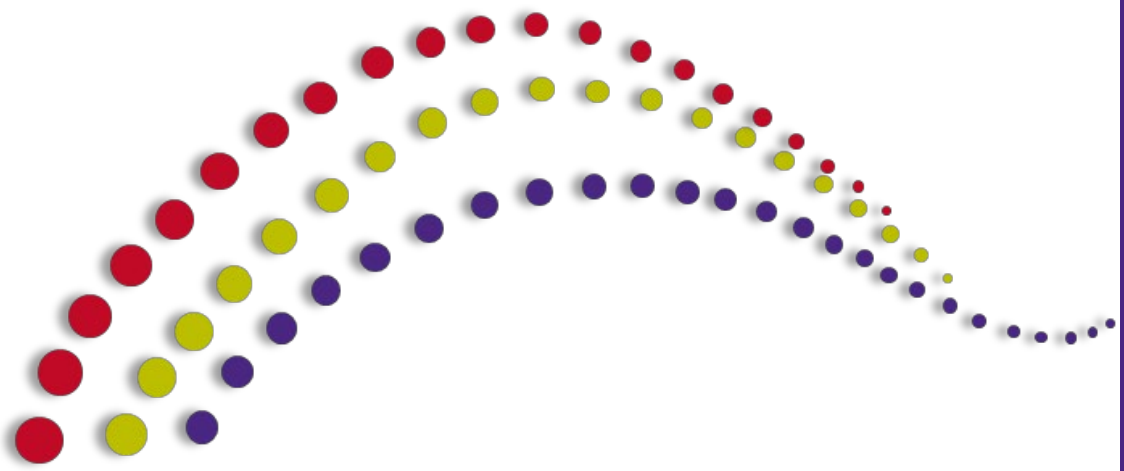
ePPOC Clinical Reference Manual

New Zealand
Version 2 Dataset



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INTRODUCTION

The ePPOC Clinical Reference Manual for the Version 2 Dataset is designed for use by clinicians, managers, administrators and data entry personnel. This manual provides a guide to the collection and use of the information entered into epiCentre and submitted to ePPOC.

The ePPOC dataset consists of five levels of linked information – Patient, Episode, Pathway, Service Events and Patient-Reported Outcome Measures. This manual describes the information collected at each of these five levels and includes a description of the pathways and the protocol for collection of the patient-rated outcome measures.

Excluded from the Clinical Reference Manual are the technical items required for data entry and extraction purposes. This information is contained in the ePPOC Version 2 Data Dictionary and Technical Guidelines.

Also excluded are data items collected by the pain management service but not submitted to ePPOC. These items include patient identifying information (name, address, contact details) and other information that does not form part of the ePPOC dataset and reports (e.g. individual medications taken by patients, compensation case details).

Contacts

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EPPOC CLINICAL DATA ITEMS

Level 1: Patient Information

This information relates to patient demographics. The items collected at the patient level (such as date of birth and country of birth) are unlikely to change over time. An exception to this is postcode and province however, as a patient may change address.

In ePPOC analysis and reporting, patient information defines the patient population and contextualises the patient outcomes.

Patient identifier

Description:	The *Patient identifier* is an alphanumeric code used to identify an individual at a pain management service. This code may be a medical record number generated for each patient within a service. The *Patient identifier* ensures that information recorded at each level (e.g. service and pathway) can be associated with that individual, and also allows tracking of the patient through different episodes of care at a pain management service. This number must be used at all times when recording patient, episode, service, pathway and/or patient-reported outcome level information. An encrypted version of this identifier is included in the data submitted to ePPOC.

Gender

Description:	G*ender* is used in demographic analysis of ePPOC data and may assist to analyse service utilisation, service needs and epidemiological studies, and is used as part of the code to generate a Statistical Linkage Key (SLK).
Document:	One of the following:

Male
Female
Not stated/Inadequately described

Date of birth

Description:	*Date of birth* is used by ePPOC to calculate patient age for demographic analysis, and is used as part of the code to generate a Statistical Linkage Key (SLK).
Document:	The patient's date of birth as DD/MM/YYYY

Postcode

Description: The postcode of the patient's usual place of residence. *Postcode* is used in demographic analysis of ePPOC data and may assist in description of service utilisation, service needs and epidemiological studies.

