Online Paediatric Chronic Pain Management: assessing the needs of young people and their parents

Start of Block: Consent

Study Info **Study Information**

 **Study title:** **Online Paediatric Chronic Pain Management: assessing the needs of young people and their parents**
 **Study reference number [ERGO ID]:**48723 The Pain Research Laboratory at the University of Southampton is currently conducting a variety of different studies that will contribute towards the development of an online, interdisciplinary intervention (an internet-based resource) for chronic pain management in adolescents. The purpose of this study is to find out: Which online resources young people and their parents currently use to manage chronic pain; what content and features would young people with chronic pain and their parents like to see in an online pain management resource. The insights gained from this survey will be combined with insights from healthcare professionals, and young people who are currently undergoing treatment for chronic pain via NHS services, so that the research team can create a new resource covering many different aspects of pain management.This survey is for adolescents with chronic pain aged 16 to 18 years OR parents of adolescents with chronic pain aged 12 to 18 years. The first section of this survey will check that you are eligible to participate, followed by the main section of questions, and an explanation (debrief) at the end.

 Please note that as your participation is anonymous, you will not be able to withdraw your data from the study once you have completed and submitted this survey.

 If you have decided you do not want to take part in the survey, that is OK, simply close this window to exit. Here is a link to an online resource for teenagers with chronic pain, in case you would like any more information: <http://www.aci.health.nsw.gov.au/chronic-pain/painbytes> (recommended by Great Ormond Street Hospital).

 This survey should not take longer than **30 minutes** to complete. This study has been approved by the Psychology Department Ethics Committee at the University of Southampton.

 Please click the arrow to continue to the survey.

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

Consent Form **Consent Form**

 **Study title:** **Online Paediatric Chronic Pain Management: assessing the needs of young people and their parents**
 **Study reference number [ERGO ID]:** 48723

 **Please tick the boxes below if you agree with each statement:**

* I am aged 16 years or over. (1)
* I have read and understood the study information provided on the previous page. (2)
* I agree to take part in this research project and agree for my data to be used for the purpose of this study. (3)
* I understand my participation is voluntary. (4)
* I understand that once I have completed and submitted this survey I cannot withdraw my data. (5)

End of Block: Consent

Start of Block: CYP or adult (branch Q)

Screening Are you a young person aged 16 to 18 years or are you a parent of a young person aged 12 to 18 years?

* I am aged 16 to 18 years. (1)
* I am a parent/ guardian of a young person aged 12 to 18 years. (2)

End of Block: CYP or adult (branch Q)

Start of Block: Demographic (1)

Age How old are you?

* 16 (1)
* 17 (2)
* 18 (3)

Sex What sex were you assigned at birth, on your original birth certificate?

* Male (1)
* Female (2)

Gend How do you describe yourself?

* Male (1)
* Female (2)
* Transgender (3)
* Do not identify as female, male, or transgender (4)

Geo Please enter the first FOUR characters of your postcode (e.g. SO11)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

End of Block: Demographic (1)

Start of Block: CYP Pain Conds (1)

|  |
| --- |
|  |

Screening What type of chronic pain do you have? (please note: you can select multiple options).

* Chronic primary pain (including nonspecific back pain, any other area-specific chronic pain (e.g. back pain), chronic widespread pain and fibromyalgia) (1)
* Chronic cancer pain (2)
* Chronic post-surgical or post-traumatic pain (3)
* Chronic neuropathic pain (4)
* Chronic headache or orofacial pain (including primary and secondary headaches) (5)
* Chronic visceral pain (i.e. pain originating from internal organs) (6)
* Chronic musculoskeletal pain (i.e. pain arising as part of a disease process that affects the bones, joints, muscles, or related soft tissues; examples: arthritis, Ehlers-Danlos syndrome) (7)

Diag Who diagnosed your chronic pain?

* GP (1)
* Consultant (a medical doctor, e.g. paediatrician, rheumatologist) (2)
* Nurse (clinical nurse specialist or advanced nurse practitioner) (3)
* Someone else (please specify) (4) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |
| --- |
|  |

Dura How long have you been experiencing chronic pain for?

