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**UK Medical Cannabis Registry**

**Data Management Plan**

**Version 2.1**

**Date: 8th November 2022**

**Sponsor: Sapphire Medical Clinics**

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Title: UK Medical Cannabis Registry

Data Management Plan Reference: UKMCR IRAS Number: 296473

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|  |  |  |
| --- | --- | --- |
| Version Number | Date | Key Updates |
| V2.00 | 15th July 2022 | Change in hosting platform for Registry |
| V1.00 | 1st December 2019 | - |

**Abbreviations**

|  |  |
| --- | --- |
| CBMPs | Cannabis-based medicinal products |
| CTCAE | Common Terminology Criteria for Adverse Events |
| HRQoL | Health-related quality of life |
| PROMs | Patient reported outcome measures |
| SNOMED-CT | Systematised Nomenclature of Medicine - Clinical Terms |
| UK | United Kingdom |
| UKMCR | UK Medical Cannabis Registry |

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## 1. Registry Summary

The United Kingdom (UK) Medical Cannabis Registry (UKMCR) is an observational real-world data collection platform developed for bespoke evidence generation on cannabis-based medicinal products (CBMPs) prescribed in the UK. It was devised to bridge the gap in evidence on the benefits and potential safety implications of prescribing CBMPs for chronic health conduction.

The primary objective of the UKMCR is to collect a comprehensive data source of real-world evidence that can be utilised by researchers to answer outstanding questions such as the following:

1. To study the epidemiological and clinic-pathological characteristics of patients prescribed CBMPs in the UK and Channel Islands.
2. To study the safety of CBMPs.
3. To study effects of CBMPs on concomitantly prescribed medications.
4. To study the effects of prior cannabis, alcohol, and tobacco consumption on outcomes of patients prescribed CBMPs.
5. To study the socio-economic effects of CBMPs.
6. To study the effectiveness of CBMPs.

Patients are identified from those enrolled at clinics which have agreed to contribute to the UKMCR. Eligible participants are subsequently identified by the local clinical care team. Inclusion criteria extends to patients who are prescribed CBMPs. CBMPs must adhere to the criteria for Good Manufacturing Practice (1). These can contain either isolated cannabinoids or be a broad/full spectrum extract. For broad/full spectrum extracts and dry flower the chemovars were either Cannabis sativa, Cannabis indica, or a hybrid species. CBMPs must only be initiated by clinicians abiding by the latest national guidance, which at present is those on the General Medical Council’s specialist register supported by a discussion of the decision to prescribe with a multidisciplinary team (1).

## 2. Schedule of Events and Timepoints

### 2.1 Pre-Registration

Patients are enrolled prospectively prior to first appointment (Figure 1). Patients shall be approached to provide informed consent in line with Good Clinical Practice guidelines (2). Participants are not required to provide informed consent within any specific timeframe to allow them to fully consider the implications of enrolling and discuss enrolment with local research/clinical team as appropriate. Consent will be provided electronically, and a copy will be held in a patient’s electronic health records. A copy will be available to the participant. As there is no required clinical intervention as part of participation in the registry, patients will only consent to the collection of their data. Patients under the age of 16 will require proxy consent by a parent or guardian.

Patient enrolment into the study will occur once consent is taken and eligibility criteria is met. A randomised 20-character unique registry identification number is generated utilising computer-based fair randomisation for each patient for pseudonymisation of data.

### 2.2 Baseline

Participants will engage with clinic within the guidance of usual care as delivered by participating clinics. There are no additional interventions required through enrolment in the UKMCR to deviate from usual standard of care.

All pertinent demographic, medical and condition-specific history, as well as previous drug and alcohol exposure will be entered into the UKMCR. This shall be completed at baseline during the patient’s initial visit by their prescribing physician through inputting of information on the clinician’s data reporting portal for the UKMCR which is directly linked to the participant’s electronic healthcare record.

Diagram

Description automatically generated**Figure 1.** UK Medical Cannabis Registry Schema

Outline of participant flow through the UK Medical Cannabis Registry and data items collected during treatment. Participants complete routine follow up at 1, 3, and 6 months. Repeat measures are subsequently administered every 6 months. (C) – Clinical team completed data entry; (P) – Participant completed data entry; (C/P) – Clinical team or participant completed data entry. *CBMPs – cannabis-based medicinal products; PROMs – patient reported outcome measures.*

Participants and/or clinicians can record any concomitant medications at baseline.

At baseline each participant completes a set of patient reported outcome measures (PROMs) electronically. These are set according to primary indication for treatment with CBMPs and include general measures of health-related quality of life (HRQoL), anxiety- and sleep-specific scores, and condition specific questionnaires.

Once a prescription for one or more CBMPs has been written, the details of the medication including name, dose, and start date shall be recorded in the UKMCR.

### 2.3 Follow Up

Follow up time points are set to 1 month, 3 months, 6 months, and every 6 months thereafter. These timings are set according to the date a prescription for CBMPs is written and inserted in the UKMCR.

Changes to CBMPs with respect to products and doses are recorded in real-time when alterations are made to any prescription by a member of the clinical team.

PROMs shall be completed online at each of these time periods via the UKMCR data reporting portal. Participants shall be prompted to complete the questionnaires via an email directing them to the portal on each follow up date. If the questionnaires are not completed an automated follow up email reminder shall be sent every 72 hours until they have been completed, as this has been shown to improve completion rates of PROMs (3).

Participants are required to record any adverse events they may have experienced, and their severity and duration, prior to completing any PROMs. In addition, participants can report these at any time through a separate form within their bespoke UKMCR data reporting portal page. Clinicians can also record adverse events during clinical consultations.

Changes to concomitant medications taken alongside CBMPs can be recorded by either the clinical team or participant themselves.

## 3. Data Collection

3.1 Participant Data Reporting Portal

Participants are provided access to a bespoke webpage through a unique web address which corresponds to only their participant identification number for reporting of data items. At baseline and each follow up period participants are emailed to inform them that outcome measures are awaiting completion. If they are not completed within three days, participants are sent a reminder emails every 72 hours until they are completed, or participants opt out.

PROMs are completed via a dedicated dashboard for data collection (Figure 2). Participants are displayed individual questions as set out within the parameters of the guidance provided by validated PROMs. Participants are presented with individual PROMs sequentially. Each webpage in addition to being developed for computer use, has been formulated for web browsers on mobile phones.

Participants can complete adverse events, as mentioned, prior to completing any PROMs at each follow up period, or outside of this period by accessing their bespoke web address and utilising the adverse event reporting tool at any time. Participants are initially asked if they have experienced any adverse events (Figure 3). They are then presented with the most common adverse events that have previously been reported in clinical trials and observational studies (4). In addition to this they are presented with the opportunity to report any supplementary adverse events they may have experienced using a free text box. They are subsequently prompted to complete information on the severity and length of any adverse event.

**Figure 2.** Example of collection of patient reported outcome measures by participants

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**Figure 3.** Example of collection of adverse events by participants