Document: The numerical postcode of the location where the patient usually resides.

Province

Description: The New Zealand province in which the patient lives. This is a geographic indicator to enable analysis of pain management service utilisation.

Document: One of the following:

Northland
Auckland
Waikato
Bay of Plenty
Gisborne
Hawkes Bay
Taranaki
Manawatu-Wanganui
Wellington
Tasman
Nelson
Marlborough
West Coast
Canterbury
Otago
Southland
Other/Unknown

Country of birth

Description: The country in which the patient was born, used to describe the population of patients seeking pain management services, service utilisation, service needs and epidemiological studies.

Document: Indicate whether the patient was born in New Zealand, Australia or another country. If another country, record the name of the country of birth.

Interpreter required

Description: Identification of whether a patient requires an interpreter. This will be used to describe the patient population and may assist in determining the impact on access to services and interventions. If yes, record the language.

Document: One of the following:

Yes
No

Hearing/sight impairment

Description: Identification of whether a patient has a hearing or sight impairment. This will be used to describe the patient population and may assist in determining the impact on access to services and interventions.

Document: One of the following:

Yes
No

Communication assistance required

Description: Identification of whether a patient requires assistance with written or spoken communication. This will be used to describe the population of people seeking pain management services and may allow assessment of the impact that communication difficulty has on treatment and interventions (e.g. the ability to complete patient-reported outcomes and participate in group activities).

Document: One of the following:

Yes
No

Ethnicity

Description: Records the ethnic group(s) with whom the patient identifies. This will be used to describe the patient population and may assist in description of service utilisation, service needs and epidemiological studies.

Document: One or more of the following:

New Zealand European
Maori
Samoan
Cook Islands Maori
Tongan
Niuean
Chinese
Indian
Prefer not to state
Other (please specify)

Statistical Linkage Key

Description: The *Statistical Linkage Key (SLK)* enables patient data reported by different service providers to be matched, enabling a more accurate picture of client numbers and patterns of assistance. The *SLK* preserves the anonymity of patient data collected by service providers.

The *SLK* is derived by joining the 2nd, 3rd and 5th letters of the family name/surname, and 2nd and 3rd letters of the first given name, 'date of birth', and 'gender' to create a 14 character identifier. In this way, patient John Smith, with date of birth 12/03/1949 becomes "MIHOH120319491"

Document: The *SLK* will be computed by epiCentre, and requires characters from the mandatory fields *Given Names*, *Family Name*, *Date of birth* and *Gender*.

Level 2: Episode Information

An episode is defined as a continuous period of care for a patient in one pain management service. Under this definition, a patient may have more than one episode. For example, a patient may receive treatment for pain at more than one pain management service, or be re-referred to a service following completion of a previous episode. There should however, be only **one active** episode at any one time for a patient at a pain management service.

The information collected at the episode level reflects the circumstances at the beginning and end of the particular episode. This information may be different for subsequent episodes. Further information about episodes and the collection protocol is in the Appendix.

Referral date

Description:	The date a pain management service receives a referral to provide pain management for a patient for this episode. It is not the date of the original referral. *Referral date* is used to measure the time between referral and subsequent dates, e.g. the start and end of the episode.
Document:	The date the referral for this episode of care was received.

Referral source

Description:	The clinician type, facility or organisation that referred the patient for this episode of care. *Referral source* assists in understanding referral patterns, patient flow and service planning.
Document:	One of the following:

General practitioner/nurse practitioner (where the client was not an admitted patient at a public/private hospital at the time of referral).
Specialist practitioner (where the client was not an admitted patient at a public/private hospital at the time of referral).
Other pain management service
Public hospital (where the client was an admitted patient at the time of referral – including the emergency or outpatient department).
Private hospital (where the client was an admitted patient at the time of referral – including the emergency or outpatient department).
Rehabilitation provider/private insurer
Other (please specify)

Cancer pain

Description: Record of whether this episode is for the management of cancer pain, to assist in describing the pattern of referrals to pain management services. 'Cancer pain' refers to pain due directly to cancer, and/or pain as a consequence of the treatment for cancer even if the cancer is no longer present. This information might be contained in the referral letter or obtained from discussion with the patient.