* 4-weeks or less (1)
* Less than 3-months (2)
* 3-months or longer (3)
* 6-months or longer (4)
* 1-year or longer (5)
* 3-years or longer (6)
* 5-years or longer (7)

|  |  |
| --- | --- |
| Page Break |  |

BPI Please rate your pain by selecting the box beside the number that best describes your pain at its worst in the last 24 hours.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0. No Pain (1) | 1. (2) | 2. (3) | 3. (4) | 4. (5) | 5. Moderate Pain (6) | 6. (7) | 7. (8) | 8. (9) | 9. (10) | 10. Pain as bad as you can imagine (11) |
| Pain rating (1)  |  |  |  |  |  |  |  |  |  |  |  |

BPI2 Please rate your pain by selecting the box beside the number that best describes your pain at its **least**in the last 24 hours.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0. No Pain (1) | 1. (2) | 2. (3) | 3. (4) | 4. (5) | 5. Moderate Pain (6) | 6. (7) | 7. (8) | 8. (9) | 9. (10) | 10. Pain as bad as you can imagine (11) |
| Pain Rating (1)  |  |  |  |  |  |  |  |  |  |  |  |

BPI3 Please rate your pain by selecting the box beside the number that best describes your pain **on average.**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0. No Pain (1) | 1. (2) | 2. (3) | 3. (4) | 4. (5) | 5. Moderate Pain (6) | 6. (7) | 7. (8) | 8. (9) | 9. (10) | 10. Pain as bad as you can imagine (11) |
| Pain Rating (1)  |  |  |  |  |  |  |  |  |  |  |  |

|  |  |
| --- | --- |
| Page Break |  |

PEDSQL On the following page is a list of things that might be a problem for you.
 Please tell us**how much of a problem**each one has been for you in the **LAST MONTH** by selecting:

 **0**if it is **never**a problem
 **1** if it is **almost never**a problem
 **2** if it is **sometimes**a problem
 **3**if it is **often** a problem
 **4** if it is **almost always**a problem

 There are no right or wrong answers.

|  |  |
| --- | --- |
| Page Break |  |

Phys In the ***LAST MONTH*** , how much of a **problem** has this been for you...

 About my health and activities (problems with...)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 0. Never (1) | 1. Almost Never (2) | 2. Sometimes (3) | 3. Often (4) | 4. Almost Always (5) |
| 1. It is difficult for me to walk more than 100 metres (1)  |  |  |  |  |  |
| 2. It is difficult for me to run (2)  |  |  |  |  |  |
| 3. It is difficult for me to play sport or do exercise (3)  |  |  |  |  |  |
| 4. It is difficult for me to lift something heavy (4)  |  |  |  |  |  |
| 5. It is difficult for me to have a bath or shower by myself (5)  |  |  |  |  |  |
| 6. It is difficult for me to help around the house (6)  |  |  |  |  |  |
| 7. I get aches and pains (7)  |  |  |  |  |  |
| 8. I have low energy (8)  |  |  |  |  |  |

EF About my feelings (problems with...)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 0. Never (1) | 1. Almost Never (2) | 2. Sometimes (3) | 3. Often (4) | 4. Almost Always (5) |
| 1. I feel afraid or scared (1)  |  |  |  |  |  |
| 2. I feel sad (2)  |  |  |  |  |  |
| 3. I feel angry (3)  |  |  |  |  |  |
| 4. I have trouble sleeping (4)  |  |  |  |  |  |
| 5. I worry about what will happen to me (5)  |  |  |  |  |  |

Soc How I get along with others (problems with...)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 0. Never (1) | 1. Almost Never (2) | 2. Sometimes (3) | 3. Often (4) | 4. Almost Always (5) |
| 1. I have trouble getting along with other teenagers (1)  |  |  |  |  |  |
| 2. Other teenagers do not want to be my friend (2)  |  |  |  |  |  |
| 3. Other teenagers tease me (3)  |  |  |  |  |  |
| 4. I cannot do things that other people my age can do (4)  |  |  |  |  |  |
| 5. It is hard to keep up with other teenagers (5)  |  |  |  |  |  |