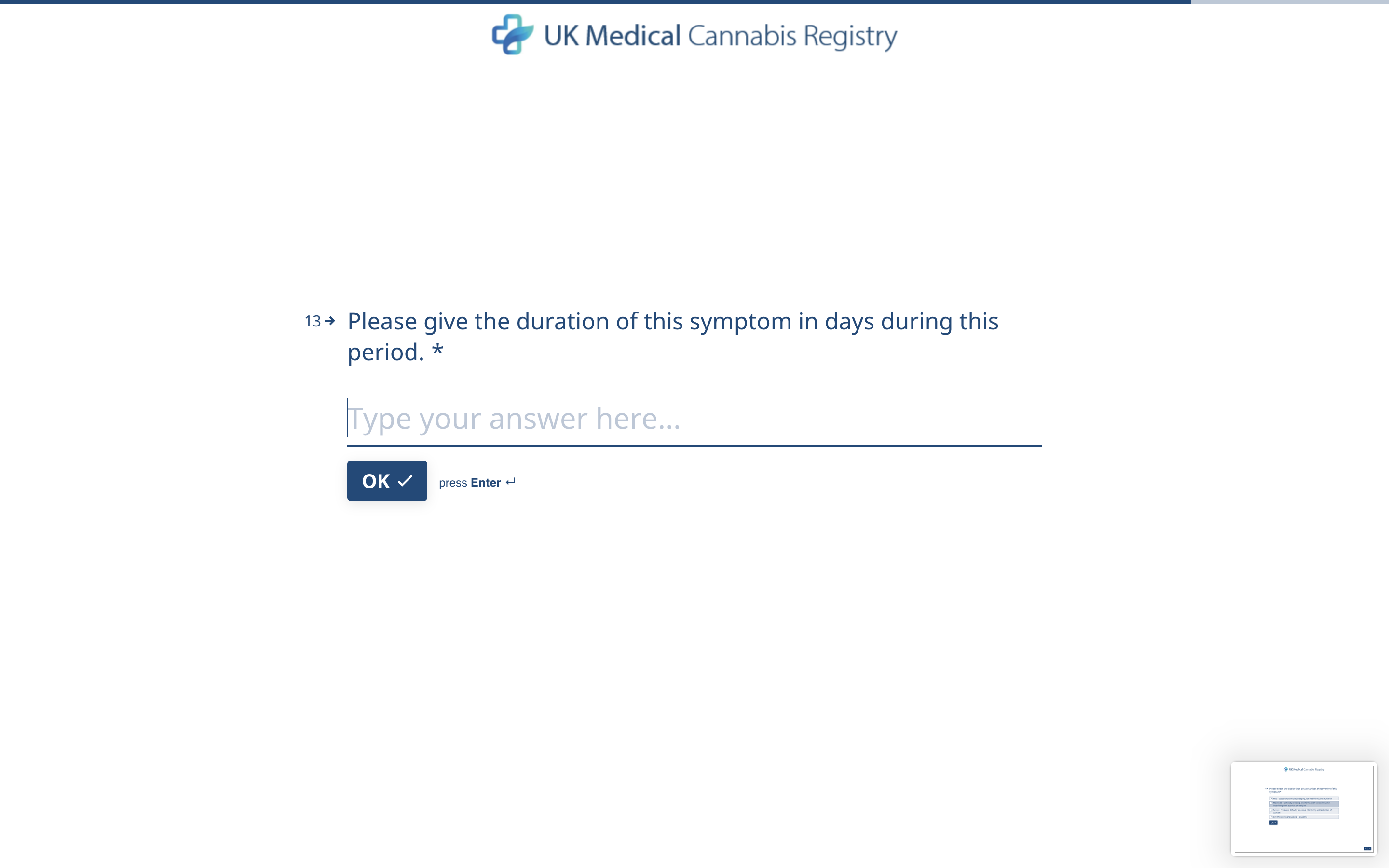
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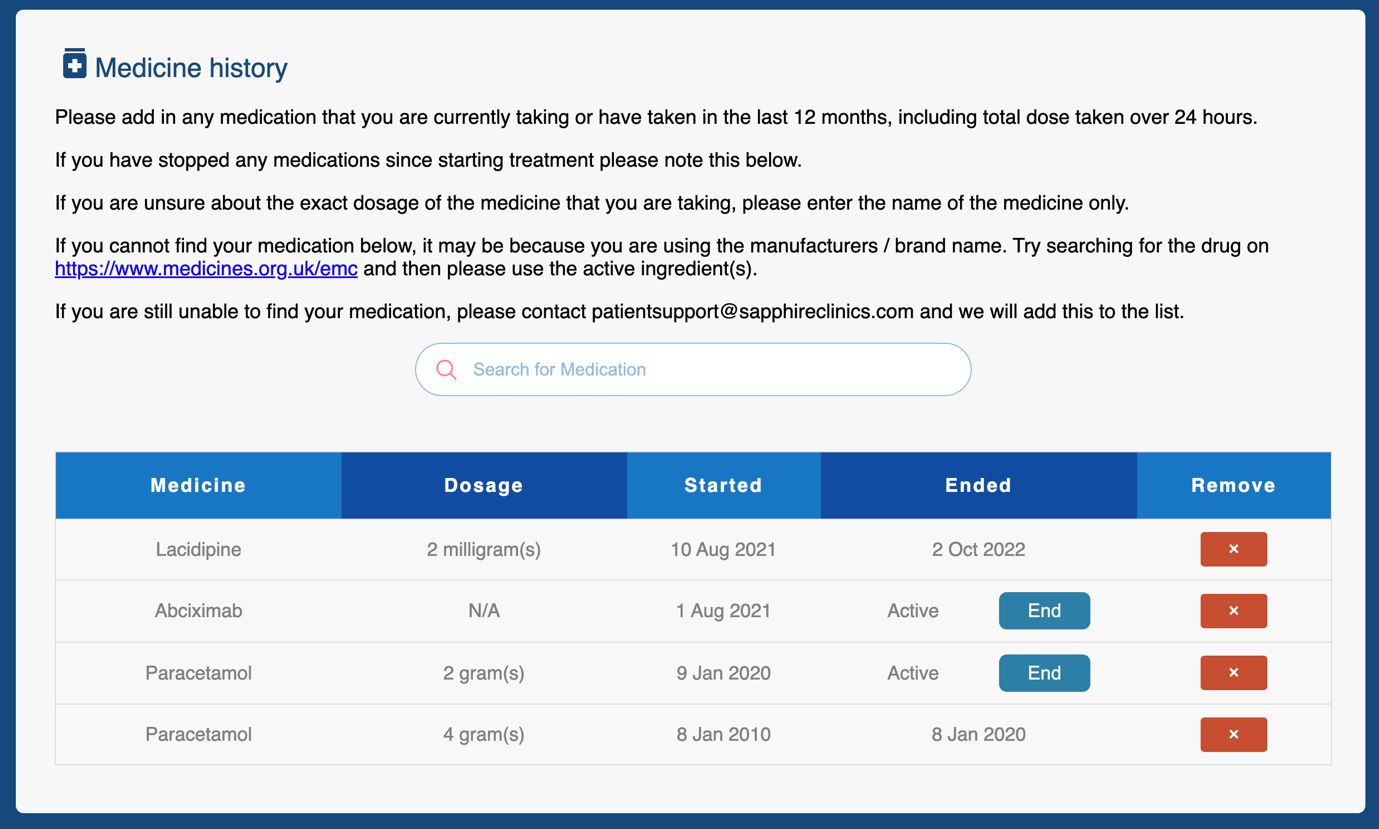
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Medications which are reported by participants can be completed via the medication history section of the UKMCR participant data reporting portal (Figure 4). On this, participants can search for medications according to their generic name, as well as insert the dose and date the medication was started and when it was stopped. This can be utilised at baseline, but also throughout treatment as required.

**Figure 4.** Example of medication reporting by participants.



### 3.2 Clinical Team Reporting Portal

In additional to a participant reporting portal, there is also a respective portal through which the clinical team can record data points and outcome measures for the UKMCR.

The clinical team have similar reporting mechanisms for concomitant medications and adverse events as participants. There are no reporting mechanisms for PROMs for the clinical team due to these being patient reported, rather than clinician reported. However, the results of these are provided back to the clinical team through the reporting portal, to allow for safetynetting of any concerning PROM scores, which would be concerning and require clinical intervention.

The clinical team reporting portal also has facility to report demographic details, occupation, comorbidities, and drug and alcohol history via drop down menus or free text as appropriate. For variables which are reported as free text but are numerical, there are restrictions placed on the reporting field such that clinicians cannot accidentally insert a string variable.

## 4. Data Points

The data sources which currently comprise the UKMCR are outlined in Table 1 and are collected within routine delivery of care.

**Table 1.** Data sources of the UK Medical Cannabis Registry

|  |  |
| --- | --- |
| **Data Arm** | **Summary** |
| **Clinicopathological Characteristics** | Demographic details of participants at baseline of study period, supplemented by comorbidities, and drug and alcohol data |
| **Medication Data** | Concomitant medications taken by participants, including information about dose and method of administration |
| **Prescribed CBMPs** | Information regarding prescribed CBMPs, including products prescribed and dose |
| **PROMs** | Validated questionnaires to assess general changes in HRQoL as well as those specific to primary indication for treatment |
| **Adverse Events** | Incidence of adverse events, in addition to length of adverse event and grade |

*CBMPs – cannabis-based medicinal products; HRQoL – health-related quality of life; PROMs – patient reported outcome measures*

The principal outcome measures for the UKMCR are PROMs. For each condition participants are asked to complete a general set of PROMs, in addition to condition-specific measures.

Appendix 1 details a comprehensive list of each data item included within the UKMCR.

The NHS number of each patient is inputted by the clinical team, however this is excluded from the data output available to researchers.

## 5. Outcome Measures

### 5.1 Patient Reported Outcome Measures

PROMs are used to assess the changes in health status according to the subjective reporting by patients. They are increasingly recognised as important outcome measures with more frequent utilisation in clinical trials and real-world data collection. They embolden the understanding of the patients’ experience with information that could not be gained from other clinical measures (5). Moreover, for common conditions captured in the UKMCR, such as chronic pain, psychiatric conditions, headaches, and palliative care subjective assessments of severity and impact are gold-standard measures for assessment (5,6). Finally, for HRQoL assessment the EQ-5D-5L is the assessment of choice for the National Institute for Health and Care Excellence (NICE) (7). In their published guideline and review on CBMPs, they emphasised a paucity of examinations of cost-effectiveness of CBMPs (1,8). Inclusion of the EQ-5D-5L in the assessment of HRQoL for participants therefore offers a direct opportunity for data from the UKMCR to contribute to national guidance. Table 2 outlines those PROMs chosen for inclusion in the UKMCR, including the EQ-5D-5L, with supporting references for their validation/utilisation. Appendix 2 outlines which PROMs are allocated according to the set primary diagnostic indication for treatment with CBMPs, whilst Appendix 3 outlines each question which is asked of patients through PROMs.