Document: One of the following:

Yes
No

Episode start date

Description: The date of the first clinical contact with the patient. The start of the episode may therefore be:

- an assessment with a clinician or team of clinicians (e.g. a multidisciplinary team assessment)
- the first day of participation in a group pain management program or education/orientation program

This date is used to determine the length of each episode of care.

Document: The date the episode commenced.

Episode start mode

Description: Describes how the episode began (see *Episode start date*) above

Document: One of the following:

Multidisciplinary assessment and /or treatment
Single clinician assessment and /or treatment
Education/orientation program

Note: if two or more contact types are delivered on the same day, apply the hierarchy of multidisciplinary, followed by single clinician and then education/orientation.

ACC funded episode

Description: Records whether this episode of care is funded by the Accident Compensation Corporation (ACC). This item is completed by staff at the pain management service.

Document: One of the following:

Yes
No

Cause of pain – precipitating event

Description: This question asks how the patient's main pain began (precipitating event)..

Document: One of the following:

Injury at home
Injury at work/school
Injury in another setting
Motor vehicle crash
Cancer
Medical condition other than cancer
After surgery
No obvious cause
Other cause (specify in free text)

Pain duration

Description: The length of time for which the patient's pain has been present.

Document: One of the following:

Less than 3 months
3-12 months
12 months to 2 years
2-5 years
More than 5 years

Comorbidities

Description: Comorbid conditions the patient has at the start of the episode of care.

Document: One or more of the following:

A mental condition, in particular; PTSD, Anxiety, Depression, Other *(specify 'other' in free text)*
Arthritis *(including Rheumatoid/Osteoarthritis)*
Muscle, bone and joint problems other than arthritis *(including Osteoporosis, Fibromyalgia)*
Heart and circulation *problems* *(including Heart Disease, Pacemaker, Blood Disease)* in particular; High Blood Pressure, High Cholesterol
Diabetes
Digestive problems *(including IBS, GORD, Stomach Ulcers, Reflux, Bowel Disease)*
Respiratory problems *(including Asthma, Lung Disease, COPD, Sleep Apnoea)*
Neurological problems *(including Stroke, Epilepsy, Multiple Sclerosis, Parkinson's Disease)*
Cancer
Liver, Kidney and Pancreas problems *(including pancreatitis, Kidney Disease)*
Thyroid problems *(including Hyperactive and Hypoactive Thyroid, Graves' Disease)*
Any other medical conditions *(specify in free text)*

Episode end date

Description: The date the patient's episode of care at the pain management service ends. The episode ends when:

- the patient is discharged; or
- there is no intention to continue *active* treatment at the pain service. Active treatment refers to a period of relatively intensive intervention, such as a group pain program or series of individual appointments. Periodic review of a patient is not considered active treatment. Examples of an episode end include when a group pain program ends and there is no intention to continue *active* treatment, or when the treating clinician begins to taper individual appointments.

Document: The date the episode ends.

Episode end mode

Description: The reason the episode of care ends.

Document: One of the following:

Treatment complete – self management/referral to primary care
Referral to another pain service
Patient discontinued by choice
Died
Active treatment completed – ongoing review
Referral did not proceed to episode start
Lost to contact/Not to follow-up

The option "Active treatment completed (ongoing review)" may be selected for patients who have completed treatment but have not been discharged from the pain management service. These patients may have periodical appointments at the pain service (e.g. six monthly) but are not undergoing active treatment and there is no intention to collect further patient-reported outcome measures.

'Lost to contact/Not to follow up' is only to be used for patients who can no longer be contacted, and for those where there are reasons (e.g. legal) why the patient **should not** be contacted. If 'lost to follow-up' is selected an explanatory note should be entered into epiCentre.

Level 3: Pathway information

The "Pathway" describes the type of treatment the patient receives during the episode of care at the PMS. Pathways generally begin after education/orientation programs and appointments designed to assess the patient and determine the most appropriate treatment pathway. Further information about pathways and the collection protocol is in the Appendix.

There are four primary pathways:

Pathway 1	Group pain management program(s) (PMP)
Pathway 2	Individual appointments with clinicians (e.g. medical, nursing and allied health practitioners)
Pathway 3	Concurrent pathways where group programs and individual appointments are provided at the same time
Pathway 4	One-off interventions, where it is not expected that any further intervention will be provided. These might include a procedural intervention with no further individual appointments planned, or a single appointment with a medical specialist.