Sch About school (problems with...)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 0. Never (1) | 1. Almost Never (2) | 2. Sometimes (3) | 3. Often (4) | 4. Almost Always (5) |
| 1. It is hard to pay attention in class (1)  |  |  |  |  |  |
| 2. I forget things (2)  |  |  |  |  |  |
| 3. I have trouble keeping up with my school work (3)  |  |  |  |  |  |
| 4. I am away from school because I feel sick (4)  |  |  |  |  |  |
| 5. I am away from school to go to the doctor or hospital (5)  |  |  |  |  |  |

End of Block: CYP Pain Conds (1)

Start of Block: Current Usage (1)

Healthcare Are you currently attending an NHS-based pain management service or programme?

* Yes (1)
* No (2)

Skip To: CP If Healthcare = No

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

NHSM Which healthcare professionals have been helping you to manage chronic pain? (please note: you can select multiple options)

* GP (1)
* Consultant (a medical doctor, e.g. paediatrician, rheumatologist) (2)
* Nurse (clinical nurse specialist or advanced nurse practitioner) (3)
* Occupational Therapist (4)
* Physiotherapist (5)
* Psychologist (6)

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

CP Do you currently use any mobile apps or websites to manage **chronic pain**? (please note: you can select multiple options)

* YouTube videos (1)
* MeToo (2)
* PainBytes (3)
* Facebook (4)
* Online forum (5)
* No - I do not use websites/ apps for pain management (6)
* Instagram (7)
* I use a different app/ website (8) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Reddit (9)
* Twitter (10)

|  |
| --- |
|  |

MH Do you use any mobile apps or websites to manage other **mental health** issues (e.g. depression, anxiety)? (please note: you can select multiple options)

* Headspace (1)
* Calm (2)
* MeToo (3)
* YouTube videos (4)
* Facebook (5)
* Instagram (6)
* Online forum (7)
* No - I do not use websites/ apps for mental health (8)
* I use a different app/ website (9) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Reddit (10)
* Twitter (11)
* Young Minds (12)

|  |  |
| --- | --- |
| Page Break |  |

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

NA3 Please use the boxes below to indicate your **top 3** most helpful pain management techniques.

Please type numbers 1, 2 and 3 into the boxes provided  (1 = most helpful).

\_\_\_\_\_\_ Medication/ pain-killers (1)

\_\_\_\_\_\_ Getting good nights sleep (2)

\_\_\_\_\_\_ Getting help and support with school work (3)

\_\_\_\_\_\_ Improving my understanding of chronic pain (4)

\_\_\_\_\_\_ Improving other peoples understanding of chronic pain (5)

\_\_\_\_\_\_ Physiotherapy exercises (6)

\_\_\_\_\_\_ Keeping active (7)

\_\_\_\_\_\_ Pacing myself (8)

\_\_\_\_\_\_ Relaxation and breathing (9)

\_\_\_\_\_\_ Mindfulness and/ or meditation (10)

\_\_\_\_\_\_ Other physical pain management methods (e.g. using TENS, thermal analgesia, desensitisation) (11)

\_\_\_\_\_\_ Psychological therapy - Cognitive Behavioural Therapy (CBT) (12)

\_\_\_\_\_\_ Hypnosis (13)

\_\_\_\_\_\_ Massage (14)

\_\_\_\_\_\_ Biofeedback (increasing awareness and modifying physiological processes e.g. heart rate) (15)

\_\_\_\_\_\_ Psychological therapy - Exposure therapy (16)

\_\_\_\_\_\_ Art therapy (17)

\_\_\_\_\_\_ Guided imagery and/or visualization (18)

\_\_\_\_\_\_ Rest (19)

End of Block: Current Usage (1)

Start of Block: Needs assessment - main (1)

|  |
| --- |
|  |

NA1 What are your initial thoughts about creating a **new online resource** that could help **young people** manage chronic pain?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |
| --- | --- |
| Page Break |  |

