

# UK Biobank

## Pain web questionnaire

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Version 2.1

<http://www.ukbiobank.ac.uk/>

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This document details the rationale and procedure for administration of the pain web-based questionnaire for UK Biobank.

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## 1 Introduction

### *The impact of chronic pain on human health*

Chronic pain is maladaptive and a major cause of human suffering. Chronic pain can be clinically defined as pain lasting more than 3 months and affects 1 in 5 of the general population (Breivik, Collett et al. 2006). In many cases such pain is exaggerated in relation to the degree of tissue injury and is poorly responsive to analgesics, in marked contrast to acute pain. Current treatments have poor efficacy and tolerability (Grosser, Woolf et al. 2017). The prevalence of chronic pain will increase as predisposing conditions (such as diabetes mellitus and malignancy) become more common and as a consequence of the ageing population. Chronic pain has a major economic impact due to the use of health resources and impact on ability to work. Chronic pain can be broadly divided into sub-types: inflammatory/nociceptive pain (such as pain associated with arthritis), neuropathic pain (which arises as a consequence of injury to the sensory nervous system e.g. diabetic neuropathy) and sensitised pain states (in which chronic pain arises in the absence of overt pathology e.g. fibromyalgia). It is increasingly understood that pain is not a ‘unitary’ phenomenon but a multi-dimensional experience combining sensory discriminative features (e.g. where the pain is and the quality of the pain) with important affective components. Pain is associated with co-morbidities such as anxiety, depression and sleep disturbance all of which enhance suffering (Colloca, Ludman et al. 2017).

## 2 Scientific rationale

There are specific challenges associated with phenotyping pain since patients may suffer from multiple pains of diverse aetiologies with the additional key interaction of psychological factors that can make the perception and thus impact of chronic pain, considerably worse. It is essential to carefully record the duration, location, intensity and quality of pain as well as the temporal relationship to predisposing factors and co-morbidities (such as sleep, anxiety and depression). Whilst UK Biobank gathered data on pain during the baseline assessment, the level of phenotyping is not sufficient to undertake any pain-related GWAS.

The need to capture these various data led to the development of the current questionnaire in consultation with a group of leaders in the field (a list of the main contributors and their affiliations is included in Section 3).

The questionnaire incorporates a number of elements which have been previously tested and validated in cohorts of patients suffering from pain as well as in population-based studies. These questionnaires are all well validated and in routine use by pain researchers and/or clinical practitioners and are fully aligned with major international consortia studying chronic pain (such as DOLORisk, Generation Scotland and the International Diabetic Neuropathy Consortium).

A detailed guide to the contents of the questionnaire is included in Section 4. Here we provide a brief overview with a guide to the approximate numbers of questions in each section of the questionnaire (as the exact number depends on answers provided). It is very unlikely that participants will need to complete every question in every section:

- Section A: Introductory checks. 3 questions.
- Section B: Medical conditions you may have. 14-19 questions.
- Section C: Location of pain. 8-38 questions.
- Section D: Nature of pain. 0-7 questions.
- Section E: Headache. 1-19 questions.
- Section F: Legs and feet. 0-15 questions.
- Section G: Impact of pain. 0-12 questions.
- Section H: Health outcomes. 6 questions.
- Section I: Current depression. 9-10 questions.
- Section J: Fatigue. 1-16 questions.
- Section K. End page.

We have used the following principles:

- We have focussed on chronic pain which is the leading cause of disability and used the widely accepted definition of pain present for more than 3 months duration.
- For efficiency we have applied disease specific pain questionnaires in a targeted fashion, e.g. the Michigan Neuropathy Screening Instrument (Feldman, Stevens et al. 1994) is only asked of respondents that have (or are at risk of) peripheral neuropathy.
- The number of body regions has been extended from those asked in the UK Biobank baseline questionnaire to cover all body regions commonly affected by chronic pain.
- Because many people have multiple pains we have asked respondents to focus on the pain that 'bothers them most' in order to improve specificity.
- Pain intensity, pain interference and pain qualities are captured using the Douleur Neuropathic 4 (DN4) (Bouhassira, Attal et al. 2005) and questions taken from the Brief Pain Inventory (BPI) (Cleeland and Ryan 1994, Zelman, Gore et al. 2005), both of which have been widely used and extensively validated. However, given questions have been omitted from the BPI, no validity based on the BPI scoring can be claimed.
- We have also included measures of quality of life which are validated in pain cohorts (EQ-5D-5L) (Group. 1990) and also assessment of anxiety and depression (PHQ-9) (Kroenke, Spitzer et al. 2001), a common co-morbidity with chronic pain.

### **3 List of main contributors**

Professor David Wynick, Professor of Molecular Medicine, University of Bristol.

