

Table S1

Three versions of the survey

Version 1 of survey: Self-report Child Version

Consent

By doing this survey you are letting us know that you are happy for us to look at the answers you have provided. Also, you understand that you can change your mind about taking part in the survey at any time.

The survey has questions about any pain or hurt that you have. This is **pain lasting for 3 months or more and is not pain from recent injury or recent surgery**. The survey will also ask you how pain or hurt affects what you do and how you cope with your pain. The survey will take about 20 minutes.

Pain profile

1. Who is completing this survey?

Child (aged 8-12) with CP, supervised by a parent or carer

Parent or carer physically entering the responses given to you by the child (aged 8-12) with CP

If you are a parent or carer answering on behalf of a child with CP (without their input) please complete the parent survey at <https://www.surveymonkey.com/r/parentCP>

* 2. Have you felt pain or has something been hurting for 3 months or more?

Yes

No

3. Which parts of you body hurt? You can choose more than one area.

Head

Neck

Shoulder/s

Arm/s

Hand/s

Chest

Tummy

Upper and/or lower back

Hip/s

Front and/or back of thigh/s

Knee/s

Calf/calves

Foot/feet

* 4. Which of these areas is hurting the most? Choose one area.

Head
Neck
Shoulder/s
Arm/s
Hand/s
Chest
Tummy
Upper and/or lower back
Hip/s
Front and/or back of thigh/s
Knee/s
Calf/calves
Foot/feet

* 5. How much pain/hurt do you feel in this body part? 0 that means you have no pain at all, and 10 means it is the worst pain you can think of.

0- no pain at all

1

2

3

4

5

6

7

8

9

10-worst pain imaginable

- | | | | | | | |
|----------------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 19. Sleep | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. Riding a bike or scooter | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 21. Being up all day (without a nap or rest) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

7. Are there any other activities that your pain/hurt makes difficult or bothersome for you?

8. What activity would you **most** like to do that your pain or hurt stops you from doing?

Coping Strategies for Pain

* 9. Here is a list of things that children sometimes do when they are in pain or hurt. For each one of the things, click if you do it **not at all**, **sometimes** or **a lot**. Please be sure to click one for **each** of the things on the list

	Not at all	Sometimes	A lot
1. Go to bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Ask for medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Ask for a hug or kiss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Ask for someone to understand how I hurt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Cry or yell	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Think about going away on vacation or a trip	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Play with my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Watch TV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Play a game	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Eat or drink something	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Rub the sore spot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Tell myself to be brave	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Have my mother, father or a friend sit with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Try not to think about the pain or hurt or ignore the pain or hurt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Take deep breaths	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Think about happy things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Play with my pet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Read a book or colour in a colouring book	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Talk about what I did today	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Think it will just get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Wish for it to go away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Imagine that I can make the pain or hurt disappear by myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Pretend I don't have any pain or hurt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Tell myself that it will be alright	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Try to be brave and not say anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Sit quietly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Lie down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Tell my mother or father	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. Ask to stay by myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. Ask to go to the doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. Know that I can do something to make the pain or hurt feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Know that I can ask for something that will make the pain or hurt feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Ask someone to explain to me why I hurt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. Put ice or heat on the sore sport	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. Go to sleep until it feels better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. Get mad or mean to other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

37. Squeeze someone's hand or something else	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. Ask someone to tell me that the pain or hurt will go away and I will feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. Pray, mediate, or ask God for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. Pretend that the pain or hurt doesn't hurt as much as it really does	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41. Think that I can't do anything to stop the pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Is there anything else you would like to tell us about your pain or hurt?

Finally, a few questions about you (a child with CP).
* 11. What is your date of birth? DD/MM/YYYY
* 12. How old are you now?
* 13. Are you a boy or a girl? Boy Girl
* 14. Do you walk (either with or without assistance)? Yes No
* 15. If you can, please tell us your type of CP. Spastic Dyskinetic (Choreoathetosis and/or Dystonia) Ataxic Not sure
* 16. If you can, please tell us the parts of your body affected by CP. Hemiplegia Diplegia Quadriplegia Not sure
End of survey

Version 2 of survey: Self-report Teen Version

Teenager Survey

Consent

By doing this survey you are letting us know that you are happy for us to look at the answers you have provided. Also, you understand that you can change your mind about taking part in the survey at any time.