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

NA2 What sort of techniques do you think would be helpful to include in an **online resource** for chronic pain? (please note: you can select multiple options)

* Advice/ guidance on pain medications (1)
* Methods to improve sleep (2)
* Support for returning to school (3)
* Advice on explaining chronic pain to others (e.g. friends and family) (4)
* An explanation of what chronic pain is ('pain education') (5)
* Physiotherapy examples (6)
* Advice on how to pace yourself in daily activities (7)
* Advice on how to pace yourself for exercise/ sport (8)
* Relaxation and breathing techniques (9)
* Mindfulness and/ or meditation techniques (10)
* Advice on transitioning from 'paediatric' (child) to adult healthcare (11)
* Examples of other physical pain management methods (e.g. using TENS, thermal analgesia, desensitisation) (12)
* Challenging and restructuring negative thoughts (13)
* Hypnosis (14)
* Massage techniques (15)
* Biofeedback (increasing awareness and modifying physiological processes e.g. heart rate) (16)
* Exposure therapy techniques (i.e. gradually exposing yourself to situations that you would usually avoid) (17)
* Art therapy (18)
* Guided imagery and/or visualization (19)

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

NA4 Is there any technique or therapy (not yet mentioned) that you think would be especially useful for you to be able to access **at home**?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |
| --- | --- |
| Page Break |  |

NA5 What sort of structure would you like a resource with multiple pain management techniques to have?

* I would like a flexible structure where I could choose which sections I want to use. (1)
* I would like something that has a set structure and is completed over a number of days/ weeks. (2)
* I do not mind how the resource is structured. (3)
* I would like something else (please describe). (4) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

NA5a Would you like to have professional support **over the telephone** whilst accessing the intervention?

* Definitely yes (1)
* Probably yes (2)
* Might or might not (3)
* Probably not (4)
* Definitely not (5)

NA5b Would you like to have professional support **online** whilst accessing the intervention?

* Definitely yes (1)
* Probably yes (2)
* Might or might not (3)
* Probably not (4)
* Definitely not (5)

NA6 Some pain programmes have a theme, for example one online programme we know of has a travel theme.
   Would this appeal to you in any way?

* Yes (1)
* Maybe (2)
* No (6)

|  |  |
| --- | --- |
| Page Break |  |

D1 In your opinion, how important is the design of an online resource for chronic pain?

* Extremely important (1)
* Very important (2)
* Moderately important (3)
* Slightly important (4)
* Not at all important (5)

D2 How important is it for online pain management programmes to be linked with a hospital or clinic?

* Extremely important (1)
* Very important (2)
* Moderately important (3)
* Slightly important (4)
* Not at all important (5)

D3 Are pictures and videos important for online pain management?

* Extremely important (1)
* Very important (2)
* Moderately important (3)
* Slightly important (4)
* Not at all important (5)

|  |  |
| --- | --- |
| Page Break |  |

D3a If videos, e.g. videos of physiotherapy, were included in an online pain management resource, would you prefer the person in the video to be a professional or a patient?

* A healthcare professional (1)
* A (teenage) patient (2)
* No preference (3)

D3b Would you prefer the person in the video(s) to be male or female?

* Male (1)
* Female (2)
* No preference (3)

|  |
| --- |
|  |

D3c Would you prefer the person in the video(s) to be of a particular ethnicity?

* No preference (1)
* White (2)
* Mixed/ Multiple ethnic groups (3)
* Asian/ Asian British (4)
* Black / African / Caribbean / Black British (5)

|  |  |
| --- | --- |
| Page Break |  |

Adher Is there anything that could **motivate or prevent** you from using an online pain programme on a regular basis?

* Not that I know of (1)
* Yes (please state) (2) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

Add Are there any additional comments you would like to make about **online chronic pain management** for young people?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

End of Block: Needs assessment - main (1)

Start of Block: Demographic (2)

hy **The following questions are about YOU:**

\*Age Please select your age group.