More than one pathway may be followed during an episode however multiple pathways cannot be active at the same time. Depending on the PMS and its specialisation as well as individual patient needs, pathways may:

- change during an episode. For example, a patient's episode may begin with a group PMP but it is then decided that the patient also, and at the same time, requires individual appointments with a clinician. In this case the pathway would change from Pathway 1 to Pathway 3.
- be provided sequentially. For example, a patient may complete a group PMP which is then followed by individual appointments. This is a completed pathway 1 and a completed pathway 2.

Pathway Type

Description:	The type of intervention or pathway the patient follows during the episode of care. This will be used to describe interventions and assess outcomes by pathway type.
Document:	One of the following:

Pathway 1 - Group pain management program(s)
Pathway 2 - Individual appointments
Pathway 3 - Concurrent pathways (1 and 2)
Pathway 4 - One-off intervention

Pathway start date

Description:	The date that treatment commences for the pathway. This could be the first day of a pain management program, the first appointment with a clinician for the management of a patient's pain or the day on which a patient underwent a procedural intervention. Pathways generally begin after education/orientation programs and appointments designed to assess the patient and determine the most appropriate treatment.
Document:	The start date for each pathway followed during the episode of care.

Pathway end date

Description:	The date that treatment ends for each pathway. This could be the last day of a pain management program or the last appointment with a clinician.
Document:	The end date for each pathway followed during the episode of care.

Group program start date

Description:	This additional start date can only be used during Concurrent pathways, where a group program is offered concurrently with individual clinical appointments. Under the ePPOC protocol, the start and end of a group program trigger a patient-reported outcome assessment. Therefore, for concurrent pathways, the start dates of both the pathway as a whole and the group program can be entered. If the concurrent pathway begins with the start of the group pain management program, these two dates will be the same.
Document:	The date within a concurrent pathway that the group program begins.

Group program end date

Description:	This additional end date can only be used during Concurrent pathways, where a group program is offered concurrently with individual clinical appointments. Under the ePPOC protocol, the start and end of a group program trigger a patient-reported outcome assessment. Therefore, for concurrent pathways, the start dates of both the pathway as a whole and the group program can be entered. If the concurrent pathway ends with the completion of the group pain management program, these two dates will be the same.
Document:	The date within a concurrent pathway that the group program ends.

Level 4: Service event information

This level describes the service events (also known as occasions of service) a patient receives during an episode of care at your pain service. These include individual appointments with a physiotherapist (or nurse, psychologist, specialist), multidisciplinary assessments and discussions, pain management programs, procedures, education/orientation programs. This information is collected to allow assessment of patient outcomes as a function of intensity and focus of the treatment delivered.

Service event description

Description: The type of service the patient received. Note:

- Some patients are not suitable to participate in a group pain management program, but instead receive the contents of the group program on an individual basis. The service events below therefore distinguish between 'pain management program (group)' and 'pain management program (individual)'
- Telephone consultations (with patient or with patient's doctor) must involve provision of advice and/or pain management strategies. Administrative tasks (such as making appointments) are not recorded.

Document: One or more of the following:

Service event description
Individual appointment with medical practitioner
Individual appointment with physiotherapist
Individual appointment with psychologist
Individual appointment with occupational therapist
Individual appointment with nurse
Individual appointment with one or more clinicians
Individual appointment - other
Multidisciplinary team assessment
Multidisciplinary panel discussion
Telephone/email consultation with patient/carer
Telephone/email consultation with another clinician
Pain management program (group)
Pain management program (individual)
Procedural intervention – implant (drug delivery)
Procedural intervention – implant (neurostimulation)
Procedural intervention – non-implant
Procedural intervention – cancer block
Procedural intervention – other
Education/Orientation Program

Other

Date of service event

Description:	The date that the service event was provided to the patient
Document:	The service event date

Duration of service event

Description:	The duration of the service event delivered to the patient. Regardless of the number of clinicians present during the service event, the duration recorded should reflect the treatment time the patient receives rather than the (additive) clinician time. For example if two clinicians jointly completed an assessment of a patient which lasted 1 hour, the duration of the service event is 1 hour, not 2 hours of individual clinician time.
Document:	The duration of the service event, recorded in hours and/or minutes.