The survey has questions about any ongoing pain that you have, **pain lasting 3 months or more and is not pain from recent injury or recent surgery**. The survey will also ask you how pain affects what you do and how you manage your pain. The survey will take about 20 minutes.

Pain profile

1. Who is completing this survey?

Teenager (aged 13-18) with CP, supervised by a parent or carer

Parent or carer physically entering the responses given to you by the teenager (aged 13-18) with CP

If you are a parent or carer answering on behalf of a teenager with CP (without their input) please complete the parent survey at <https://www.surveymonkey.com/r/parentCP>

* 2. Do you have ongoing pain?

Yes

No

* 3. Where is your pain located? Select all relevant areas.

Head

Neck

Shoulder/s

Arm/s

Hand/s

Chest

Tummy

Upper and/or lower back

Hip/s

Front and/or back of thigh/s

Knee/s

Calf/calves

Foot/feet

*

4. Where is your worst pain located? Select one area.

Head

Neck

Shoulder/s

Arm/s

Hand/s

Chest

Tummy

Upper and/or lower back

Hip/s

Front and/or back of thigh/s

Knee/s

Calf/calves

Foot/feet

* 5. How much pain do you feel at this location? 0 equals no pain at all and 10 being the worst pain imaginable.

0- no pain at all

1

2

3

4

5

6

7

8

9

10-worst pain imaginable

19. Sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Riding a bike or scooter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Being up all day (without a nap or rest)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. Are there any other activities that your pain makes difficult or bothersome for you?

8. What activity would you **most** like to do that your pain stops you from doing?

Coping Strategies for Pain

* 9. Here is a list of things that teenagers sometimes do when they are in pain. For each one of the items, please indicate if you do it **never**, **sometimes** or **often**. Please be sure to select an option for **each** of the items on the list

	Never	Sometimes	Often
42. Go to bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. Ask for medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. Ask for a hug or kiss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. Ask for someone to understand my pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. Cry or yell	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. Think about going away on vacation or a trip	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. Visit with my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. Watch TV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. Play a game	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. Eat or drink something	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. Rub the sore spot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53. Tell myself I can handle it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Have a parent or friend sit with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55. Try not to think about the pain or ignore the pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56. Breathe deeply	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. Think about happy things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58. Play with my pet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

59. Read a book	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
60. Talk about what I did today	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
61. Think it will just get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
62. Wish for it to go away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
63. Imagine that I can make the pain disappear by myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
64. Pretend I don't have any pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
65. Tell myself that it will be alright	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
66. Try to be strong and not say anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
67. Sit quietly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
68. Lie down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
69. Tell my parent(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
70. Ask to be left alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
71. Ask to see a doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72. Know that I can do something to make the pain feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
73. Know that I can ask for something that will make the pain feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
74. Ask someone to explain to my pain to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
75. Use ice or heat on the sore spot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
76. Sleep it off	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
77. Get angry, irritable or cranky	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

78. Squeeze someone's hand or an object	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
79. Ask for reassurance that you will feel better or the pain will decrease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80. Pray, meditate, or ask God for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
81. Pretend that the pain isn't as bad as it really is	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
82. Think that there is nothing I can do to stop the pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Is there anything else you would like to tell us about your pain?

Finally, a few questions about you (a teenager with CP).

* 11. What is your date of birth?

DD/MM/YYYY

* 12. How old are you now?

* 13. Are you a boy or a girl?

Boy

Girl

* 14. Do you walk (either with or without assistance)?

Yes

No

* 15. If you can, please tell us your type of CP.

Spastic

Dyskinetic (Choreoathetosis and/or Dystonia)

Ataxic

Not sure

* 16. If you can, please tell us the parts of your body affected by CP.

Hemiplegia

Diplegia

Quadriplegia

Not sure

End of survey

Version 3 of survey: Carer-report (Proxy) Version

Parent/Carer (Proxy) Survey

Consent

By completing this survey you accept that you...

- 1) Have read the Information Sheet provided and been given a full explanation of the purpose of this research, the procedures involved and of what is expected of me and my child,
- 2) Understand that all information provided by me or my child is treated as confidential and will not be released by the researcher to a third party unless required to do so by law,
- 3) Agree that my child has ongoing pain which for the purpose of this study is defined as **pain lasting 3 months or more and is not pain from recent injury or recent surgery.**
- 4) Agree that any research data gathered for the study may be published provided my name or my child's name or other identifying information is not disclosed,
- 5) Understand that research data gathered may be used for future research but my name or my child's name and other identifying information will be removed.