* 18-35 years (1)
* 36-55 years (2)
* 55+ years (3)

Sex\* What sex were you assigned at birth, on your original birth certificate?

* Male (1)
* Female (2)

\*Gend How do you describe yourself?

* Male (1)
* Female (2)
* Transgender (3)
* Do not identify as female, male, or transgender (4)

\*Geo Please enter the first FOUR characters of your postcode (e.g. SO11)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

End of Block: Demographic (2)

Start of Block: CYP pain conds (2)

ht **The following questions are about YOUR TEENAGER:**

|  |
| --- |
|  |

\*Screening What type of chronic pain does **your teenager** have? (please note: you can select multiple options).

* Chronic primary pain (including nonspecific back pain, any other area-specific chronic pain (e.g. back pain), chronic widespread pain and fibromyalgia) (1)
* Chronic cancer pain (2)
* Chronic post-surgical or post-traumatic pain (3)
* Chronic neuropathic pain (4)
* Chronic headache or orofacial pain (including primary and secondary headaches) (5)
* Chronic visceral pain (i.e. pain originating from internal organs) (6)
* Chronic musculoskeletal pain (i.e. pain arising as part of a disease process that affects the bones, joints, muscles, or related soft tissues; examples: arthritis, Ehlers-Danlos syndrome) (7)

\*Diag Who diagnosed **your teenagers** chronic pain?

* GP (1)
* Consultant (a medical doctor, e.g. paediatrician, rheumatologist) (2)
* Nurse (clinical nurse specialist or advanced nurse practitioner) (3)
* Someone else (please specify) (4) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |
| --- |
|  |

\*Dura How long has **your teenager** been experiencing chronic pain for?

* 4-weeks or less (1)
* Less than 3-months (2)
* 3-months or longer (3)
* 6-months or longer (4)
* 1-year or longer (5)
* 3-years or longer (6)
* 5-years or longer (7)

|  |  |
| --- | --- |
| Page Break |  |

\*BPI Please rate **your teenagers** pain by selecting the box beside the number that best describes their pain at its **worst** in the last 24 hours.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0. No Pain (1) | 1. (2) | 2. (3) | 3. (4) | 4. (5) | 5. Moderate Pain (6) | 6. (7) | 7. (8) | 8. (9) | 9. (10) | 10. Pain as bad as you can imagine (11) |
| Pain Rating (1)  |  |  |  |  |  |  |  |  |  |  |  |

\*BPI2 Please rate **your teenagers** pain by selecting the box beside the number that best describes their pain at its **least** in the last 24 hours.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0. No Pain (1) | 1. (2) | 2. (3) | 3. (4) | 4. (5) | 5. Moderate Pain (6) | 6. (7) | 7. (8) | 8. (9) | 9. (10) | 10. Pain as bad as you can imagine (11) |
| Pain Rating (1)  |  |  |  |  |  |  |  |  |  |  |  |

\*BPI3 Please rate **your teenagers** pain by selecting the box beside the number that best describes their pain **on** **average.**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0. No Pain (1) | 1. (2) | 2. (3) | 3. (4) | 4. (5) | 5. Moderate Pain (6) | 6. (7) | 7. (8) | 8. (9) | 9. (10) | 10. Pain as bad as you can imagine (11) |
| Pain Rating (1)  |  |  |  |  |  |  |  |  |  |  |  |

|  |  |
| --- | --- |
| Page Break |  |

PEDSQL -P On the following page is a list of things that might be a problem for **your teenager**. Please tell us**how much of a problem**each one has been for **your teenager** during the **past ONE month** by selecting:

 **0**if it is **never**a problem
 **1** if it is **almost never**a problem
 **2** if it is **sometimes**a problem
 **3**if it is **often** a problem
 **4** if it is **almost always**a problem

 There are no right or wrong answers.

|  |  |
| --- | --- |
| Page Break |  |

Phys\* In the *past* ***ONE month*** , how much of a **problem** has your teenager had with...