Professor Blair Smith, Head of Population Sciences Division and Professor of Population Science, University of Dundee.

Professor David Bennett, Professor of Neurology and Neurobiology, University of Oxford.

Professor Gary Macfarlane, Clinical Chair in Epidemiology, University of Aberdeen.

### **4 Content**

Details of rationale and tools used in sensation and chronic pain questionnaire are shown on the following page.

The full list of questions can be found in Appendix 1.

| <b>Domain/question topic</b>               | <b>Purpose</b>   | <b>Source/tool</b>  | <b>Notes about source/tool</b>  | <b>Reference</b>                |
|--|--|---|---|---------------------------------|
| Section A: Introductory checks.            | To confirm personal details.   | Bespoke   | --  | None                            |
| Section B: Medical conditions you may have | To ascertain whether the participant has had a diagnosis of any of the common conditions associated with chronic pain. | Bespoke   | --  | None                            |
| Section C: Location of pain                | To capture information about the location of pain.   | Bespoke, based on the UK Biobank location of pain questions.  | Simplified survey format for use in epidemiological studies.  | None                            |
|  |  | American College of Rheumatology 2010 preliminary diagnostic criteria for fibromyalgia                      |   | (Wolfe, Clauw et al. 2011)      |
| Section D: Nature of pain                  | To obtain self-report data on neuropathic pain.  | Douleur Neuropathique 4 (DN4) (excluding clinician assessment)  | An easy-to-use screening tool that is reliable for discriminating between neuropathic and nociceptive pain conditions Widely used in both research and clinical settings. | (Bouhassira, Attal et al. 2005) |
| Section E: Headache                        | To obtain self-report data on headache symptoms and severity.  | Bespoke section based on the questions used in the American Migraine Prevalence and Prevention (AMPP) Study | Simplified version of questionnaire utilised in a large-scale population-based study.   | (Lipton, Bigal et al. 2007)     |
| Section F: Legs and feet                   | To screen for the presence of diabetic neuropathy.   | Michigan Neuropathy Screening Instrument (MNSI)   | Commonly used assessment tool.  | (Feldman, Stevens et al. 1994)  |

|                               |  |   |   |                                |
|-------------------------------|--|---|---|--------------------------------|
| Section G: Impact of pain     | To assess the severity of pain and its impact on functioning.  | Bespoke section which includes some questions found in the Brief Pain Inventory (Short Form). | This section includes questions taken from the BPI. However, no validity based on the BPI scoring can be claimed.   | None                           |
| Section H: Health outcomes    | To measure health-related quality of life.   | EQ-5D-5L  | A standardised instrument widely used as a measure of health outcome.   | (Group. 1990)                  |
| Section I: Current depression | To screen for likely presence / absence and severity of current depression. This will allow assessments of how depression is related to other illnesses or situations. | Patient Health Questionnaire-9 (PHQ-9)  | An established research and clinical tool. All or part of the scale has previously been completed at baseline assessment and in the mental health questionnaire | (Kroenke, Spitzer et al. 2001) |
| Section J: Fatigue            | To measure the severity of fatigue symptoms.   | Bespoke questions on Chronic Fatigue Syndrome, plus Fatigue Severity Scale (FSS)              |   | (Krupp, LaRocca et al. 1989)   |

## **5 Piloting**

Prior to inviting all participants with a contact email address (approximately 320,000 – 340,000) to complete it, UK Biobank piloted this questionnaire with 10,000 participants to ensure the platform and procedures were adequately robust in terms of acceptability of content and length.

## **6 Administration**

- 6.1 UK Biobank's re-contact approach for those participants with an email address as follows:
  - an initial invitation email (which included a hyperlink to their personalised questionnaire);
  - a reminder email to non-responders sent two weeks after the initial invite;
  - a reminder to partial responders (i.e. who only completed part of the questionnaire) two weeks after they started the questionnaire;
  - a 'last-chance' reminder sent to non-responders four months after the initial invite.
- 6.2 69.9% of participants completed the questionnaire in less than 20 minutes.
- 6.3 Overall, 335,587 participants were sent an email invitation, of whom 166,733 (49.7%) fully completed the questionnaire (as of November 2019). A further 495 participants accessed the questionnaire via the participant website without having received an email invite (because they have not provided UK Biobank with a valid email address or completed the questionnaire via the participant website prior to an invite being sent).
- 6.4 Participants for whom we do not have an email address were encouraged via the annual newsletter (sent Q3 2017) to complete the online questionnaire by logging directly onto the participant website.
- 6.5 Email invitations are also routinely sent to those participants who have recently updated their email address (and who have not yet completed the questionnaire). We therefore anticipate that data will continue to accrue for a small number of participants.
- 6.6 Please note that UK Biobank has identified a small number of possible mismatches in the linkage of the questionnaire (e.g., where participants who share an email address, or a computer/tablet may have completed their partner's questionnaire). These data have not been released.