**Table 2.** Patient Reported Outcome Measures captured in the UK Medical Cannabis Registry

|  |  |
| --- | --- |
| **Patient Reported Outcome Measure** | **Reference** |
| Generalised Anxiety Disorder 7 (GAD-7) | *Spitzer et al.* (9) |
| EQ-5D-5L | *Van Hout et al.* (10) |
| Sleep Quality Scale | *Snyder et al.* (11) |
| Patient's Global Impression of Change (PGIC) | *Hurst et al.* (12) |
| Brief Pain Inventory - Short Form | *Keller et al.* (13) |
| Symptom Distress Scale | *McCorkle et al.* (14) |
| McGill Pain Questionnaire (SF MPQ-2) | *Melzack et al.* (15) |
| Visual Analogue Pain Score | *Zisapel et al.* (16) |
| Headache Impact Test (HIT-6) score | *Kosinski et al.* (17) |
| Migraine Disability Assessment (MIDAS) score | *Stewart et al.* (18) |
| Short Inflammatory Bowel Disease Questionnaire (SIBDQ) | *Irvine et al.* (19) |
| Patient Health Questionnaire (PHQ-9) | *Kroenke et al.* (20) |
| Eating Disorder Examination Questionnaire (EDE-Q 6.0) | *Bohn et al.* (21) |
| Quality of Life in Epilepsy Questionnaire (QOLIE-31-P) | *Cramer et al.* (22) |
| Impact of Paediatric Epilepsy Scale (IEPS) | *Camfield et al.* (23) |
| Fibromyalgia Symptom Severity Score | *Wolfe et al.* (24) |
| Multiple Sclerosis Quality of Life Questionnaire (MSQoL) | *Vickrey et al.* (25) |
| Obsessive Compulsive Inventory (OCI) | *Foa et al.* (26) |
| The Australia-modiﬁed Karnofsky performance status (AKPS) | *Abernethy et al.* (27) |
| Panic Rating Scale | *Clark et al.* (28) |
| Parkinson’s Disease Score (PDQ-39) | *Peto et al.* (29) |
| Impact of Events Scale | *Weiss et al.* (30) |
| Social Phobia Inventory (SPIN) | *Connor et al.* (31) |
| Palliative Care Outcome Scale (POS) | *Murtagh et al.* (32) |

### 5.2 Adverse Events

Participants also record adverse events. These are mapped to the grade outlined in the Common Terminology Criteria for Adverse Events (CTCAE) version 4.0 to allow for direct comparison to clinical trials (33). Participants also record the length of each adverse event.

The adverse events are directly available to the clinical team to also complete Yellow Card reporting as required for any unlicensed medical product (34).

### 5.3 Medications

Concomitant medications are recorded at baseline, with any changes throughout treatment with CBMPs also recorded by either the clinical team or participants. The medication names are linked to Systematised Nomenclature of Medicine -- Clinical Terms (SNOMED-CT) for consistent terminology. The start and end date of any prescription is also recorded, along with the dosage if known.

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## Appendix 1 - UK Medical Cannabis Registry Data Items

|  |  |
| --- | --- |
| **UK Medical Cannabis Registry by Sapphire Medical Clinics** | |
| **Field Descriptions** |  |
|  |  |
| **Patient** |  |
| **Column name** | **Description** |
| Age | Patient's age |
| Gender | Patient's gender |
| Patient Identifier | Randomised unique identifier given to patients within the registry for pseudonymous linkage |
| NHS number | Patient's NHS number (collected but not presented in research output to maintain pseudonymisation) |
| Occupation | Occupation/job role |
| Weight | Weight at latest clinical appointment (in kilograms) |
| Height | Height at latest clinical appointment (in metres) |
|  |  |
|  |  |
| **Clinical** |  |
| **Column name** | **Description** |
| Primary Diagnosis | Unique code for medical term selected by clinical staff which represents main reason for clinic appointment |
| Secondary Diagnosis | Unique code for medical term selected by clinical staff which represents secondary reason for clinic appointment |
| Tertiary Diagnosis | Unique code for medical term selected by clinical staff which represents tertiary reason for clinic appointment |
| Myocardial Infarction | Yes/No logic for whether patient has a medical history of |
| Congestive heart failure | Yes/No logic for whether patient has a medical history of |
| Peripheral vascular disease | Yes/No logic for whether patient has a medical history of |
| Cerebrovascular accident or transient ischemic attack | Yes/No logic for whether patient has a medical history of |
| Dementia | Yes/No logic for whether patient has a medical history of |
| Chronic obstructive pulmonary disease | Yes/No logic for whether patient has a medical history of |
| Connective tissue disease | Yes/No logic for whether patient has a medical history of |
| Peptic Ulcer Disease | Yes/No logic for whether patient has a medical history of |
| Liver disease | Yes/No logic for whether patient has a medical history of |
| Diabetes | Yes/No logic for whether patient has a medical history of |
| Hemiplegia | Yes/No logic for whether patient has a medical history of |
| Moderate to severe chronic kidney disease | Yes/No logic for whether patient has a medical history of |
| Solid tumour | Yes/No logic for whether patient has a medical history of |
| Leukaemia | Yes/No logic for whether patient has a medical history of |
| Lymphoma | Yes/No logic for whether patient has a medical history of |
| AIDS | Yes/No logic for whether patient has a medical history of |
| Charlson Comorbidity | Charlson Comorbidity score |
| Hypertension | Yes/No logic for whether patient has a medical history of |
| Depression / anxiety | Yes/No logic for whether patient has a medical history of |
| Arthritis | Yes/No logic for whether patient has a medical history of |
| Epilepsy | Yes/No logic for whether patient has a medical history of |
| VTE | Yes/No logic for whether patient has a medical history of |
| Endocrine / thyroid dysfunction | Yes/No logic for whether patient has a medical history of |
| Allergy | Free text field |
|  |  |
| **Drug and Alcohol History** |  |
| **Column name** | **Description** |
| Smoking Status | Smoking status of patient (i.e. non-smoker, ex-smoker, current smoker) |
| Pack years | Number of pack years patient has smoked for where one year of smoking 20 cigarettes/day = 1 pack year |
| Alcohol Intake | Units of alcohol consumed on a weekly basis |
| Cannabis Status | Cannabis status of patient (i.e. non-user ex-user, current user) |
| Frequency of cannabis use | How often the patient uses cannabis containing products (i.e. Every day, every other day, 1-2x/week, >1x/month, <1x/month) |
| Route of cannabis administration | Route of administration of cannabis products |
| Quantity of cannabis | Quantity of usual cannabis use per day in grams |
| Life-time cannabis use | Life-time cannabis use in gram years |
|  |  |
| **Cannabis Based Medicinal Product** |  |
| **Column name** | **Description** |
| Cannabis-Based Medicinal Product | The name of the Cannabis Based Medicinal Product Prescribed including CBD and THC dose |
| Date of Prescription | Date prescription was written |
| Dose/Titration | Quantity of cannabis-based medicinal product administered per dose (in grams or millilitres) ± titration |
| Total Quantity | Total quantity of prescribed cannabis-based medicinal products in grams/millilitres |
| Route of administration | Route of administration (e.g. topical, vapourisation, oral, sublingual) |
| Active | True/False logic for whether prescription is still active |
| Discontinuation Data | If false response for active field, then date of discontinuation of medication |
|  |  |
| **Patient Reported Outcome Measures** |  |
| **Column name** | **Description** |
| GAD-7 | Generalised Anxiety Disorder 7 (GAD-7) |
| EQ-5D-5L | EQ-5D-5L |
| Sleep Quality Scale | Sleep Quality Scale |
| PGIC | Patient's Global Impression of Change (PGIC) |
| Brief Pain Inventory - Short Form | Brief Pain Inventory - Short Form |
| Symptom Distress Scale | Symptom Distress Scale |
| McGill Pain Questionnaire (SF MPQ-2) | McGill Pain Questionnaire (SF MPQ-2) |
| VAS Pain Score | Visual Analogue Pain Score |
| HIT-6 score | Headache Impact Test (HIT-6) score |
| MIDAS score | Migraine Disability Assessment (MIDAS) score |
| Short Inflammatory Bowel Disease Questionnaire (SIBDQ) | Short Inflammatory Bowel Disease Questionnaire (SIBDQ) |
| PHQ-9 | Patient Health Questionnaire (PHQ-9) |
| EDE-Q 6.0 | Eating Disorder Examination Questionnaire (EDE-Q 6.0) |
| QOLIE-31-P | Quality of Life in Epilepsy Questionnaire (QOLIE-31-P) |
| IEPS | Impact of Paediatric Epilepsy Scale (IEPS) |
| Fibromyalgia Symptom Severity Score | Fibromyalgia Symptom Severity Score |
| MSQoL | Multiple Sclerosis Quality of Life Questionnaire (MSQoL) |
| OCI | Obsessive Compulsive Inventory (OCI) |
| AKPS | The Australia-modiﬁed Karnofsky performance status (AKPS) |
| Panic Rating Scale | Panic Rating Scale |
| PDQ-39 | Parkinson’s Disease Score (PDQ-39) |
| Impact of Events Scale | Impact of Events Scale |
| SPIN | Social Phobia Inventory (SPIN) |
| POS | Palliative Care Outcome Scale (POS) |
|  |  |
| **Adverse Events** |  |
| **Column name** | **Description** |
| Adverse event | Name of recorded adverse event |
| Adverse events Grade | Grade of severity according to Common Terminology Criteria for Adverse Events version 4.0 |
| Adverse events Duration | Duration of reported adverse event in days |
| Adverse events Date | Date of recording adverse event |
|  |  |
| **Concomitant Medications** |  |
| **Column name** | **Description** |
| Medicine | Name of medication |
| SNOMED | SNOMED Clinical Terms code for medication |
| Dose | Numeric recording of dose |
| Units | Units of dose measurement |
| Start Date | Date of starting medication |
| End Date | Date of stopping medication if appropriate |