 Physical functioning (problems with...)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 0. Never (1) | 1. Almost Never (2) | 2. Sometimes (3) | 3. Often (4) | 4. Almost Always (5) |
| 1. Walking more than one block (1)  |  |  |  |  |  |
| 2. Running (2)  |  |  |  |  |  |
| 3. Participating in sports activity or exercise (3)  |  |  |  |  |  |
| 4. Lifting something heavy (4)  |  |  |  |  |  |
| 5. Taking a bath or shower by him or herself (5)  |  |  |  |  |  |
| 6. Doing chores around the house (6)  |  |  |  |  |  |
| 7. Having aches or pains (7)  |  |  |  |  |  |
| 8. Having a low energy level (8)  |  |  |  |  |  |

EF\* Emotional functioning (problems with...)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 0. Never (1) | 1. Almost Never (2) | 2. Sometimes (3) | 3. Often (4) | 4. Almost Always (5) |
| 1. Feeling afraid or scared (1)  |  |  |  |  |  |
| 2. Feeling sad (2)  |  |  |  |  |  |
| 3. Feeling angry (3)  |  |  |  |  |  |
| 4. Having trouble sleeping (4)  |  |  |  |  |  |
| 5. Worrying about what will happen to him or her (5)  |  |  |  |  |  |

Soc\* Social functioning (problems with...)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 0. Never (1) | 1. Almost Never (2) | 2. Sometimes (3) | 3. Often (4) | 4. Almost Always (5) |
| 1. Getting along with other teenagers (1)  |  |  |  |  |  |
| 2. Other teenagers wanting to be his or her friend (2)  |  |  |  |  |  |
| 3. Getting teased by other teenagers (3)  |  |  |  |  |  |
| 4. Not being able to do things that other teenagers his or her age can do (4)  |  |  |  |  |  |
| 5. Keeping up with other teenagers (5)  |  |  |  |  |  |

Sch\* School functioning (problems with...)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 0. Never (1) | 1. Almost Never (2) | 2. Sometimes (3) | 3. Often (4) | 4. Almost Always (5) |
| 1. Paying attention in class (1)  |  |  |  |  |  |
| 2. Forgetting things (2)  |  |  |  |  |  |
| 3. Keeping up with school work (3)  |  |  |  |  |  |
| 4. Missing school because of not feeling well (4)  |  |  |  |  |  |
| 5. Missing school to go to the doctor or hospital (5)  |  |  |  |  |  |

End of Block: CYP pain conds (2)

Start of Block: Current usage (2)

ht2 **The questions in the following section are about pain management techniques for YOUR TEENAGER.**

|  |  |
| --- | --- |
| Page Break |  |

\*HC Is **your teenager** currently attending an NHS-based pain management service or programme?

* Yes (1)
* No (2)

Skip To: \*CP If \*HC = No

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

NHSM\* Which healthcare professionals have been helping **your teenager** to manage chronic pain? (please note: you can select multiple options)

* GP (1)
* Consultant (a medical doctor, e.g. paediatrician, rheumatologist) (2)
* Nurse (clinical nurse specialist or advanced nurse practitioner) (3)
* Occupational Therapist (4)
* Physiotherapist (5)
* Psychologist (6)

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

\*CP Does **your teenager** currently use any mobile apps or websites (that your know of) to manage **chronic pain**? (please note: you can select multiple options)

* YouTube videos (1)
* MeToo (2)
* PainBytes (3)
* Facebook (4)
* Online forum (5)
* No - They do not use websites/ apps for pain management (6)
* Instagram (7)
* They use a different app/ website (8) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Reddit (9)
* Twitter (10)

|  |
| --- |
|  |

\*MH Does **your teenager** use any mobile apps or websites (that you know of) to manage other **mental health** issues (e.g. depression, anxiety)? (please note: you can select multiple options)

* Headspace (1)
* Calm (2)
* MeToo (3)
* YouTube videos (4)
* Facebook (5)
* Instagram (6)
* Online forum (7)
* No - They do not use websites/ apps for mental health (8)
* They use a different app/ website (9) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Reddit (10)
* Twitter (11)
* Young Minds (12)

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

CPP\* As a parent/ guardian, do **YOU** use any online resources to help you understand or manage **your teenagers** **chronic pain**? (please note: you can select multiple options)

* YouTube videos (1)
* PainBytes (2)
* Facebook (3)
* Online forum (4)
* No - I do not use online resources to understand/ manage my teenagers chronic pain (5)
* Instagram (6)
* I use a different online resource (7) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Reddit (8)
* Twitter (9)

|  |  |
| --- | --- |
| Page Break |  |

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

NA3\*\* Please use the boxes below to indicate **your teenagers top 3** most helpful pain management techniques.