Telehealth

Description:	This item records whether the service event was provided via Telehealth, that is, via teleconferencing or videoconferencing. One-on-one phone consultations with a patient or patient's physician are not considered telehealth.
Document:	One of the following:

Yes
No

Level 5: Patient-reported outcome measures

Standardised patient questionnaires are completed by the patient in 'referral' and 'follow-up' questionnaires at:

- initial referral to the pain management service
- the beginning and end of each pathway within an episode
- follow-up three to six months after the end of the episode.

Reponses to these questionnaires allows assessment of patient improvement and progress throughout and following an episode of care. Further information about collection of the outcome measures is in the Appendix.

Height

Description:	The height of the patient in centimetres, used with *Weight* to calculate *Body Mass Index.*
Document:	Height in centimetres.

Weight

Description:	The weight of the patient in kilograms, used with *Height* to calculate *Body Mass Index.*
Document:	Weight in kilograms.

Body Mass Index (BMI)

Description:	A measure of body fat based on a person's height and weight. *BMI* is calculated using the formula: BMI = weight in kg/ (height in metre's x height in metre's)
Document:	This item is calculated by epiCentre.

Pain description

Description: This question asks the patient to select the statement that best describes the frequency of their pain.

Document: One of the following:

Always present (always the same intensity)
Always present (level of pain varies)
Often present (pain free periods last less than 6 hours)
Occasionally present (pain occurs once to several times per day, lasting up to an hour)
Rarely present (pain occurs every few days or weeks)
Pain is no longer present*

**This response option is not available in referral questionnaires*

Rating of change – overall

Description: This item records the patient response to the question "Compared with before receiving treatment at this pain management service, how would you describe yourself now overall?"

This question is not asked at referral, but at all subsequent questionnaire collection occasions.

Document: On a scale of -3 to 3 where -3 is 'very much worse', 0 is 'unchanged' and '3' is 'very much better'.

Rating of change – physical

Description: This item records the patient response to the question "Compared with before receiving treatment at this pain management service, how would you describe your physical abilities now?"

This question is not asked at referral, but at all subsequent questionnaire collection occasions.

Document: On a scale of -3 to 3 where -3 is 'very much worse', 0 is 'unchanged' and '3' is 'very much better'.

Work status and productivity

Description: Patient report of whether or not they are employed (working for pay).

Document: One of the following:

Yes
No

If Yes, record one of the following:

Working Full time
Working Part time

Then, record the patient responses to the following questions:

During the past 7 days, how many hours did you miss from work because of problems associated with your pain?
During the past 7 days, how many hours did you actually work?
During the past 7 days, how much did your pain affect your productivity while you were working?

If No, record one of the following:

Unable to work due to a condition other than pain
Unable to work due to pain
Not working by choice (student, retired, homemaker)
On leave from work due to pain
Seeking employment (I consider myself able to work but cannot find a job)

Reference: Work productivity questions from the Work Productivity and Activity Impairment Questionnaire, Reilly MC, Zbrozek AS & Dukes EM (1993)

Health service usage

Description:	These questions ask the patient about their utilisation of health services over the past three months *(other than visits to the pain clinic).*
Document:	The number of times in the past 3 months the patient has: • seen general practitioners in regard to their pain • seen medical specialists (e.g. orthopaedic surgeon) in regard to their pain • seen health professionals other than doctors (e.g. physiotherapist, chiropractor, psychologist) in regard to their pain • visited hospital emergency departments in regard to their pain • been admitted to hospital as an inpatient because of their pain AND The number of diagnostic tests (e.g. X-rays, scans) the patient has had in the last 3 months relating to their pain

Description: Report of where on a body map the patient feels pain

Document: ***One or more*** of the following:

Head (excluding the face)
Face/jaw/temple
Throat/neck
Shoulder (Left/Right)
Chest
Upper arm (Left/Right)
Elbow (Left/Right)
Forearm (Left/Right)
Wrist (Left/Right)
Hand (Left/Right)
Abdomen
Hip (Left/Right)
Groin/pubic area
Thigh (Left/Right)
Knee (Left/Right)
Calf (Left/Right)
Ankle (Left/Right)
Foot (Left/Right)
Upper back
Mid back
Low back

Reference: Childhood Arthritis and Rheumatology Research Alliance, www.carragroup.org. von Baeyer CL et al, Pain Management, 2011;1(1):61-68.