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## Appendix 1: Questions and format of the questionnaire

| Q. No | Field ID | Stem   | Responses |
|-------|----------|--|-----------|
| INTRO | N/A      | <p>Chronic pain (pain lasting more than 3 months) is a major cause of human suffering and affects 1 in 5 of the general population. We need to know more about the causes of chronic pain if we are going to improve current treatments or develop new treatments.</p> <p>UK Biobank provides a unique opportunity to better understand chronic pain. We hope to combine the results of this questionnaire with other information you have provided to gain a deeper understanding of the risk factors, triggers and underlying causes of the different kinds of chronic pain.</p> <p>Please answer all the following questions even if you do not suffer from chronic pain – having information from people who do not experience chronic pain is critical to allow us to better understand the information from people who do experience chronic pain.</p> <p>The questionnaire is split into sections, each section having a slightly different purpose. The questionnaire will automatically skip questions that do not apply to you so don't worry if it looks like you missed questions out. However, you may notice that there is still some overlap in several questions; this is necessary to ensure that all the information we collect is completely reliable. We would therefore be grateful if you can answer all the questions you are asked, even if you think you have already provided the information.</p> | Next      |
|       | N/A      | <p>To help you as you work your way through the questionnaire:</p> <ul style="list-style-type: none"> <li>• Most devices will allow you to click or tap the description beside a choice button to select it.<br/>Click or tap on this sentence.<br/>Click /tap here.<br/>and over here.</li> <li>• A slider allows you to select a value from a range. Click or tap or drag the slider pointer until your chosen value is displayed.</li> <li>• The progress bar at the bottom of each page (see below) is split into blocks, with each block representing a different section of the questionnaire.</li> </ul>  | Next      |

| Section A: Checks |          |  |  |
|-------------------|----------|--|--|
| Q. No             | Field ID | Stem   | Response   |
| AIntro            | N/A      | <p>This questionnaire is participant specific. It should only be completed by the person named on the email invite OR the person who logged into the participant website.</p> <p>First, we need to check a few things.</p> |  |
| AIntro<br>A1      | N/A      | Please confirm your month and year of birth  | 01 = January<br>02 = February<br>03 = March<br>04 = April<br>05 = May<br>06 = June<br>07 = July<br>08 = August<br>09 = September<br>10 = October<br>11 = November<br>12 = December |
| A2                | N/A      | Please confirm your sex  | 01 = Male<br>02 = Female   |
| AINTROr restart   | N/A      | Now let's continue from where you left off....   |  |
| ACLOSE            | N/A      | Now let's start the questionnaire.   |  |

| Section B: Medical Conditions |          |  |  |
|-------------------------------|----------|--|--|
| Q. No                         | Field ID | Stem   | Response   |
| BINTRO                        | N/A      | Let's start with a few general questions about your health and pain that you may have. |  |
| BLOCKB1                       | N/A      | Have you ever been told by a doctor that you have had any of the following conditions? |  |
| B1a                           | 120000   | Osteoarthritis affecting one or more joints (e.g. hip, knee, shoulder)                 | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| B1b                           | 120001   | Rheumatoid arthritis affecting one or more joints                                      | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| B1c                           | 120002   | Cancer pain  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| B1d                           | 120003   | Carpal tunnel syndrome   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |

|        |        |   |  |
|--------|--------|---|--|
| B1e    | 120004 | Complex regional pain syndrome<br>(also known as CRPS)  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1f    | 120005 | Chronic post-surgical pain  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1fi   | 120006 | When was this surgery performed?  | Allows selection of an integer between YOB and current year<br>DK=Do not know<br>DA=Prefer not to answer |
| B1g    | 120007 | Diabetes (Type I or Type II)  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1h    | 120008 | Any cause of nerve damage/neuropathy other than diabetic neuropathy   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1i    | 120009 | Fibromyalgia syndrome   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1j    | 120010 | Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (M.E.)  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1k    | 120011 | Gout  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1ki   | 120012 | Do you think you are currently experiencing a gout flare?   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1kii  | 120013 | Is your gout causing you to have a swollen joint now?   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1kiii | 120014 | Is your gout causing you to have a warm joint now?  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer   |
| B1kiv  | 120015 | What was the average pain from your gout in the <b>past 24 hours</b> while you were resting?<br><br><i>Please indicate a number from 0 to 10, with 0 meaning "no pain" and 10 meaning "worst possible pain"</i> | 0-10 VAS with 0 marked as no pain and 10 marked as worst possible pain<br><br>DA=Prefer not to answer    |