The survey has questions about any pain that your child with CP has. This is not pain from a recent injury or recent surgery, but ongoing pain. The survey will also ask you how pain affects what they do and how they manage their pain. The survey will take about 20 minutes.

Pain profile

1. Who is completing this survey?

Parent or carer, answering on behalf of a child/teenager with CP (without their input)

If you are a parent or carer physically entering the responses given to you by the child (aged 8-12) with CP please complete the child survey at
<https://www.surveymonkey.com/r/childCP>

If you are a parent or carer physically entering the responses given to you by the teenager (aged 13-18) with CP please complete the teenager survey at
<https://www.surveymonkey.com/r/teenCP>

* 2. Do you believe your child experiences ongoing pain?

Yes

No

* 3. Where is your child's pain located? Select all relevant areas.

Head
Neck
Shoulder/s
Arm/s
Hand/s
Chest
Tummy
Upper and/or lower back
Hip/s
Front and/or back of thigh/s
Knee/s
Calf/calves
Foot/feet

* 4. Which of these locations is your child's worst pain? Select one option

Head
Neck
Shoulder/s
Arm/s
Hand/s
Chest
Tummy
Upper and/or lower back
Hip/s
Front and/or back of thigh/s
Knee/s
Calf/calves
Foot/feet

* 5. How much pain is your child experiencing at this location? 0 equals no pain at all and 10 being the worst pain imaginable.

0- no pain at all

1
2
3
4
5
6
7
8
9

10-worst pain imaginable

19. Sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Riding a bike or scooter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Being up all day (without a nap or rest)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. Are there any other activities that pain makes difficult or bothersome for your child?

8. What activity would they **most** like to do that is limited or prevented by pain?

Coping Strategies for Pain

* 9. Here is a list of things that children sometimes do when they are in pain. For each one of the items, please indicate if your child does it **never**, **sometimes** or **often** when he/she experiences pain. Please be sure to select an option for **each** of the items on the list

	Never	Sometimes	Often
83. Goes to bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
84. Asks for medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
85. Asks for a hug or kiss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
86. Asks for someone to understand his or her pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
87. Cries or yells	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88. Thinks or talks about going away on vacation or a trip	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
89. Visits with friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
90. Watches TV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
91. Plays a game	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
92. Eats or drinks something	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
93. Rubs the sore spot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
94. Tell him/herself to be brave	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
95. Has a parent or friend sit with him/her	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
96. Tries not to think about the pain or ignores the pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
97. Breathes deeply	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
98. Thinks or talks about happy things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
99. Plays with a pet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

100.	Reads a book	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
101.	Talks about what he/she did today	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
102.	Thinks it will just get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
103.	Wishes for the pain to go away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
104.	Imagines that he/she can make the pain disappear by him/herself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
105.	Pretends that he/she doesn't have any pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
106.	Tells him/herself that it will be alright	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
107.	Tries to be strong and not say anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
108.	Sits quietly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
109.	Lies down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
110.	Tells parent(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111.	Asks to be left alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
112.	Asks to see a doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
113.	Knows that he/she can do something to make his/her pain feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
114.	Knows that he/she can ask for something that will make his/her pain feel better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
115.	Asks for someone to explain his/her pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
116.	Uses heat or ice on the sore sport	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
117.	Sleeps it off	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
118.	Gets angry, irritable or cranky	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

119.	Squeeze someone's hand or an object	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
120.	Asks for reassurance that he/she will feel better or the pain will decrease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
121.	Prays, mediates, or asks God for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
122.	Pretends the pain is not as bad as it really is	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
123.	Thinks that there is nothing he/she can do to stop the pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Is there anything else you would like to tell us about your child's pain?

Finally, a few questions about your child.

* 11. What is your child's date of birth?

DD/MM/YYYY

* 12. How old is your child now?

* 13. What is your child's gender?

Boy

Girl

* 14. Does your child you walk (either with or without assistance)?

Yes

No

* 15. If you can, please tell us your child's type of CP.

Spastic

Dyskinetic (Choreoathetosis and/or Dystonia)

Ataxic

Not sure

* 16. If you can, please tell us the parts of your child's body affected by CP.

Hemiplegia

Diplegia

Quadriplegia

Not sure

End of survey