Description: Report of the ONE area on a body map the patient feels the most pain

Document: **One** of the following:

Head (excluding the face)
Face/jaw/temple
Throat/neck
Shoulder (Left/Right)
Chest
Upper arm (Left/Right)
Elbow (Left/Right)
Forearm (Left/Right)
Wrist (Left/Right)
Hand (Left/Right)
Abdomen
Hip (Left/Right)
Groin/pubic area
Thigh (Left/Right)
Knee (Left/Right)
Calf (Left/Right)
Ankle (Left/Right)
Foot (Left/Right)
Upper back
Mid back
Low back

Reference: Childhood Arthritis and Rheumatology Research Alliance, www.carragroup.org. von Baeyer CL et al, Pain Management, 2011;1(1):61-68.

Pain severity

Description:	The patient is asked to rate the intensity of their pain: 1. at its *worst* in the last week 2. at its *least* in the last week 3. on *average* *4. right now*
Document:	For each of the four questions above, the patient rates their pain on a scale of 0 to 10, where 0 = 'No pain' and 10 = 'Pain as bad as you can imagine'
Scoring:	An average rating of pain severity is calculated by summing the scores for the four questions above, divided by the number of questions the patient completed. If more than one number has been circled for a question, use the *highest* score for 2a, 2c and 2d, and the *lowest* score for 2b.
Validity:	All items must be completed to compute an average pain rating
Interpretation:	Higher scores equal more severe pain 1-4 = mild pain 5-6 = moderate pain 7-10 = severe pain Change on these items is measured by the percentage change from Time 1 to Time 2, (i.e. Time 1 score minus Time 2 score, divided by Time 1 score). ePPOC reports clinically significant change on the worst and average pain items. According to the IMMPACT recommendations, an improvement of 10% or more indicates minimally important change, 30% or more moderately important change, and 50% or more substantial clinically important change.
Reference:	Modified Brief Pain Inventory, reproduced with acknowledgement of the Pain Research Group, University of Texas, MD Anderson Cancer Centre, USA. Dworkin, R. H., et al. (2008). "Interpreting the Clinical Importance of Treatment Outcomes in Chronic Pain Clinical Trials: IMMPACT Recommendations." The Journal of Pain **9**(2): 105-121

Pain interference

Description:	The patient is asked to rate how much their pain has interfered with the following in the past week: 1. general activity 2. mood 3. walking ability 4. normal work (both outside the home and housework) 5. relations with other people 6. sleep 7. enjoyment of life
Document:	For each of the seven questions above, the patient rates their pain on a scale of 0 to 10, where 0 = 'Does not interfere' and 10 = 'Completely interferes'
Scoring:	An average rating of pain interference is calculated by summing the scores for the seven questions above, divided by the number of questions the patient completed. If more than one number has been circled for a question, use the *highest* score.
Validity:	At least 4 of the 7 items must be completed
Interpretation:	Higher scores equal greater interference According to the IMMPACT recommendations, a change of one point or more over the average of the seven interference items points to clinically significant change.
Reference:	Modified Brief Pain Inventory, reproduced with acknowledgement of the Pain Research Group, University of Texas, MD Anderson Cancer Centre, USA. Dworkin, R. H., et al. (2008). "Interpreting the Clinical Importance of Treatment Outcomes in Chronic Pain Clinical Trials: IMMPACT Recommendations." The Journal of Pain **9**(2): 105-121

DASS21

Description: The DASS is a set of three self-report scales designed to measure the negative emotional states of depression, anxiety and stress. ePPOC uses the short version of the DASS, the DASS21

The patient is asked to read the following statements and indicate how much the statement applied to them over the past week:

1. I found it hard to wind down
2. I was aware of dryness of my mouth
3. I couldn't seem to experience any positive feeling at all
4. I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)
5. I found it difficult to work up the initiative to do things
6. I tended to over-react to situations
7. I experienced trembling (e.g., in the hands)
8. I felt that I was using a lot of nervous energy
9. I was worried about situations in which I might panic and make a fool of myself
10. I felt that I had nothing to look forward to
11. I found myself getting agitated
12. I found it difficult to relax
13. I felt down-hearted and blue
14. I was intolerant of anything that kept me from getting on with what I was doing
15. I felt I was close to panic
16. I was unable to become enthusiastic about anything
17. I felt I wasn't worth much as a person
18. I felt that I was rather touchy
19. I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)
20. I felt scared without any good reason
21. I felt that life was meaningless