|     |        |   |  |
|-----|--------|---|--|
| B1l | 120016 | Migraine                                      | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| B1m | 120017 | Pelvic pain                                   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| B1n | 120018 | Post herpetic neuralgia (pain after shingles) | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |

| Section C: Location of pain            |          |  |   |
|--|----------|--|---|
| Q. No                                  | Field ID | Stem   | Response  |
| CINTRO                                 | N/A      | This section is about where you experience pain.   |   |
| <b>Pain over the last three months</b> |          |  |   |
| C1                                     | 120019   | Are you troubled by pain or discomfort, either all the time or on and off, that has been present <b>for more than 3 months?</b>  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer  |
| C2                                     | 120020   | How long have you been suffering with this pain or discomfort?   | 01=3-12 months<br>02=1-5 years<br>03=More than 5 years<br>DK=Do not know<br>DA=Prefer not to answer       |
| BLOCKC3                                | N/A      | <b>Now we are going to ask you about where you experience this pain or discomfort.</b><br><br><b>In the last 3 months</b> have you experienced pain or discomfort in any of the following areas? |   |
| C3a                                    | 120021   | Pain all over the body   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer  |
| C3ai                                   | 120022   | <b>Thinking about the last 24 hours</b> , how would you rate your <b>pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?                                      | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3b                                    | 120023   | Head   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer  |
| C3c                                    | 120024   | Face   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer  |

|      |        |  |  |
|------|--------|--|--|
| C3d  | 120025 | Neck or shoulders  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3e  | 120026 | Back   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
|      | N/A    | <b>In the last 3 months</b> have you experienced pain or discomfort in any of the following areas? |  |
| C3f  | 120027 | Stomach or abdomen   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3g  | 120028 | Hips   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3h  | 120029 | Knees  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3i  | 120030 | Arms   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
|      | N/A    | <b>In the last 3 months</b> have you experienced pain or discomfort in any of the following areas? |  |
| C3j  | 120031 | Hands  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3k  | 120033 | Feet   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3ki | 120032 | Is the pain present in both your feet?   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3l  | 120034 | Legs   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3m  | 120035 | Chest  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| C3n  | 120036 | (An)other part(s) of your body   | 01=Yes<br>00=No<br>DA=Prefer not to answer                   |

|       |        |  |   |
|-------|--------|--|---|
| C3bi  | 120023 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>head pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?               | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3ci  | 120024 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>facial pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?             | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3di  | 120025 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>neck or shoulder pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?   | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3ei  | 120026 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>back pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?               | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3fi  | 120027 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>stomach or abdomen pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’? | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3gi  | 120028 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>hip pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?                | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3hi  | 120029 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>knee pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?               | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3ii  | 120030 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>arm pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?                | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3ji  | 120031 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>hand pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?               | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3kii | 120033 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>foot pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?               | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer |
| C3li  | 120034 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>leg pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?                | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.                            |

|                                |        |   |   |
|--------------------------------|--------|---|---|
|                                |        |   | DA=Prefer not to answer   |
| C3mi                           | 120035 | <b>Thinking about the last 24 hours</b> , how would you rate your <b>chest pain</b> on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?                           | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as it could be.<br>DA=Prefer not to answer   |
| C4                             | 120037 | Which one of the pains you have experienced in the last 3 months has bothered you most?   | 01=Headache<br>02=Facial pain<br>03=Neck or shoulder pain<br>04=Back pain<br>05=Stomach or abdominal pain<br>06=Hip pain<br>07=Knee pain<br>08=Pain in arms<br>09=Pain in hands<br>10=Pain in the feet<br>11=Chest pain<br>12=Legs<br>NN=None of the above<br>DA=Prefer not to answer   |
| <b>Pain over the last week</b> |        |   |   |
| <b>Widespread pain</b>         |        |   |   |
| C5INTRO                        | N/A    | You may notice that the next few questions are similar to the ones you have just answered. This information is important so that we can find out a bit more about your <b>recent pain</b> . |   |
| C5a                            | 120038 | Have you been troubled by pain or tenderness during the past week?  | 01=Yes<br>00>No<br>DK=Do not know<br>DA=Prefer not to answer  |
| C5b                            | 120039 | Please indicate if you have had pain or tenderness <b>during the past week</b> in each of the areas listed below.   | 01=Shoulder girdle, left<br>02=Shoulder girdle, right<br>03=Upper arm, left<br>04=Upper arm, right<br>05=Lower arm, left<br>06=Lower arm, right<br>07=Hip (buttock), left<br>08=Hip (buttock,) right<br>09 Upper leg, left<br>10=Upper leg, right<br>11=Lower leg, left<br>12=Lower leg, right<br>13=Jaw, left<br>14=Jaw, right<br>15=Chest<br>16=Abdomen<br>17=Neck<br>18=Upper back<br>19=Lower back<br>NN=None of these areas<br>DA=Prefer not to answer |