Please type numbers 1, 2 and 3 into the boxes provided  (1 = most helpful).

\_\_\_\_\_\_ Medication/ pain-killers (1)

\_\_\_\_\_\_ Getting good nights sleep (2)

\_\_\_\_\_\_ Getting help and support with school work (3)

\_\_\_\_\_\_ Improving my understanding of chronic pain (4)

\_\_\_\_\_\_ Improving other peoples understanding of chronic pain (5)

\_\_\_\_\_\_ Physiotherapy exercises (6)

\_\_\_\_\_\_ Keeping active (7)

\_\_\_\_\_\_ Pacing myself (8)

\_\_\_\_\_\_ Relaxation and breathing (9)

\_\_\_\_\_\_ Mindfulness and/ or meditation (10)

\_\_\_\_\_\_ Other physical pain management methods (e.g. using TENS, thermal analgesia, desensitisation) (11)

\_\_\_\_\_\_ Psychological therapy - Cognitive Behavioural Therapy (CBT) (12)

\_\_\_\_\_\_ Hypnosis (13)

\_\_\_\_\_\_ Massage (14)

\_\_\_\_\_\_ Biofeedback (increasing awareness and modifying physiological processes e.g. heart rate) (15)

\_\_\_\_\_\_ Psychological therapy - Exposure therapy (16)

\_\_\_\_\_\_ Art therapy (17)

\_\_\_\_\_\_ Guided imagery and/or visualization (18)

\_\_\_\_\_\_ Rest (19)

End of Block: Current usage (2)

Start of Block: Needs assessment (2)

|  |
| --- |
|  |

\*NA1 What are your initial thoughts about creating a **new online resource** that could help **young people** manage chronic pain?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |
| --- | --- |
| Page Break |  |

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

\*NA2 What sort of techniques do you think would be helpful to include in an online resource for **chronic pain in teenagers**? (please note: you can select multiple options)

* Advice/ guidance on pain medications (1)
* Methods to improve sleep (2)
* Support for returning to school (3)
* Advice on explaining chronic pain to others (e.g. friends and family) (4)
* An explanation of what chronic pain is ('pain education') (5)
* Physiotherapy examples (6)
* Advice on how to pace yourself in daily activities (7)
* Advice on how to pace yourself for exercise/ sport (8)
* Relaxation and breathing techniques (9)
* Mindfulness and/ or meditation techniques (10)
* Advice on transitioning from 'paediatric' (child) to adult healthcare (11)
* Examples of other physical pain management methods (e.g. using TENS, thermal analgesia, desensitisation) (12)
* Challenging and restructuring negative thoughts (13)
* Hypnosis (14)
* Massage techniques (15)
* Biofeedback (increasing awareness and modifying physiological processes e.g. heart rate) (16)
* Exposure therapy techniques (i.e. gradually exposing yourself to situations that you would usually avoid) (17)
* Art therapy (18)
* Guided imagery and/or visualization (19)

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

\*NA4 Is there any technique or therapy (not yet mentioned) that you think would be especially useful for your teenager to be able to access at home?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |
| --- | --- |
| Page Break |  |

\*NA5 What sort of structure would you like a resource with multiple pain management techniques to have?

* I would like a flexible structure where I could choose which sections I want to use. (1)
* I would like something that has a set structure and is completed over a number of days/ weeks. (2)
* I do not mind how the resource is structured. (3)
* I would like something else (please describe). (4) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

NA5a\* Would you like your teenager to have professional support **over the telephone** whilst accessing the intervention?