Document: For each of the statements, the patient indicates how much the statement applied to them according to the following scale:

0 – did not apply to me at all
1 – applied to me to some degree, or some of the time
2 – applied to me to a considerable degree, or a good part of the time
3 – applied to me very much, or most of the time

Scoring: Scores for Depression, Anxiety and Stress are calculated by summing the scores for the relevant items as follows:

Depression: *(sum of scores for 3, 5, 10, 13, 16, 17, 21) x 2*

Anxiety: *(sum of scores for 2, 4, 7, 9, 15, 19, 20) x 2*
Stress: *(sum of scores for 1, 6, 8, 11, 12, 14, 18) x 2*
Total: *(sum of all scores) x 2*

Note: the total score and scores for each scale are multiplied by 2 to enable comparison with the full-scale DASS42, for which norms exist.

If more than one number has been circled for a question, use the *highest* score.

Interpretation: DASS severity ratings:

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

Clinically significant change is indicated if there is a five or more point change on the full scale DASS, combined with a move to a different severity level*.

Validity: The developers of the DASS suggests that while there is no "fixed standard" the rule of thumb is that there should be no more than one missing item per 7-item scale

Reference: Lovibond, S.H. & Lovibond, P.F. (1995). *Manual for the Depression Anxiety Stress Scales*. (2nd. Ed.) Sydney: Psychology Foundation

http://www2.psy.unsw.edu.au/dass/DASSFAQ.htm

*Johnson, J. (2014, June 2). ACI Outcomes and Database Working Group. Meeting Minutes.

Pain Self-Efficacy Questionnaire

Description: The Pain Self-Efficacy Questionnaire (PSEQ) is a measure of how confident a patient is that he or she can do a range of activities despite their pain.

The patient is asked to read the following statements and rate how confident they are that they can do the following things at present:

1. I can enjoy things, despite the pain
2. I can do most of the household chores (e.g. tidying-up, washing dishes etc.) despite the pain
3. I can socialise with my friends or family members as often as I used to do, despite the pain
4. I can cope with my pain in most situations
5. I can do some form of work, despite the pain ("work" includes housework, paid and unpaid work)
6. I can still do many of the things I enjoy doing, such as hobbies or leisure activity, despite the pain
7. I can cope with my pain without medication
8. I can still accomplish most of my goals in life, despite the pain
9. I can live a normal lifestyle, despite the pain
10. I can gradually become more active, despite the pain

Document: For each of the statements, the patient indicates on a scale of 0 to 6 how confident they are, where 0 = "Not at all confident" and 6 = "Completely confident".

Scoring: Sum the scores for all items to give a total score. Higher scores indicate higher levels of self-efficacy.

If more than one number has been circled for a question, use the *lowest* score.

Interpretation: The severity levels for the PSEQ are:

<20 = severe
20-30 = moderate
31-40 = mild
>40 = minimal

Clinically significant change is indicated where there is a change of seven or more points coupled with a move to a different level of impairment[#].

The median scores for patients attending a pain clinic are around 24-25. This level is associated with moderate pain-related disability. Scores close to 40 are associated with working despite pain. Scores below about 18 are associated with stronger beliefs that pain relief must come before participation in PMP.

Validity: At least 9 of the 10 items should be completed

Reference: Nicholas M.K. Self-efficacy and chronic pain*. In Paper presented at the annual conference British Psychological Society, St. Andrews, Scotland;* 1989*.*

[#]Nicholas, M K (personal communication, July 2014)

Pain Catastrophising Scale

Description: The Pain Catastrophising Scale (PCS) is a measure of an individual's thoughts and feelings relating to their pain. The scale includes three sub scales measuring the dimensions of Rumination, Magnification and Helplessness.