| <b>Symptom Severity</b> |        |   |  |
|-------------------------|--------|---|--|
| BLOCKC6                 | N/A    | For each of these 3 symptoms, indicate the level of severity over the past week.                      |  |
| C6a                     | 120040 | Fatigue   | 01=No problem<br>02=Slight or mild problems: generally mild or intermittent<br>03=Moderate: considerable problems; often present and/or at a moderate level<br>04=Severe: pervasive, continuous, life disturbing problems<br>DA=Prefer not to answer |
| C6b                     | 120041 | Waking unrefreshed  | 01=No problem<br>02=Slight or mild problems: generally mild or intermittent<br>03=Moderate: considerable problems; often present and/or at a moderate level<br>04=Severe: pervasive, continuous, life disturbing problems<br>DA=Prefer not to answer |
| C6c                     | 120042 | Cognitive symptoms<br><i>For example, problems with memory, thinking skills and/or concentration.</i> | 01=No problem<br>02=Slight or mild problems: generally mild or intermittent<br>03=Moderate: considerable problems; often present and/or at a moderate level<br>04=Severe: pervasive, continuous, life disturbing problems<br>DA=Prefer not to answer |
| BLOCKC7                 | N/A    | During the <b>past 6 months</b> have you had any of the following symptoms?                           |  |
| C7a                     | 120043 | Pain or cramps in lower abdomen   | 01=Yes<br>00=No<br>DA=Prefer not to answer   |
| C7b                     | 120044 | Depression  | 01=Yes<br>00=No<br>DA=Prefer not to answer   |
| C7c                     | 120045 | Headache  | 01=Yes<br>00=No<br>DA=Prefer not to answer   |

| Section D: Nature of pain |          |   |  |
|---------------------------|----------|---|--|
| Q. No                     | Field ID | Stem  | Responses  |
| DINTRO                    | N/A      | The next section is about what your pain feels like. Please answer this question by <b>thinking about the pain that bothers you most</b> , i.e. your *** ***. |  |
| BLOCKD1                   | N/A      | Does the pain have one or more of the following characteristics?  |  |
| D1a                       | 120046   | Burning   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| D1b                       | 120047   | Painful cold  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| D1c                       | 120048   | Electric shocks   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| BLOCKD2                   | N/A      | Is the pain associated with one or more of the following symptoms in the same area?   |  |
| D2a                       | 120049   | Tingling  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| D2b                       | 120050   | Pins and needles  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| D2c                       | 120051   | Numbness  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| D2d                       | 120052   | Itching   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |

| Section E: Headache |          |   |   |
|---------------------|----------|---|---|
| Q. No               | Field ID | Stem  | Responses   |
| EINTRO              | N/A      | <b>Now we would like to know a bit about headaches</b>  |   |
| E1                  | 120053   | Have you ever had bad and/or recurring headaches at any time in your life?  | 01=Yes<br>00=No<br>DA=Prefer not to answer  |
| E2                  | 120054   | On how many <b>days in the past 3 months</b> did you have a headache <i>of any severity?</i><br><br>If a headache lasted more than 1 day, count each day. | EBOX2 allows an integer between 0 to 90<br>EBOX2 is suffixed “days”<br>DA=Prefer not to answer  |
| E3                  | 120055   | Think about the time when those headaches were at their worst.<br><br>About how long ago did those headaches begin?                                       | EBOX3a allows an integer between 0 and (current age – 4)<br>EBOX3a is prefixed “About” and suffixed “years ago”<br>EBOX3b allows an integer between 0 and 11<br>EBOX3b is prefixed “or about” and suffixed “months ago.”<br>DA=Prefer not to answer |
| E3a                 | 120056   | About how long ago did those headaches end?   | EBOX3aa allows an integer between 0 and 80<br>EBOX3aa is prefixed “About” and suffixed “years ago”<br>EBOX3ab allows an integer between 0 and 11<br>EBOX3ab is prefixed “or about” and suffixed “months ago.”<br>DA=Prefer not to answer            |
| E4                  | 120057   | When your headaches were at their worst, about how many days a month did you have a headache?   | EBOX4 allows an integer between 0 and 31.<br>EBOX4 is suffixed “days”<br>DA=Prefer not to answer  |
| BLOCKE5             | N/A      | When your headaches were at their worst, did you experience any of the following:   |   |
| E5a                 | 120058   | The pain was worse on just one side   | 01=Never<br>02=Rarely<br>03=Less Than Half the Time<br>04=Half the Time or More<br>DA=Prefer not to answer  |
| E5b                 | 120059   | The pain was pounding, pulsating or throbbing   | 01=Never<br>02=Rarely<br>03=Less Than Half the Time<br>04=Half the Time or More<br>DA=Prefer not to answer  |

