | | |
| 11 | Someone to prepare your meals if you were unable to do it yourself | | | | | |
| 12 | Someone to help with daily chores if you were sick | | | | | |
| 13 | Someone who shows you love and affection | | | | | |
| 14 | Someone to love and make you feel wanted | | | | | |
| 15 | Someone who hugs you | | | | | |
| 16 | Someone to have a good time with | | | | | |
| 17 | Someone to get together with for relaxation | | | | | |

| | | | | | | |
|----|--|--|--|--|--|--|
| 18 | Someone to do something enjoyable with | | | | | |
| 19 | Someone to do things with to help you get your mind off things | | | | | |

33. Social Support

Below are five columns. In the first column, please list up to five significant people in your life who provide personal support for you or who are important to you.

In the second column, please tell us how they are related to you (e.g., brother, neighbour or friend)

In the third column, please tell us whether the relationship was formed online or offline.

In the fourth column, tell us what sort of support they provide.

In the fifth column, tell us how long you have known them for.

Click on the boxes to input their names. Once you have finished this section please click on the 'Next' button.

| | Person | Relationship | Online or offline | Type of support | How long have you known them (years and months) |
|---|--------|--------------|-------------------|-----------------|---|
| 1 | | | | | |
| 2 | | | | | |
| 3 | | | | | |
| 4 | | | | | |

34. During the past year, have you lost any important relationships as a consequence of CRPS? Please click the appropriate response and then click the 'Next' button.

| |
|-----|
| Yes |
| No |

(These next two questions were only shown if the participant has indicated 'Yes' to the previous question)

35. Please indicate the number of persons from each category who are ***no longer available*** to you. Once you have finished this section please click on the 'Next' button.

| | |
|-----------------------------|--|
| Spouse or partner | |
| Family members or relatives | |
| Friends | |
| Work/School associates | |
| Neighbours | |
| Health care providers | |
| Counsellor/therapist | |
| Minister/priest/rabbi/imam | |

36. Overall, how much of your support was provided by these people who are no longer available to you? Please click the appropriate number. Once you have finished this section please click on the 'Next' button.

None at all

A little

A moderate
amount

Quite a bit

A great deal

| | | | | |
|--|--|--|--|--|
| | | | | |
|--|--|--|--|--|

Information seeking and use of the Internet: This next section of the questionnaire is going to ask you about how you obtain information relating to your CRPS. There are two stages to this part of the questionnaire.

37. We are interested in how easy or difficult it is for you to find information about your CRPS. Consider each of the terms and decide how much each statement applies to you by clicking the appropriate response.

| | Never | Rarely | Sometimes | Often | Always |
|--|-------|--------|-----------|-------|--------|
| a. I know exactly what it is that I want to learn about my health care | | | | | |
| b. I can figure out how and where to get the information I need | | | | | |
| c. Health information is more difficult for me to obtain than other types of information | | | | | |
| d. I am satisfied about the way I currently learn about health issues | | | | | |
| e. I feel that I am in control over how and what I learn about my health | | | | | |

38. We would like to know about your health information needs and whether you feel that you have enough information about your CRPS. Please read the following items and click to indicate how strongly you agree or disagree with each one.

| | Disagree very much | Disagree | Neutral | Agree | Agree very much |
|---|--------------------|----------|---------|-------|-----------------|
| a. I needed more information about CRPS from the point of view of people who have had CRPS. | | | | | |
| b. I needed more understandable information about CRPS. | | | | | |
| c. I needed more information about the latest CRPS news. | | | | | |
| d. I needed more contact with people who understood what I was going through. | | | | | |
| e. I needed help making decisions. | | | | | |

Internet use: In this section we would like you to tell us about your knowledge and experiences of using the Internet.

39. Different people use the Internet for different ways and for different purposes. Please read the following list of items and click on the item that most closely describes how you use the Internet.

| | |
|--|---|
| | I do not use the Internet. |
| | I only use the Internet occasionally to do a specific task like using email or searching for information. |
| | I use the Internet a lot for email, information seeking and recreational activities like downloading or playing music and games |
| | I regularly use the Internet to perform specific tasks like shopping, online banking and to obtain information. |
| | I am very interested in the Internet and use it for a wide and varied range of purposes. |

40. Some people only use the Internet occasionally while others use it very frequently. Please read the following list and click on the statement that best describes your internet use over the past year.

| | |
|--|---|
| | I have not used the Internet during the past year. |
| | I occasionally use the Internet. |
| | I frequently use the Internet but only for 1-2 purposes |
| | I frequently use the Internet for 3 or more purposes. |

41. How long is it since you first started using the internet? (years): _____

42. We would like to know more about how often you do certain activities. Please read the following items and click to indicate **how regularly** you have done each one during the past year.

| | Never | Once | Rarely | Several times | Regularly |
|--|-------|------|--------|---------------|-----------|
| a. I Have used a social networking website like Facebook or Twitter. | | | | | |
| b. I have used an online non-health-related discussion forum, e.g. to talk about hobbies or other interests. | | | | | |
| c. I have used an online health-related support group. | | | | | |
| d. I have attended a face-to-face | | | | | |

| | | | | | |
|---------------|--|--|--|--|--|
| support group | | | | | |
|---------------|--|--|--|--|--|

Internet attitudes

This section of the questionnaire will ask about your attitudes towards the Internet.

43. There are several items. Please read each statement carefully and indicate how strongly you agree or disagree with each item.

| | Strongly disagree | Disagree | Slightly disagree | Neutral | Slightly agree | Agree | Strongly agree |
|---|-------------------|----------|-------------------|---------|----------------|-------|----------------|
| a. I enjoy shopping online. | | | | | | | |
| b. I enjoy browsing (surfing) websites without a specific purpose. | | | | | | | |
| c. I feel anxious that online communications can potentially be seen, heard, or otherwise accessed by other people. | | | | | | | |
| d. I feel that the Internet limits my productivity. | | | | | | | |
| e. I feel that the Internet has allowed me to keep in touch with many people. | | | | | | | |
| f. I feel anxious that my personal information may be available over the Internet. | | | | | | | |
| g. I like to look up information about businesses, services, and/or products on the Internet. | | | | | | | |
| h. I have had more good experiences than bad experiences using the Internet. | | | | | | | |
| i. I would prefer communication through writing a letter or a memo rather than an | | | | | | | |

| | | | | | | | |
|---|--|--|--|--|--|--|--|
| email. | | | | | | | |
| J. I feel uncomfortable using my credit card online. | | | | | | | |
| k. I enjoy using the Internet to pass time and/or to g=have fun. | | | | | | | |
| l. I would prefer to go online to conduct most of my banking. | | | | | | | |
| m. When searching for information, I would rather read books, magazines, and newspapers than browse the Internet. | | | | | | | |
| n. I only feel comfortable using online stores to browse or compare prices. | | | | | | | |
| o. I avoid using the Internet whenever possible. | | | | | | | |
| p. I enjoy using the Internet for instant messaging or other types of real-time communication. | | | | | | | |
| q. Overall, I enjoy using the Internet. | | | | | | | |

Final Comments

44. This is the final section. If there is anything else that you would like to add that will help us to better understand how you cope with your CRPS, please use the box below to write down your thoughts. Once you have done this, please click on the 'Continue' button.

45. Now we need you to give us an email address, so that we can contact you in a couple of months time to tell us how things are going and to complete a follow-up questionnaire.

Once filled out, please click 'Continue' at the bottom of the page.

SURVEY COMPLETE

Thank you for filling in this questionnaire. The CRPS forum will launch on June 1. We will email you shortly prior to the launch with a link to the forum registration page.