* Definitely yes (1)
* Probably yes (2)
* Might or might not (3)
* Probably not (4)
* Definitely not (5)

NA5b\* Would you like your teenager to have professional support **online** whilst accessing the intervention?

* Definitely yes (1)
* Probably yes (2)
* Might or might not (3)
* Probably not (4)
* Definitely not (5)

\*NA6 Some pain programmes have a theme, for example one online programme we know of has a travel theme.
   Do you think this would appeal to **your teenager** in any way?

* Yes (1)
* Maybe (2)
* No (3)

|  |  |
| --- | --- |
| Page Break |  |

\*D1 In your opinion, how important is the design of an online resource for chronic pain which is directed at teenagers?

* Extremely important (1)
* Very important (2)
* Moderately important (3)
* Slightly important (4)
* Not at all important (5)

\*D2 How important is it for online pain management programmes for teenagers to be affiliated with a hospital or clinic?

* Extremely important (1)
* Very important (2)
* Moderately important (3)
* Slightly important (4)
* Not at all important (5)

\*D3 Do you think that pictures and videos are important for online pain management in teenagers?

* Extremely important (1)
* Very important (2)
* Moderately important (3)
* Slightly important (4)
* Not at all important (5)

|  |  |
| --- | --- |
| Page Break |  |

D3a\* If videos, e.g. videos of physiotherapy, were included in an online pain management resource, would you prefer the person in the video to be a professional or a patient?

* A healthcare professional (1)
* A (teenage) patient (2)
* No preference (3)

D3b\* Would you prefer the person in the video(s) to be male or female?

* Male (1)
* Female (2)
* No preference (3)

|  |
| --- |
|  |

D3c\* Would you prefer the person in the video(s) to be of a particular ethnicity?

* No preference (1)
* White (2)
* Mixed/ Multiple ethnic groups (3)
* Asian/ Asian British (4)
* Black / African / Caribbean / Black British (5)

|  |  |
| --- | --- |
| Page Break |  |

\*Adher Is there anything that could motivate or prevent **your teenager** from using an online pain programme on a regular basis?

* Not that I know of (1)
* Yes (please state) (2) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |
| --- | --- |
| Page Break |  |

|  |
| --- |
|  |

\*Add Are there any additional comments you would like to make about **online chronic pain management** for young people?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

End of Block: Needs assessment (2)

Start of Block: Debrief

Debrief form **Study title: Online Paediatric Chronic Pain Management: assessing the needs of young people and their parents**

 **Debriefing Statement** *(written)* (version 0.1, 11-04-2019)
 **ERGO ID: 48723**

 The aims of this research were to investigate a) which online resources young people currently use to manage chronic pain, and b) what content and features young people and their parents would like to see in an online pain management intervention.

 It is expected that we will find there are a variety of online resources that young people use to manage chronic pain, and that there will be some key similarities between the resources young people with different types of chronic pain use. We also believe there will be some key aspects of pain management that young people and their parents would like to be able to access online.

 Your data will help our understanding of how young people use online resources to manage chronic pain and will contribute to the development of a new intervention. The intervention currently being developed will also be drawing insights from healthcare professionals who work in chronic pain management, and young people who are undergoing treatment for chronic pain via NHS services.

 Once again, the results of this study will not include your name or any other identifying characteristics. The research did not use deception. You may print or save a copy of this summary if you wish.

 If you have any further questions about this study or the research project, or would like to find out the results of this survey please contact me (Anna Hurley-Wallace; A.Hurley-Wallace@soton.ac.uk), or alternatively you may contact my research supervisor (Prof Christina Liossi; C.Liossi@soton.ac.uk).

 A useful resource you could look at if you would like some more general information about chronic pain in young people is: <http://www.aci.health.nsw.gov.au/chronic-pain/painbytes> (recommended by Great Ormond Street Hospital Pain Control Service).

 Thank you for your participation in this research.

 Signature:

 ​
 Miss Anna Hurley-Wallace            Date: 11-04-2019

 If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

End of Block: Debrief