|         |        |  |  |
|---------|--------|--|--|
| E5c     | 120060 | The pain was moderate or severe  | 01=Never<br>02=Rarely<br>03=Less Than Half the Time<br>04=Half the Time or More<br>DA=Prefer not to answer |
| E5d     | 120061 | The pain was made worse by routine activities such as walking or climbing stairs   | 01=Never<br>02=Rarely<br>03=Less Than Half the Time<br>04=Half the Time or More<br>DA=Prefer not to answer |
| E5e     | 120062 | You felt, or were sick   | 01=Never<br>02=Rarely<br>03=Less Than Half the Time<br>04=Half the Time or More<br>DA=Prefer not to answer |
| E5f     | 120063 | Light bothered you (more than when you did not have headaches)   | 01=Never<br>02=Rarely<br>03=Less Than Half the Time<br>04=Half the Time or More<br>DA=Prefer not to answer |
| E5g     | 120064 | Sound bothered you (more than when you did not have headaches)   | 01=Never<br>02=Rarely<br>03=Less Than Half the Time<br>04=Half the Time or More<br>DA=Prefer not to answer |
| BLOCKE6 | N/A    | Do you or did you develop any of the following warning symptoms <b>before or near the onset of your headache?</b>                            |  |
| E6a     | 120065 | I develop visual changes such as spots, lines and heat waves or greying out of my vision.  | 01=Yes<br>00>No<br>DA=Prefer not to answer   |
| E6ai    | 120066 | My visual changes develop slowly over several minutes or more.   | 01=Yes<br>00>No<br>DA=Prefer not to answer   |
| E6b     | 120067 | I develop tingling or numbness in my face arms or legs.  | 01=Yes<br>00>No<br>DA=Prefer not to answer   |
| E6bi    | 120068 | The tingling and/or, numbness spreads slowly over several minutes over some part of my body.   | 01=Yes<br>00>No<br>DA=Prefer not to answer   |
| E6c     | 120069 | I develop tiredness, yawning, concentration problems, changes in mood or appetite, irritability, neck stiffness, light or sound sensitivity. | 01=Yes<br>00>No<br>DA=Prefer not to answer   |
| E7      | 120070 | On <b>how many days</b> in the last <b>3 months</b> did your headaches interfere with your ability to work, study or enjoy life?             | Allows selection of an integer from 0 to 90<br>DA=Prefer not to answer                                     |

| Section F: About your legs and feet |          |  |  |
|-------------------------------------|----------|--|--|
| Q. No                               | Field ID | Stem   | Responses  |
| FINTRO                              | N/A      | We would now like to ask about the feeling in your legs and feet. Select yes or no <b>based on how you usually feel.</b> |  |
| F1                                  | 120071   | Are your legs and/or feet numb?  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F2                                  | 120072   | Do you ever have any burning pain in your legs and/or feet?  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F3                                  | 120073   | Are your feet too sensitive to touch?  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F4                                  | 120074   | Do you get muscle cramps in your legs and/or feet?   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F5                                  | 120075   | Do you ever have any prickling feelings in your legs or feet?  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F6                                  | 120076   | Does it hurt when the bed covers touch your skin?  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F7                                  | 120077   | When you get into the bath or shower, are you able to tell the hot water from the cold water?                            | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F8                                  | 120078   | Have you ever had an open sore on your foot?   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F9                                  | 120079   | Has the doctor ever told you that you that you have diabetic neuropathy?   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |

|     |        |  |  |
|-----|--------|--|--|
| F10 | 120080 | Do you feel weak <b>all over</b> most of the time?   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F11 | 120081 | Are your symptoms worse at night?                    | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F12 | 120082 | Do your legs hurt when you walk?                     | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F13 | 120083 | Are you able to sense your feet when you walk?       | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F14 | 120084 | Is the skin on your feet so dry that it cracks open? | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| F15 | 120085 | Have you ever had an amputation?                     | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |

| Section G: Impact of pain |          |  |   |
|---------------------------|----------|--|---|
| Q. No                     | Field ID | Stem   | Responses   |
| GINTRO                    | N/A      | Now we would like to know a bit about how your pain impacts on your life.<br><br>Please answer this question by <b>thinking about the pain that bothers you most</b> , i.e. your *** ****. | Please answer this question by <b>thinking about the pain that bothers you most</b> , i.e. your *** ****.     |
| G1                        | 120086   | Please rate your pain by selecting the number that best describes your pain at its <b>worst</b> in the <b>last 24 hours</b> .  | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as you can imagine.<br>DA=Prefer not to answer |