## Appendix 2 – Patient Reported Outcome Measures Per Condition

|  |  |
| --- | --- |
| Primary Diagnosis | PROMs Sent to Patients with this Diagnosis |
| Agoraphobia | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| Anxiety | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| Autism spectrum disorder | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| Cancer pain | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Pain Inventory Short Form |
| •VAS Pain Score |
| Chemotherapy induced nausea and vomiting | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Symptom Distress Scale |
| Chronic pain | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Pain Inventory Short Form |
| •McGill Pain Questionnaire (SF MPQ-2) |
| •VAS Pain Score |
| Cluster headaches | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Headache Impact Test (HIT-6) |
| •Migraine Disability Assessment Test (MIDAS) |
| Complex regional pain syndrome | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Pain Inventory Short Form |
| •McGill Pain Questionnaire (SF MPQ-2) |
| •VAS Pain Score |
| Crohns | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Short Inflammatory Bowel Disease Questionnaire (SIBDQ) |
| Depression | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Patient Health Questionnaire (PHQ-9) |
| Eating disorder | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Eating Disorder Examination Questionnaire (EDE-Q 6.0) |
| Ehlers-Danlos | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Pain Inventory Short Form |
| •McGill Pain Questionnaire (SF MPQ-2) |
| •VAS Pain Score |
| Epilepsy adult | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Quality of Life in Epilepsy Questionnaire (QOLIE-31-P) |
| Epilepsy child | •Impact of Paediatric Epilepsy Scale (IEPS) |
| Fibromyalgia | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Fibromyalgia Symptom Severity Score |
| •VAS Pain Score |
| Headache | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Headache Impact Test (HIT-6) |
| •Migraine Disability Assessment Test (MIDAS) |
| Insomnia | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| Migraine | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Headache Impact Test (HIT-6) |
| •Migraine Disability Assessment Test (MIDAS) |
| Multiple sclerosis | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Multiple Sclerosis Quality of Life Questionnaire (MSQoL) |
| Neuropathic pain | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Pain Inventory Short Form |
| •McGill Pain Questionnaire (SF MPQ-2) |
| •VAS Pain Score |
| OCD | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Obsessive Compulsive Inventory |
| Palliative care | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Palliative Care Outcome Scale (POS) |
| •VAS Pain Score |
| •The Australia-modiﬁed Karnofsky performance status (AKPS) |
| Panic disorder | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Panic Rating Scale |
| Parkinson's | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Parkinson’s Disease Score (PDQ-39) |
| PTSD | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Impact of Events Scale |
| Social phobia | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Social Phobia Inventory (SPIN) |
| Trigeminal neuralgia | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Pain Inventory Short Form |
| •McGill Pain Questionnaire (SF MPQ-2) |
| •VAS Pain Score |
| Ulcerative colitis | •GAD-7 Questionnaire |
| •EQ-5D-5L Health Questionnaire |
| •Patients' Global Impression of Change (PGIC) |
| •Sleep Quality Scale |
| •Short Inflammatory Bowel Disease Questionnaire (SIBDQ) |

## Appendix 3 – UK Medical Cannabis Registry Patient Reported Outcome Measure Questions

|  |  |  |  |
| --- | --- | --- | --- |
| **Questionnaire** | **Question number** | **Section heading** | **Question** |
| **GAD-7** | 1 | Over the last 2 weeks, how often have you been bothered by the following problems? | Feeling nervous, anxious, or on edge |
| **GAD-7** | 2 | Over the last 2 weeks, how often have you been bothered by the following problems? | Not being able to stop or control worrying |
| **GAD-7** | 3 | Over the last 2 weeks, how often have you been bothered by the following problems? | Worrying too much about different things |
| **GAD-7** | 4 | Over the last 2 weeks, how often have you been bothered by the following problems? | Trouble relaxing |
| **GAD-7** | 5 | Over the last 2 weeks, how often have you been bothered by the following problems? | Being so restless that it's hard to sit still |
| **GAD-7** | 6 | Over the last 2 weeks, how often have you been bothered by the following problems? | Becoming easily annoyed or irritable |
| **GAD-7** | 7 | Over the last 2 weeks, how often have you been bothered by the following problems? | Feeling afraid as if something awful might happen |
| **GAD-7** | 8 | Over the last 2 weeks, how often have you been bothered by the following problems? | If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? |
| **EQ-5D-5L** | 1 | Under each heading, please tick the ONE box that best describes your health TODAY. | MOBILITY |
| **EQ-5D-5L** | 2 | Under each heading, please tick the ONE box that best describes your health TODAY. | SELF-CARE |
| **EQ-5D-5L** | 3 | Under each heading, please tick the ONE box that best describes your health TODAY. | USUAL ACTIVITIES |
| **EQ-5D-5L** | 4 | Under each heading, please tick the ONE box that best describes your health TODAY. | PAIN / DISCOMFORT |
| **EQ-5D-5L** | 5 | Under each heading, please tick the ONE box that best describes your health TODAY. | ANXIETY / DEPRESSION |
| **EQ-5D-5L** | 6 |  | We would like to know how good or bad your health is TODAY. Please enter a number from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. |
| **PGIC** | 1 |  | Since beginning treatment at this clinic, how would you describe the change (if any) in ACTIVITY LIMITATIONS, SYMPTOMS, EMOTIONS AND OVERALL QUALITY OF LIFE, related to your painful condition? |
| **PGIC** | 2 |  | In a similar way, please choose a number, that matches your degree of change since beginning care at this clinic |
| **SQS** | 1 |  | During the past 7 days, how would you rate your sleep quality overall? Where 0 is terrible, 1-3 is poor, 4-6 is fair, 7-9 is good and 10 is excellent |
| **PHQ-9** | 1 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | Little interest or pleasure in doing things |
| **PHQ-9** | 2 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | Feeling down, depressed, or hopeless |
| **PHQ-9** | 3 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | Trouble falling or staying asleep, or sleeping too much |
| **PHQ-9** | 4 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | Feeling tired or having little energy |
| **PHQ-9** | 5 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | Poor appetite or overeating |
| **PHQ-9** | 6 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | Feeling bad about yourself or that you are a failure or have let yourself or your family down |
| **PHQ-9** | 7 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | Trouble concentrating on things, such as reading the newspaper or watching television |
| **PHQ-9** | 8 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | 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 |
| **PHQ-9** | 9 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | Thoughts that you would be better off dead or of hurting yourself in some way |
| **PHQ-9** | 10 | Over the last 2 weeks, how often have you been bothered by any of the following problems? | If you checked off any problems, 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? |
| **VAS Pain Score** | 1 |  | Please enter a number between 0-10 to describe the intensity of pain you have experienced in the last 24 hours |
| **SF MPQ-2** | 1 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Throbbing pain |
| **SF MPQ-2** | 2 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Shooting pain |
| **SF MPQ-2** | 3 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Stabbing pain |
| **SF MPQ-2** | 4 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Sharp pain |
| **SF MPQ-2** | 5 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Cramping pain |
| **SF MPQ-2** | 6 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Gnawing pain |
| **SF MPQ-2** | 7 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Hot-burning pain |
| **SF MPQ-2** | 8 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Aching pain |
| **SF MPQ-2** | 9 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Heavy pain |
| **SF MPQ-2** | 10 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Tender |
| **SF MPQ-2** | 11 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Splitting pain |
| **SF MPQ-2** | 12 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Tiring-exhausting |
| **SF MPQ-2** | 13 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Sickening |
| **SF MPQ-2** | 14 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Fearful |
| **SF MPQ-2** | 15 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Punishing-cruel |
| **SF MPQ-2** | 16 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Electro-shock pain |
| **SF MPQ-2** | 17 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Cold-freezing pain |
| **SF MPQ-2** | 18 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Piercing |
| **SF MPQ-2** | 19 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Pain caused by light touch |
| **SF MPQ-2** | 20 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Itching |
| **SF MPQ-2** | 21 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Tingling or 'pins and needles' |
| **SF MPQ-2** | 22 | Please select the option that best describes the intensity of each of the pain and related symptoms you felt during the past week. Use 0 (None) if the word does not describe your pain or related symptoms. A score of 10 represents the worst possible intensity of each of the types of pain and related symptoms | Numbness |
| **HIT-6** | 1 | Efficacy measure - Headache | Number of headaches in the last month |
| **HIT-6** | 2 |  | When you have headaches, how often is the pain severe? |
| **HIT-6** | 3 |  | How often do headaches limit your ability to do usual daily activities including household work, work, school, or social activities |
| **HIT-6** | 4 |  | When you have a headache, how often do you wish you could lie down |
| **HIT-6** | 5 |  | In the past 4 weeks, how often have you felt too tired to do work or daily activities because of your headaches |
| **HIT-6** | 6 |  | In the past 4 weeks, how often have you felt fed up or irritated because of your headaches |
| **HIT-6** | 7 |  | In the past 4 weeks, how often did headaches limit your ability to concentrate on work or daily activities |
| **SIBDQ** | 1 | Efficacy measure - Inflammatory Bowel Disease | How many bowel motions do you have each day |
| **SIBDQ** | 2 |  | How often has the feeling of fatigue or being tired and worn out been a problem for you during the past 2 weeks |
| **SIBDQ** | 3 |  | How often during the last 2 weeks have you delayed or canceled a social engagement because of your bowel problem |
| **SIBDQ** | 4 |  | As a result of your bowel problems, how much difficulty did you experience doing leisure or sports activities during the past 2 weeks |
| **SIBDQ** | 5 |  | How often during the past 2 weeks have you been troubled by pain in the abdomen |
| **SIBDQ** | 6 |  | How often during the past 2 weeks have you felt depressed or discouraged |
| **SIBDQ** | 7 |  | Overall, in the past 2 weeks, how much of a problem have you had with passing large amounts of gas |
| **SIBDQ** | 8 |  | Overall, in the past 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be |
| **SIBDQ** | 9 |  | How often during the past 2 weeks have you felt relaxed and free of tension |
| **SIBDQ** | 10 |  | How much of the time during the past 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels were empty |
| **SIBDQ** | 11 |  | How often during the past 2 weeks have you felt angry as a result of your bowel problem |
| **EDE-Q 6.0** | 1 | On how many days in the past 28 days... | Have you been deliberately trying to limit the amount of food you eat to influence your shape or weight (whether or not you have succeeded) |
| **EDE-Q 6.0** | 2 | On how many days in the past 28 days... | Have you gone for long periods of time (8 waking hours or more) without eating anything at all in order to influence your shape or weight |
| **EDE-Q 6.0** | 3 | On how many days in the past 28 days... | Have you tried to exclude from your diet any foods that you like in order to influence your shape or weight (whether or not you have succeeded) |
| **EDE-Q 6.0** | 4 | On how many days in the past 28 days... | Have you tried to follow definite rules regarding your eating (for example, a calorie limit) in order to influence your shape or weight (whether or not you have succeeded) |
| **EDE-Q 6.0** | 5 | On how many days in the past 28 days... | Have you had a definite desire to have an empty stomach with the aim of influencing your shape or weight |
| **EDE-Q 6.0** | 6 | On how many days in the past 28 days... | Have you had a definite desire to have a totally flat stomach |
| **EDE-Q 6.0** | 7 | On how many days in the past 28 days... | Has thinking about food, eating or calories made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading) |
| **EDE-Q 6.0** | 8 | On how many days in the past 28 days... | Has thinking about shape or weight made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading) |
| **EDE-Q 6.0** | 9 | On how many days in the past 28 days... | Have you had a definite fear of losing control over eating? |
| **EDE-Q 6.0** | 10 | On how many days in the past 28 days... | Have you had a definite fear that you might gain weight |
| **EDE-Q 6.0** | 11 | On how many days in the past 28 days... | Have you felt fat |
| **EDE-Q 6.0** | 12 | On how many days in the past 28 days... | Have you had a strong desire to lose weight |
| **EDE-Q 6.0** | 13 | Over the past 28 days... | ... how many times have you eaten what other people would regards as an unusually large amount of food (given the circumstances) |
| **EDE-Q 6.0** | 14 | Over the past 28 days... | ... on how many of these times did you have a sense of having lost control over your eating (at the time you were eating) |
| **EDE-Q 6.0** | 15 | Over the past 28 days... | ... on how many DAYS have such episodes of overeating occurred |
| **EDE-Q 6.0** | 16 | Over the past 28 days... | ... how many times have you made yourself sick (vomit) as a means of controlling your shape or weight |
| **EDE-Q 6.0** | 17 | Over the past 28 days... | ... how many times have you taken laxatives as a means of controlling your shape or weight |
| **EDE-Q 6.0** | 18 | Over the past 28 days... | ... how many times have you exercised in a â€œdrivenâ€ or â€œcompulsiveâ€ way as a means of controlling your weight, shape or amount of fat, or to burn off calories |
| **EDE-Q 6.0** | 19 | Over the past 28 days... | ... on how many days have you eaten in secret (ie, furtively) â€¦ do not count episodes of binge eating |
| **EDE-Q 6.0** | 20 | Over the past 28 days... | ... on what proportion of the times that you have eaten have you felt guilty (felt that youâ€™ve done wrong) because of its effect on your shape or weight â€¦ do not count episodes of binge eating |
| **EDE-Q 6.0** | 21 | Over the past 28 days... | ... how concerned have you been about other people seeing you eat â€¦ do not count episodes of binge eating |
| **EDE-Q 6.0** | 22 |  | Has your weight influenced how you think about (judge) yourself as a person |
| **EDE-Q 6.0** | 23 |  | Has your shape influenced how you think about (judge) yourself as a person |
| **EDE-Q 6.0** | 24 |  | How much would it have upset you if you had been asked to weigh yourself once a week (no more, or less, often) for the next four weeks |
| **EDE-Q 6.0** | 25 |  | How dissatisfied have you been with your weight |
| **EDE-Q 6.0** | 26 |  | How dissatisfied have you been with your shape |
| **EDE-Q 6.0** | 27 |  | How uncomfortable have you felt seeing your body (for example, seeing your shape in the mirror, in a shop window reflection, while undressing or taking a bath or shower) |
| **EDE-Q 6.0** | 28 |  | How uncomfortable have you felt about others seeing your shape or figure (for example, in communal changing rooms, when swimming, or wearing tight clothes) |
| **EDE-Q 6.0** | 29 |  | What is your weight at present (please give your best estimate) |
| **EDE-Q 6.0** | 30 |  | What is your height (please give your best estimate) |
| **Brief Pain Inventory - Short Form** | 1 |  | Throughout our lives,most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had any pain other than these everyday kinds of pain |
| **Brief Pain Inventory - Short Form** | 2 |  | From looking at the diagram below please select the number corresponding to the areas in which you feel the MOST pain |
| **Brief Pain Inventory - Short Form** | 3 |  | From looking at the diagram below please select the numbers of the corresponding areas in which you feel ANY pain |
| **Brief Pain Inventory - Short Form** | 4 |  | Please rate your pain by choosing the number that best describes your pain at its WORST in the last 24 hours |