|          |        |   |   |
|----------|--------|---|---|
| G2       | 120087 | Please rate your pain by selecting the number that best describes your pain at its <b>least</b> in the <b>last 24 hours</b> .   | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as you can imagine.<br>DA=Prefer not to answer   |
| G3       | 120088 | Please rate your pain by selecting the number that best describes your pain on <b>average</b> .   | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as you can imagine.<br>DA=Prefer not to answer   |
| G4       | 120089 | Please rate your pain by selecting the number that tells how much pain you have <b>right now</b> .  | 0-10 VAS with 0 marked as no pain and 10 marked as pain as bad as you can imagine.<br>DA=Prefer not to answer   |
| G5       | 120090 | In the <b>last 24 hours</b> , how much relief have pain treatments or medications provided?<br><i>Please select the percentage that most shows how much relief you have received.</i> | 0-100 VAS in 10% increments with 0% marked as no relief and 100% marked as complete relief.<br>NA = I am not taking any pain treatments or medications<br>DA=Prefer not to answer |
| BLOCK G6 | N/A    | Select the number that describes how, <b>during the past 24 hours</b> , pain has interfered with your:  |   |
| G6a      | 120091 | General Activity  | 0-10 VAS with 0 marked as does not interfere and 10 marked as completely interferes.<br>DA=Prefer not to answer   |
| G6b      | 120092 | Mood  | 0-10 VAS with 0 marked as does not interfere and 10 marked as completely interferes.<br>DA=Prefer not to answer   |

|     |        |   |   |
|-----|--------|---|---|
| G6c | 120093 | Walking ability   | 0-10 VAS with 0 marked as does not interfere and 10 marked as completely interferes.<br>DA=Prefer not to answer |
| G6d | 120094 | Normal Work (includes both work outside the home and housework) | 0-10 VAS with 0 marked as does not interfere and 10 marked as completely interferes.<br>DA=Prefer not to answer |
| G6e | 120095 | Relations with other people                                     | 0-10 VAS with 0 marked as does not interfere and 10 marked as completely interferes.<br>DA=Prefer not to answer |
| G6f | 120096 | Sleep   | 0-10 VAS with 0 marked as does not interfere and 10 marked as completely interferes.<br>DA=Prefer not to answer |
| G6g | 120097 | Enjoyment of life   | 0-10 VAS with 0 marked as does not interfere and 10 marked as completely interferes.<br>DA=Prefer not to answer |

| Section H: Health outcomes |          |   |           |
|----------------------------|----------|---|-----------|
| Q. No                      | Field ID | Stem  | Responses |
| HINTRO                     | N/A      | Please click the ONE box that best describes your health <b>TODAY</b> . |           |

|    |        |   |  |
|----|--------|---|--|
| H1 | 120098 | MOBILITY  | 01=I have no problems in walking about<br>02=I have slight problems in walking about<br>03=I have moderate problems in walking about<br>04=I have severe problems in walking about<br>05=I am unable to walk about   |
| H2 | 120099 | SELF-CARE   | 01=I have no problems washing or dressing myself<br>02=I have slight problems washing or dressing myself<br>03=I have moderate problems washing or dressing myself<br>04=I have severe problems washing or dressing myself<br>05=I am unable to wash or dress myself |
| H3 | 120100 | USUAL ACTIVITIES<br>(e.g. work, study, housework, family or leisure activities) | 01=I have no problems doing my usual activities<br>02=I have slight problems doing my usual activities<br>03=I have moderate problems doing my usual activities<br>04=I have severe problems doing my usual activities<br>05=I am unable to do my usual activities   |
| H4 | 120101 | PAIN/DISCOMFORT   | 01=I have no pain or discomfort<br>02=I have slight pain or discomfort<br>03=I have moderate pain or discomfort<br>04=I have severe pain or discomfort<br>05=I have extreme pain or discomfort   |
| H5 | 120102 | ANXIETY/DEPRESSION  | 01=I am not anxious or depressed<br>02=I am slightly anxious or depressed<br>03=I am moderately anxious or depressed<br>04=I am severely anxious or depressed<br>05=I am extremely anxious or depressed  |

|    |        |  |   |
|----|--------|--|---|
| H6 | 120103 | <p>We would like to know how good or bad your health is <b>TODAY</b>.</p> <p>This scale is numbered from 0 to 100</p> <p>100 means the <u>best</u> health you can imagine.</p> <p>0 means the <u>worst</u> health you can imagine.</p> <p>Please click on the scale to indicate how your health is <b>today</b>.</p> | <ul style="list-style-type: none"> <li>We would like to know how good or bad your health is TODAY.</li> <li>This scale is numbered from 0 to 100</li> <li>100 means the <u>best</u> health you can imagine.</li> <li>0 means the <u>worst</u> health you can imagine.</li> <li>Please click on the scale to indicate how your health is TODAY.</li> </ul> <div style="text-align: center;"> <br/> <span style="border: 1px solid black; padding: 2px;">Previous</span> <span style="border: 1px solid black; padding: 2px;">Next</span> </div> <p><small>Copyright © EuroQoL Research Foundation<br/>EQ-5D™ is a trademark of the EuroQoL Research Foundation</small></p> |
|----|--------|--|---|

| Section I: Recent feelings |          |   |  |
|----------------------------|----------|---|--|
| Q. No                      | Field ID | Stem  | Responses  |
| IINTRO                     | N/A      | We next want to ask a few questions about your mood and feelings recently.                        |  |
| BLOCKI1                    | N/A      | Over the <b>last 2 weeks</b> , how often have you been bothered by any of the following problems? |  |
| I1a                        | 120104   | Little interest or pleasure in doing things   | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer |
| I1b                        | 120105   | Feeling down, depressed, or hopeless  | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer |
| I1c                        | 120106   | Trouble falling or staying asleep, or sleeping too much   | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer |
| I1d                        | 120107   | Feeling tired or having little energy   | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer |

|     |        |  |  |
|-----|--------|--|--|
| I1e | 120108 | Poor appetite or overeating  | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer           |
| I1f | 120109 | Feeling bad about yourself - or that you are a failure or have let yourself or your family down  | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer           |
| I1g | 120110 | Trouble concentrating on things, such as reading the newspaper or watching television  | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer           |
| I1h | 120111 | Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer           |
| I1i | 120112 | Thoughts that you would be better off dead or of hurting yourself in some way  | 01=Not at all<br>02=Several days<br>03=More than half the days<br>04=Nearly every day<br>DA=Prefer not to answer           |
| I2  | 120113 | How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?  | 01=Not difficult at all<br>02=Slightly difficult<br>03=Very difficult<br>04=Extremely difficult<br>DA=Prefer not to answer |

| Section J: Fatigue |          |   |  |
|--------------------|----------|---|--|
| Q. No              | Field ID | Stem  | Responses  |
| J1NTRO             | N/A      | Now we would like to know a little bit about your experience of fatigue.  |  |
| J1                 | 120114   | Do you have persistent or recurrent tiredness, weariness or fatigue that has lasted <b>for at least 6 months?</b>       | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| J1a                | 120115   | Does this tiredness, weariness or fatigue go away when you rest?  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |
| J1b                | 120116   | Is this tiredness, weariness or fatigue happening <b>only</b> because you have been exercising and/or working too much? | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer |

|         |        |   |  |
|---------|--------|---|--|
| J1c     | 120117 | Do you get tired after minimal physical or mental exertion?   | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer                           |
| J2      | 120118 | Have you suffered from fatigue or exhaustion in the last week?  | 01=Yes<br>00=No<br>DK=Do not know<br>DA=Prefer not to answer                           |
| J3INTRO | N/A    | The following questions allow us to rate the severity of your fatigue symptoms. Read each statement and select a number from 1 to 7, based on how accurately it reflects your condition during the past week and the extent to which you agree or disagree that the statement applies to you. (A low value (e.g. 1) indicates strong disagreement with the statement, whereas a high value (e.g. 7) indicates strong agreement. |  |
| BLOCKJ3 | N/A    | During the past week, I have found that:  |  |
| J3a     | 120119 | My motivation is lower when I am fatigued   | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |
| J3b     | 120120 | Exercise brings on my fatigue   | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |
| J3c     | 120121 | I am easily fatigued  | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |
| J3d     | 120122 | Fatigue interferes with my physical functioning   | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |

|     |        |  |  |
|-----|--------|--|--|
| J3e | 120123 | Fatigue causes frequent problems for me                                  | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |
| J3f | 120124 | My fatigue prevents sustained physical functioning                       | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |
| J3g | 120125 | Fatigue interferes with carrying out certain duties and responsibilities | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |
| J3h | 120126 | Fatigue is among my three most disabling symptoms                        | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |
| J3i | 120127 | Fatigue interferes with my work, family or social life                   | 01=Disagree<br>02=<br>03=<br>04=<br>05=<br>06=<br>07= Agree<br>DA=Prefer not to answer |

| Section K. CLOSE |          |  |   |
|------------------|----------|--|---|
| Q. No            | Field ID | Stem   | Responses   |
| CLOSE            | N/A      | <p>Many thanks for taking the time to answer these questions. We really appreciate your contribution. Your answers will be used, along with other UK Biobank data, to better understand chronic pain.</p> <p>If you have concerns about any of the issues covered in the questionnaire, we suggest that you contact your GP.</p> | <a href="#">Link to UKB participant website</a><br><a href="#">Link to UKB homepage</a> |