| **Brief Pain Inventory - Short Form** | 5 |  | Please rate your pain by choosing the number that best describes your pain at its LEAST in the last 24 hours |
| **Brief Pain Inventory - Short Form** | 6 |  | Please rate your pain by choosing the number that best describes your pain on the AVERAGE |
| **Brief Pain Inventory - Short Form** | 7 |  | Please rate your pain by choosing the number that tells how much pain you have RIGHT NOW |
| **Brief Pain Inventory - Short Form** | 8 |  | What treatment or medications are you receiving for your pain? |
| **Brief Pain Inventory - Short Form** | 9 |  | In the last 24 hours how much relief have pain treatments or medications provided |
| **Brief Pain Inventory - Short Form** | 10 | Choose the number that describes how, during the past 24 hours, pain has interfered with your: | ... general activity |
| **Brief Pain Inventory - Short Form** | 11 | Choose the number that describes how, during the past 24 hours, pain has interfered with your: | ... mood |
| **Brief Pain Inventory - Short Form** | 12 | Choose the number that describes how, during the past 24 hours, pain has interfered with your: | ... walking ability |
| **Brief Pain Inventory - Short Form** | 13 | Choose the number that describes how, during the past 24 hours, pain has interfered with your: | ... normal work (includes both work outside the home and housework) |
| **Brief Pain Inventory - Short Form** | 14 | Choose the number that describes how, during the past 24 hours, pain has interfered with your: | ... relations with other people |
| **Brief Pain Inventory - Short Form** | 15 | Choose the number that describes how, during the past 24 hours, pain has interfered with your: | ... sleep |
| **Brief Pain Inventory - Short Form** | 16 | Choose the number that describes how, during the past 24 hours, pain has interfered with your: | ... enjoyment of life |
| **Symptom Distress Scale** | 1 |  | Please rate the intensity of your nausea between 0 and 100. Where 0 is no nausea and 100 is intractable nausea |
| **Symptom Distress Scale** | 2 |  | Nausea |
| **Symptom Distress Scale** | 3 |  | Nausea frequency |
| **Symptom Distress Scale** | 4 |  | Appetite |
| **Symptom Distress Scale** | 5 |  | Insomnia |
| **Symptom Distress Scale** | 6 |  | Pain |
| **Symptom Distress Scale** | 7 |  | Pain frequency |
| **Symptom Distress Scale** | 8 |  | Fatigue |
| **Symptom Distress Scale** | 9 |  | Bowel |
| **Symptom Distress Scale** | 10 |  | Concentration |
| **Symptom Distress Scale** | 11 |  | Appearance |
| **Symptom Distress Scale** | 12 |  | Breathing |
| **Symptom Distress Scale** | 13 |  | Outlook |
| **Symptom Distress Scale** | 14 |  | Cough |
| **MIDAS** | 1 | Efficacy measure - Migraines | Number of migraines in the last month |
| **MIDAS** | 2 | Please answer the following questions about ALL of the headaches you have had over the last 3 months. On how many days in the last three months | ... did you miss work or school because of your headaches |
| **MIDAS** | 3 | Please answer the following questions about ALL of the headaches you have had over the last 3 months. On how many days in the last three months | .. was your productivity at work or school reduced by half or more because of your headaches |
| **MIDAS** | 4 | Please answer the following questions about ALL of the headaches you have had over the last 3 months. On how many days in the last three months | ... did you not do household work because of your headaches |
| **MIDAS** | 5 | Please answer the following questions about ALL of the headaches you have had over the last 3 months. On how many days in the last three months | ... was your productivity in household work reduced by half of more because of your headaches |
| **MIDAS** | 6 | Please answer the following questions about ALL of the headaches you have had over the last 3 months. On how many days in the last three months | ... did you miss family, social or leisure activities because of your headaches |
| **MIDAS** | 7 | Please answer the following questions about ALL of the headaches you have had over the last 3 months. On how many days in the last three months | ... did you have a headache |
| **MIDAS** | 8 | Please answer the following questions about ALL of the headaches you have had over the last 3 months. On how many days in the last three months | On average how painful were these headaches |
| **QOLIE-31-P** | 1 |  | Number of seizures you had in the last month |
| **QOLIE-31-P** | 2 |  | Overall, how would you rate your quality of life |
| **QOLIE-31-P** | 3 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you feel full of pep |
| **QOLIE-31-P** | 4 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you been a very nervous person |
| **QOLIE-31-P** | 5 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you felt so down in the dumps that nothing could cheer you up |
| **QOLIE-31-P** | 6 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you felt calm and peaceful |
| **QOLIE-31-P** | 7 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you have a lot of energy |
| **QOLIE-31-P** | 8 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you felt downhearted and blue |
| **QOLIE-31-P** | 9 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you feel worn out |
| **QOLIE-31-P** | 10 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you been a happy person |
| **QOLIE-31-P** | 11 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you feel tired |
| **QOLIE-31-P** | 12 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you worried about having another seizure |
| **QOLIE-31-P** | 13 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things) |
| **QOLIE-31-P** | 14 | These questions are about how your FEEL and how things have been for you during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... has your health limited your social activities (such as visiting with friends or close relatives) |
| **QOLIE-31-P** | 15 |  | How has the QUALITY OF YOUR LIFE been during the past 4 weeks (that is, how have things been going for you). Choose a number between 1 and 5. Where 1 is 'very well: could hardly be better', 2 is 'pretty good', 3 is 'good & bad parts about equal', 4 is 'pretty bad' and 5 is 'very bad: could hardly be worse' |
| **QOLIE-31-P** | 16 | The following question is about MEMORY. | In the past 4 weeks, have you had any trouble with your memory |
| **QOLIE-31-P** | 17 | In the past 4 weeks, how often have you had... | ... trouble remembering things people tell you |
| **QOLIE-31-P** | 18 | In the past 4 weeks, how often have you had... | ... trouble concentrating on reading |
| **QOLIE-31-P** | 19 | In the past 4 weeks, how often have you had... | ... trouble concentrating on doing one thing at a time |
| **QOLIE-31-P** | 20 | The following questions are about problems you may have with certain ACTIVITIES. Choose one number for how much during the past 4 weeks your epilepsy or antiepileptic medication has caused trouble with... | ... leisure activities (such as hobbies, going out) |
| **QOLIE-31-P** | 21 | The following questions are about problems you may have with certain ACTIVITIES. Choose one number for how much during the past 4 weeks your epilepsy or antiepileptic medication has caused trouble with... | ... driving (or transportation) (such as visiting with friends or close relatives) |
| **QOLIE-31-P** | 22 | These questions are about how you FEEL about your seizures during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | How fearful are you of having a seizure during the next month |
| **QOLIE-31-P** | 23 | These questions are about how you FEEL about your seizures during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | Do you worry about hurting yourself during a seizure |
| **QOLIE-31-P** | 24 | These questions are about how you FEEL about your seizures during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | How worried are you about embarrassment or other social problems resulting from having a seizure during the next month |
| **QOLIE-31-P** | 25 | These questions are about how you FEEL about your seizures during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | How worried are you that medications you are taking will be bad for you if taken for a long time |
| **QOLIE-31-P** | 26 | For each of these PROBLEMS, choose one number for how much they bother you on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome. | How much do your seizures bother you |
| **QOLIE-31-P** | 27 | For each of these PROBLEMS, choose one number for how much they bother you on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome. | How much do your memory difficulties bother you |
| **QOLIE-31-P** | 28 | For each of these PROBLEMS, choose one number for how much they bother you on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome. | How much do your work limitations bother you |
| **QOLIE-31-P** | 29 | For each of these PROBLEMS, choose one number for how much they bother you on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome. | How much do your social limitations bother you |
| **QOLIE-31-P** | 30 | For each of these PROBLEMS, choose one number for how much they bother you on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome. | ... how much do physical effects of antiepileptic medication bother you |
| **QOLIE-31-P** | 31 | For each of these PROBLEMS, choose one number for how much they bother you on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome. | ...how much do mental effects of antiepileptic medication bother you |
| **QOLIE-31-P** | 32 |  | How good or bad do you think your HEALTH is On the scale, the best imaginable state of health is 100 and the worst imaginable state is zero (0). Please indicate how you feel by entering a number between 0 and 100 below. Please consider your epilepsy as part of your health when you answer this question. |
| **IEPS** | 1 | Efficacy Measure - Paediatric Epilepsy | Number of seizures in the last month |
| **IEPS** | 2 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Overall health |
| **IEPS** | 3 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Relationships with parents |
| **IEPS** | 4 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Relationship with siblings |
| **IEPS** | 5 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Relationship between you and your spouse/partner |
| **IEPS** | 6 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Relationship with friends / peers |
| **IEPS** | 7 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Acceptability by others |
| **IEPS** | 8 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Number of activities |
| **IEPS** | 9 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | School academics |
| **IEPS** | 10 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Childâ€™s self-esteem |
| **IEPS** | 11 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Your loss of original hopes for your child |
| **IEPS** | 12 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Family activities |
| **IEPS** | 13 | We would like to know how you feel your child’s epilepsy affects either your child’s or your family’s everyday life at the present time and during the past 3 months. Please indicate how much impact your child’s epilepsy had on the following various aspects of you/your child’s life. | Please rate your childâ€™s overall quality of life |
| **Fibromyalgia Symptom Severity Score** | 1 | Widespread pain index - Check each area you have felt pain over the last week | Pain in the RIGHT upper region |
| **Fibromyalgia Symptom Severity Score** | 2 | Widespread pain index - Check each area you have felt pain over the last week | Pain in the LEFT upper region |
| **Fibromyalgia Symptom Severity Score** | 3 | Widespread pain index - Check each area you have felt pain over the last week | Pain in the axial region |
| **Fibromyalgia Symptom Severity Score** | 4 | Widespread pain index - Check each area you have felt pain over the last week | Pain in the RIGHT lower region |
| **Fibromyalgia Symptom Severity Score** | 5 | Widespread pain index - Check each area you have felt pain over the last week | Pain in the LEFT lower region |
| **Fibromyalgia Symptom Severity Score** | 6 | Symptom severity score | Fatigue |
| **Fibromyalgia Symptom Severity Score** | 7 | Symptom severity score | Waking unrefreshed |
| **Fibromyalgia Symptom Severity Score** | 8 | Symptom severity score | Cognitive symtoms |
| **Fibromyalgia Symptom Severity Score** | 9 | Symptoms in the last 6 months | Headaches |
| **Fibromyalgia Symptom Severity Score** | 10 | Symptoms in the last 6 months | Lower abdominal pain |
| **Fibromyalgia Symptom Severity Score** | 11 | Symptoms in the last 6 months | Depression |
| **MSQoL** | 1 |  | In general, would you say your health is |
| **MSQoL** | 2 |  | Compared to ONE YEAR AGO, how would you rate your health in general NOW |
| **MSQoL** | 3 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports |
| **MSQoL** | 4 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf |
| **MSQoL** | 5 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Lifting or carrying groceries |
| **MSQoL** | 6 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Climbing several flights of stairs |
| **MSQoL** | 7 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Climbing one flight of stairs |
| **MSQoL** | 8 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Bending, kneeling, or stooping |
| **MSQoL** | 9 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Walking more than a mile |
| **MSQoL** | 10 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Walking several blocks |
| **MSQoL** | 11 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Walking one block |
| **MSQoL** | 12 | The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? | Bathing and dressing |
| **MSQoL** | 13 | During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? | Cut down on the amount of time you could spend on work or other activities |
| **MSQoL** | 14 | During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? | Accomplished less than you would like |
| **MSQoL** | 15 | During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? | Were limited in the kind of work or other activities |
| **MSQoL** | 16 | During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? | Had difficulty performing the work or other activities |
| **MSQoL** | 17 | During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? | Cut down on the amount of time you could spend on work or other activities |
| **MSQoL** | 18 | During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? | Accomplished less than you would like |
| **MSQoL** | 19 | During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? | Didn't do work or other activities as carefully as usual |
| **MSQoL** | 20 | During the past 4 weeks... | ... to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups |
| **MSQoL** | 21 | During the past 4 weeks... | ...how much bodily pain have you had |
| **MSQoL** | 22 | During the past 4 weeks... | ...how much did pain interfere with your normal work including both work outside the home and housework |
| **MSQoL** | 23 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you feel full of pep |
| **MSQoL** | 24 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you been a very nervous person |
| **MSQoL** | 25 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you felt so down in the dumps that nothing could cheer you up |
| **MSQoL** | 26 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you felt calm and peaceful |
| **MSQoL** | 27 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you have a lot of energy |
| **MSQoL** | 28 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you felt downhearted and blue |
| **MSQoL** | 29 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you feel worn out |
| **MSQoL** | 30 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... have you been a happy person |
| **MSQoL** | 31 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you feel tired |
| **MSQoL** | 32 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | ... did you feel rested on waking in the morning |
| **MSQoL** | 33 | These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks... | During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities |
| **MSQoL** | 34 | How TRUE or FALSE is each of the following statements for you? | I seem to get sick a little easier than other people |
| **MSQoL** | 35 | How TRUE or FALSE is each of the following statements for you? | I am as healthy as anybody I know |
| **MSQoL** | 36 | How TRUE or FALSE is each of the following statements for you? | I expect my health to get worse |
| **MSQoL** | 37 | How TRUE or FALSE is each of the following statements for you? | My health is excellent |
| **MSQoL** | 38 | How much of the time during the past 4 weeks... | ... were you discouraged by your health problems |
| **MSQoL** | 39 | How much of the time during the past 4 weeks... | ... were you frustrated about your health |
| **MSQoL** | 40 | How much of the time during the past 4 weeks... | ... was your health a worry in your life |
| **MSQoL** | 41 | How much of the time during the past 4 weeks... | ... did you feel weighed down by your health problems |
| **MSQoL** | 42 | How much of the time during the past 4 weeks... | ... have you had difficulty concentrating and thinking |
| **MSQoL** | 43 | How much of the time during the past 4 weeks... | ... have you had trouble keeping your attention on an activity for long |
| **MSQoL** | 44 | How much of the time during the past 4 weeks... | ... have you had trouble with your memory |
| **MSQoL** | 45 | How much of the time during the past 4 weeks... | ... have others, such as family members or friends, noticed that you have trouble with your memory or problems with your concentration |
| **MSQoL** | 46 | The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function during the last 4 weeks only. How much of a problem was each of the following for you during the past 4 weeks? | Gender |
| **MSQoL** | 47 | The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function during the last 4 weeks only. How much of a problem was each of the following for you during the past 4 weeks? | Difficulty in getting or keeping an erection |
| **MSQoL** | 48 | The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function during the last 4 weeks only. How much of a problem was each of the following for you during the past 4 weeks? | Inadequate lubrication |
| **MSQoL** | 49 | The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function during the last 4 weeks only. How much of a problem was each of the following for you during the past 4 weeks? | Lack of sexual interest |
| **MSQoL** | 50 | The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function during the last 4 weeks only. How much of a problem was each of the following for you during the past 4 weeks? | Difficulty having orgasm |
| **MSQoL** | 51 | The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function during the last 4 weeks only. How much of a problem was each of the following for you during the past 4 weeks? | Ability to satisfy sexual partner |
| **MSQoL** | 52 | The next set of questions are about your sexual function and your satisfaction with your sexual function. Please answer as accurately as possible about your function during the last 4 weeks only. How much of a problem was each of the following for you during the past 4 weeks? | Overall, how satisfied were you with your sexual function during the past 4 weeks |
| **MSQoL** | 53 |  | During the past 4 weeks, to what extent have problems with your bowel or bladder function interfered with your normal social activities with family, friends, neighbours, or groups |
| **MSQoL** | 54 |  | During the past 4 weeks, how much did pain interfere with your enjoyment of life? |
| **MSQoL** | 55 |  | Overall, how would you rate your own quality-of-life? Please select a number between 0 and 10 which best describes your quality-of-life with reference to the scale below. |
| **MSQoL** | 56 |  | Which best describes how you feel about your life as a whole |
| **OCI** | 1 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | Unpleasant thoughts come into my mind against my will and I cannot get rid of them |
| **OCI** | 2 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I think contact with bodily secretions (perspiration, saliva, blood, urine, etc) may contaminate my clothes or somehow harm me |
| **OCI** | 3 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I ask people to repeat things to me several times, even though I understood them the first time |
| **OCI** | 4 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I wash and clean obsessively |
| **OCI** | 5 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I have to review mentally past events, conversations and actions to make sure that I didn't do something wrong |
| **OCI** | 6 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I have saved up so many things that they get in the way |
| **OCI** | 7 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I check things more often than necessary |
| **OCI** | 8 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I avoid using public toilets because I am afraid of disease or contamination |
| **OCI** | 9 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I repeatedly check doors, windows, drawers etc. |
| **OCI** | 10 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I repeatedly check gas and water taps and light switches after turning them off |
| **OCI** | 11 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I collect things I don't need |
| **OCI** | 12 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I have thoughts of having hurt someone without knowing it |
| **OCI** | 13 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I have thoughts that I might want to harm myself or others |
| **OCI** | 14 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I get upset if objects are not arranged properly |
| **OCI** | 15 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I feel obliged to follow a particular order in dressing, undressing and washing myself |
| **OCI** | 16 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I feel compelled to count while I am doing things |
| **OCI** | 17 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I am afraid of impulsively doing embarrassing or harmful things |
| **OCI** | 18 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I need to pray to cancel bad thoughts or feelings |
| **OCI** | 19 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I keep on checking forms or other things I have written |
| **OCI** | 20 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I get upset at the sight of knives, scissors and other sharp objects in case I lose control with them |
| **OCI** | 21 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I am excessively concerned about cleanliness |
| **OCI** | 22 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I find it difficult to touch an object when I know it has been touched by strangers or certain people |
| **OCI** | 23 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I need things to be arranged in a particular order |
| **OCI** | 24 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I get behind in my work because I repeat things over and over again |
| **OCI** | 25 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I feel I have to repeat certain numbers |
| **OCI** | 26 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | After doing something carefully, I still have the impression I have not finished it |
| **OCI** | 27 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I find it difficult to touch garbage or dirty things. |
| **OCI** | 28 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I find it difficult to control my own thoughts |
| **OCI** | 29 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I have to do things over and over again until it feels right |
| **OCI** | 30 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I am upset by unpleasant thoughts that come into my mind against my will |
| **OCI** | 31 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | Before going to sleep I have to do certain things in a certain way |
| **OCI** | 32 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I go back to places to make sure that I have not harmed anyone |
| **OCI** | 33 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I frequently get nasty thoughts and have difficulty in getting rid of them |
| **OCI** | 34 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I avoid throwing things away because I am afraid I might need them later |
| **OCI** | 35 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I get upset if others change the way I have arranged my things |
| **OCI** | 36 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I feel that I must repeat certain words or phrases in my mind in order to wipe out bad thoughts, feelings or actions |
| **OCI** | 37 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | After I have done things, I have persistent doubts about whether I really did them |
| **OCI** | 38 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I sometimes have to wash or clean myself simply because I feel contaminated |
| **OCI** | 39 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I feel that there are good and bad numbers |
| **OCI** | 40 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I repeatedly check anything which might cause a fire |
| **OCI** | 41 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | Even when I do something very carefully I feel that it is not quite right |
| **OCI** | 42 | The following statements refer to experiences which many people have in their everyday lives. Please select the option that best describes HOW MUCH that experience has DISTRESSED or BOTHERED YOU DURING THE PAST MONTH | I wash my hands more often or longer than necessary |
| **POS** | 1 |  | What have been your main problems or concerns over the past 3 days |
| **POS** | 2 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Pain |
| **POS** | 3 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Shortness of breath |
| **POS** | 4 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Weakness or lack of energy |
| **POS** | 5 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Nausea (feeling like being sick) |
| **POS** | 6 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Vomiting (being sick) |
| **POS** | 7 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Poor appetite |
| **POS** | 8 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Constipation |
| **POS** | 9 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Sore or dry mouth |
| **POS** | 10 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Drowsiness |
| **POS** | 11 | Out of the following symptoms, which you may or may not have experienced. For each symptom, please select the option that best describes how it has affected you over the past 3 days: | Poor mobility |
| **POS** | 12 | Please list any other symptoms not mentioned above, and select the option that best describes how it has affected you over the past 3 days | Any other symptoms not listed above |
| **POS** | 13 | Please list any other symptoms not mentioned above, and select the option that best describes how it has affected you over the past 3 days | Enter another symptom |
| **POS** | 14 | Please list any other symptoms not mentioned above, and select the option that best describes how it has affected you over the past 3 days | Symptom effect |
| **POS** | 15 | Please list any other symptoms not mentioned above, and select the option that best describes how it has affected you over the past 3 days | Enter another symptom |
| **POS** | 16 | Please list any other symptoms not mentioned above, and select the option that best describes how it has affected you over the past 3 days | Symptom effect |
| **POS** | 17 | Please list any other symptoms not mentioned above, and select the option that best describes how it has affected you over the past 3 days | Enter another symptom |
| **POS** | 18 | Please list any other symptoms not mentioned above, and select the option that best describes how it has affected you over the past 3 days | Symptom effect |
| **POS** | 19 | Over the past 3 days | Have you been feeling anxious or worried about your illness or treatment |
| **POS** | 20 | Over the past 3 days | Have any of your family or friends been anxious or worried about you |
| **POS** | 21 | Over the past 3 days | Have you been feeling depressed |
| **POS** | 22 | Over the past 3 days | Have you felt at peace |
| **POS** | 23 | Over the past 3 days | Have you been able to share how you are feeling with your family or friends as much as you wanted |
| **POS** | 24 | Over the past 3 days | Have you had as much information as you wanted |
| **POS** | 25 | Over the past 3 days | Have any practical problems resulting from your illness been addressed (such as financial or personal) |
| **POS** | 26 | Over the past 3 days | How did you complete this questionnaire |
| **AKPS** | 1 |  | The Australia-modified Karnofsky Performance Status |
| **Panic Rating Scale** | 1 | A panic attack means a sudden increase in anxiety during which four or more of the following sensations are experienced:  1. Feeling short of breath  2. Palpitations or heart racing  3. Choking  4. Chest feeling uncomfortable or painful  5. Sweating  6. Dizziness, unsteady feelings or faintness  7. Feeling unreal or detatched from yourself  8. Nausea or discomfort in the stomach  9. Hot or cold flushes  10 .Trembling or shaking  11. Numbness or tingling feelings (pins and needles)  12. Fear of dying  13. Fear of doing something uncontrolled or going crazy during an attack  Please choose an option on each of the following questions to indicate your answer | What was the frequency of your panic attacks during the last two weeks |
| **Panic Rating Scale** | 2 | A panic attack means a sudden increase in anxiety during which four or more of the following sensations are experienced: 1. Feeling short of breath  2. Palpitations or heart racing  3. Choking  4. Chest feeling uncomfortable or painful  5. Sweating  6. Dizziness, unsteady feelings or faintness  7. Feeling unreal or detatched from yourself  8. Nausea or discomfort in the stomach  9. Hot or cold flushes  10 .Trembling or shaking  11. Numbness or tingling feelings (pins and needles)  12. Fear of dying  13. Fear of doing something uncontrolled or going crazy during an attack  Please choose an option on each of the following questions to indicate your answer | How severe a problem are panic attacks for you at present |
| **Panic Rating Scale** | 3 | A panic attack means a sudden increase in anxiety during which four or more of the following sensations are experienced: 1. Feeling short of breath  2. Palpitations or heart racing  3. Choking  4. Chest feeling uncomfortable or painful  5. Sweating  6. Dizziness, unsteady feelings or faintness  7. Feeling unreal or detatched from yourself  8. Nausea or discomfort in the stomach  9. Hot or cold flushes  10 .Trembling or shaking  11. Numbness or tingling feelings (pins and needles)  12. Fear of dying  13. Fear of doing something uncontrolled or going crazy during an attack  Please choose an option on each of the following questions to indicate your answer | In the past two weeks, how much have you avoided situations (or needed someone to accompany you) due to fear that you may panic / have symptoms? Examples are: being outside home alone, travelling, being in a crowd, supermarket or department store |
| **PDQ-39** | 1 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty doing the leisure activities which you would like to do |
| **PDQ-39** | 2 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty looking after your home, e.g. DIY, housework, cooking |
| **PDQ-39** | 3 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty carrying bags of shopping |
| **PDQ-39** | 4 | Due to having Parkinson’s disease, how often during the last month have you… | ... had problems walking half a mile |
| **PDQ-39** | 5 | Due to having Parkinson’s disease, how often during the last month have you… | ... had problems walking 100 yards |
| **PDQ-39** | 6 | Due to having Parkinson’s disease, how often during the last month have you… | ... had problems getting around the house as easily as you would like |
| **PDQ-39** | 7 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty getting around in public |
| **PDQ-39** | 8 | Due to having Parkinson’s disease, how often during the last month have you… | ... needed someone else to accompany you when you went out |
| **PDQ-39** | 9 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt frightened or worried about falling over in public |
| **PDQ-39** | 10 | Due to having Parkinson’s disease, how often during the last month have you… | ... been confined to the house more than you would like |
| **PDQ-39** | 11 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty washing yourself |
| **PDQ-39** | 12 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty dressing yourself |
| **PDQ-39** | 13 | Due to having Parkinson’s disease, how often during the last month have you… | ... had problems doing up your shoe laces |
| **PDQ-39** | 14 | Due to having Parkinson’s disease, how often during the last month have you… | ... had problems writing clearly |
| **PDQ-39** | 15 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty cutting up your food |
| **PDQ-39** | 16 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty holding a drink without spilling it |
| **PDQ-39** | 17 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt depressed |
| **PDQ-39** | 18 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt isolated and lonely |
| **PDQ-39** | 19 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt weepy or tearful |
| **PDQ-39** | 20 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt angry or bitter |
| **PDQ-39** | 21 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt anxious |
| **PDQ-39** | 22 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt worried about your future |
| **PDQ-39** | 23 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt you had to conceal your Parkinson's from people |
| **PDQ-39** | 24 | Due to having Parkinson’s disease, how often during the last month have you… | ... avoided situations which involve eating or drinking in public |
| **PDQ-39** | 25 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt embarrassed in public due to having Parkinson's disease |
| **PDQ-39** | 26 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt worried by other people's reaction to you |
| **PDQ-39** | 27 | Due to having Parkinson’s disease, how often during the last month have you… | ... had problems with your close personal relationships |
| **PDQ-39** | 28 | Due to having Parkinson’s disease, how often during the last month have you… | Do you have a spouse / partner |
| **PDQ-39** | 29 | Due to having Parkinson’s disease, how often during the last month have you… | ... lacked support in the ways you need from your spouse or partner |
| **PDQ-39** | 30 | Due to having Parkinson’s disease, how often during the last month have you… | ... lacked support in the ways you need from your family or close friends |
| **PDQ-39** | 31 | Due to having Parkinson’s disease, how often during the last month have you… | ... unexpectedly fallen asleep during the day? |
| **PDQ-39** | 32 | Due to having Parkinson’s disease, how often during the last month have you… | ... had problems with your concentration, e.g. when reading or watching TV |
| **PDQ-39** | 33 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt your memory was bad |
| **PDQ-39** | 34 | Due to having Parkinson’s disease, how often during the last month have you… | ... had distressing dreams or hallucinations |
| **PDQ-39** | 35 | Due to having Parkinson’s disease, how often during the last month have you… | ... had difficulty with your speech |
| **PDQ-39** | 36 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt unable to communicate with people properly |
| **PDQ-39** | 37 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt ignored by people |
| **PDQ-39** | 38 | Due to having Parkinson’s disease, how often during the last month have you… | ... had painful muscle cramps or spasms |
| **PDQ-39** | 39 | Due to having Parkinson’s disease, how often during the last month have you… | ... had aches and pains in your joints or body |
| **PDQ-39** | 40 | Due to having Parkinson’s disease, how often during the last month have you… | ... felt unpleasantly hot or cold |
| **Impact of Events Scale** | 1 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | Any reminder brought back feelings about it |
| **Impact of Events Scale** | 2 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I had trouble staying asleep |
| **Impact of Events Scale** | 3 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | Other things kept making me think about it |
| **Impact of Events Scale** | 4 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I felt irritable and angry |
| **Impact of Events Scale** | 5 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I avoided letting myself get upset when I thought about it or was reminded of it |
| **Impact of Events Scale** | 6 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I thought about it when I didn't mean to |
| **Impact of Events Scale** | 7 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I felt as if it hadn't happened or wasn't real |
| **Impact of Events Scale** | 8 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I stayed away from reminders of it |
| **Impact of Events Scale** | 9 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | Pictures about it popped into my mind |
| **Impact of Events Scale** | 10 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I was jumpy and easily startled |
| **Impact of Events Scale** | 11 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I tried not to think about it |
| **Impact of Events Scale** | 12 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I was aware that I still had a lot of feelings about it, but I didn't deal with them |
| **Impact of Events Scale** | 13 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | My feelings about it were kind of numb |
| **Impact of Events Scale** | 14 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I found myself acting or feeling like I was back at that time |
| **Impact of Events Scale** | 15 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I had trouble falling asleep |
| **Impact of Events Scale** | 16 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I had waves of strong feelings about it |
| **Impact of Events Scale** | 17 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I tried to remove it from my memory |
| **Impact of Events Scale** | 18 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I had trouble concentrating |
| **Impact of Events Scale** | 19 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart |
| **Impact of Events Scale** | 20 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I had dreams about it |
| **Impact of Events Scale** | 21 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I felt watchful and on-guard |
| **Impact of Events Scale** | 22 | The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS. How much have you been distressed or bothered by these difficulties? | I tried not to talk about it |
| **SPIN** | 1 | Over the last week... | I am afraid of people in authority |
| **SPIN** | 2 | Over the last week... | I am bothered by blushing in front of people |
| **SPIN** | 3 | Over the last week... | Parties and social events scare me |
| **SPIN** | 4 | Over the last week... | I avoid talking to people I don't know |
| **SPIN** | 5 | Over the last week... | Being criticised scares me a lot |
| **SPIN** | 6 | Over the last week... | I avoid doing things or speaking to people for fear of embarrassment |
| **SPIN** | 7 | Over the last week... | Sweating in front of people causes me distress |
| **SPIN** | 8 | Over the last week... | I avoid going to parties |
| **SPIN** | 9 | Over the last week... | I avoid activities in which I am the centre of attention |
| **SPIN** | 10 | Over the last week... | Talking to strangers scares me |
| **SPIN** | 11 | Over the last week... | I avoid having to give speeches |
| **SPIN** | 12 | Over the last week... | I would do anything to avoid being criticised |
| **SPIN** | 13 | Over the last week... | Heart palpitations bother me when I am around people |
| **SPIN** | 14 | Over the last week... | I am afraid of doing things when people might be watching |
| **SPIN** | 15 | Over the last week... | Being embarrassed or looking stupid are among my worse fears |
| **SPIN** | 16 | Over the last week... | I avoid speaking to anyone in authority |
| **SPIN** | 17 | Over the last week... | Trembling or shaking in front of others is distressing to me |