The patient is asked to read 13 statements describing different thoughts and feelings that may be associated with pain, and indicate the degree to which they have these thoughts and feelings when they are experiencing pain:

1. I worry all the time about whether the pain will end
2. I feel I can't go on
3. It's terrible and I think it's never going to get any better
4. It's awful and I feel it overwhelms me
5. I feel I can't stand it anymore
6. I become afraid that the pain will get worse
7. I keep thinking of other painful events
8. I anxiously want the pain to go away
9. I can't seem to keep it out of my mind
10. I keep thinking about how much it hurts
11. I keep thinking about how badly I want the pain to stop
12. There's nothing I can do to reduce the intensity of the pain
13. I wonder whether something serious may happen

Document: For each of the statements, the patient indicates the degree to which they have these thoughts and feelings, according to the following scale:

0 - Not at all
1 - To a slight degree
2 - To a moderate degree
3 - To a great degree
4 - All the time

Scoring: Total and subscales are calculated by summing the scores for the relevant items as follows:

Total score *(sum of all scores)*

Rumination: *(sum of scores for questions 8,9,10,11)*

Magnification: *(sum of scores for questions 6,7,13)*

Helplessness: *(sum of scores for questions 1,2,3,4,5,12)*

If more than one number has been circled for a question, use the *highest* score.

Interpretation: Severity categories for the PCS are:

<20 = mild
20-30 = high
>30 = severe

Clinically significant change requires a change in score of six or more points, combined with movement to a different severity category‡

Clinically significant scores for each of the subscales are

Rumination: 11
Magnification: 5
Helplessness: 13

Validity: For the total score: at least 12 of the 13 items should be completed

For the individual subscales: all items must be completed

Reference: Sullivan,M.J.L., Bishop, S.R., Pivik, J. (1995). Psychological Assessment; 7:524-532

‡Sullivan, M J L, (personal communication with Nicholas, M K, July 2014)

Medication – usage

Description:	Records whether or not the patient is taking medications, based on the response provided in the Medication Use section of the ePPOC questionnaires. The response to this item is not based on information contained in the referral letter or other source (see related "Medication – possible inaccuracies" item below).
Document:	One of the following:

Yes
No

Medication – possible inaccuracies

Description:	This item allows pain management staff to highlight possible inconsistencies in the patient-reported medication information provided, compared with information from another source. For example, while the patient may have reported that he or she is not taking any medication, a referral letter may indicate otherwise. Regardless of any possible inconsistency however, the medication information entered into epiCentre should be based on the patient report.
Document:	One of the following:

Yes
No

Medication – drug groups

Description: From the medications listed in the patient questionnaire, this item records each of the drug groups the patient is taking. The medications determined by the Faculty of Pain Medicine to be of most interest in pain management fall under the drug groupings Opioids, Paracetamol, NSAIDs, Antidepressants, Anticonvulsants, Sedatives, and Medicinal Cannabinoids. To assist services to identify which medications belong to which drug groups ePPOC has developed a Drug Group Tool and education package, which is available on the ePPOC website, click here: https://ahsri.uow.edu.au/eppoc/resources/index.html

Note that benzodiazepines, 'Z' drugs, and quetiapine should be grouped under 'Sedatives' for ePPOC purposes.

Document: One or more of the following

Opioids
Antidepressants
Paracetamol
Anticonvulsants
NSAIDs
Sedatives
Medical Cannabinoids

Medication – daily oral morphine equivalent

Description: For patients **not** using opioids ensure you enter a zero (0) for the oMEDD value. For patients indicating opioid use, record the oral morphine equivalent daily dose (oMEDD) as an ***average***. The oMEDD should be calculated as an average over the previous week to better reflect a patient's usual opioid use. To assist services do this, an Average oMEDD conversion tool with formulae is embedded into epiCentre and is also available on the ePPOC website, at: https://ahsri.uow.edu.au/eppoc/resources

Document: The ***average*** oral morphine equivalent daily dose calculated over a one week period (oMEDD) in milligrams.

Medication – opioid intake frequency > 2 days per week

Description: This item records whether or not the patient is taking opioid medication on more than two days per week (as per the medications listed in the patient questionnaire).

What to do if a patient reports medications taken *PRN* or gives a *range*:

- Where the patient reports *'PRN'* or *'as required'* consult with the patient to record the correct dose where possible. You *may* also choose to tick the checkbox in epiCentre to indicate a possible inaccuracy in the patient's report of medication use.

- Where the patient gives a *range* of days (e.g. 3-4 days per week), or tablets (e.g. 2-3 tablets), record the ***highest*** number

Document: One of the following:

Yes
No

Opioid replacement/substitution program

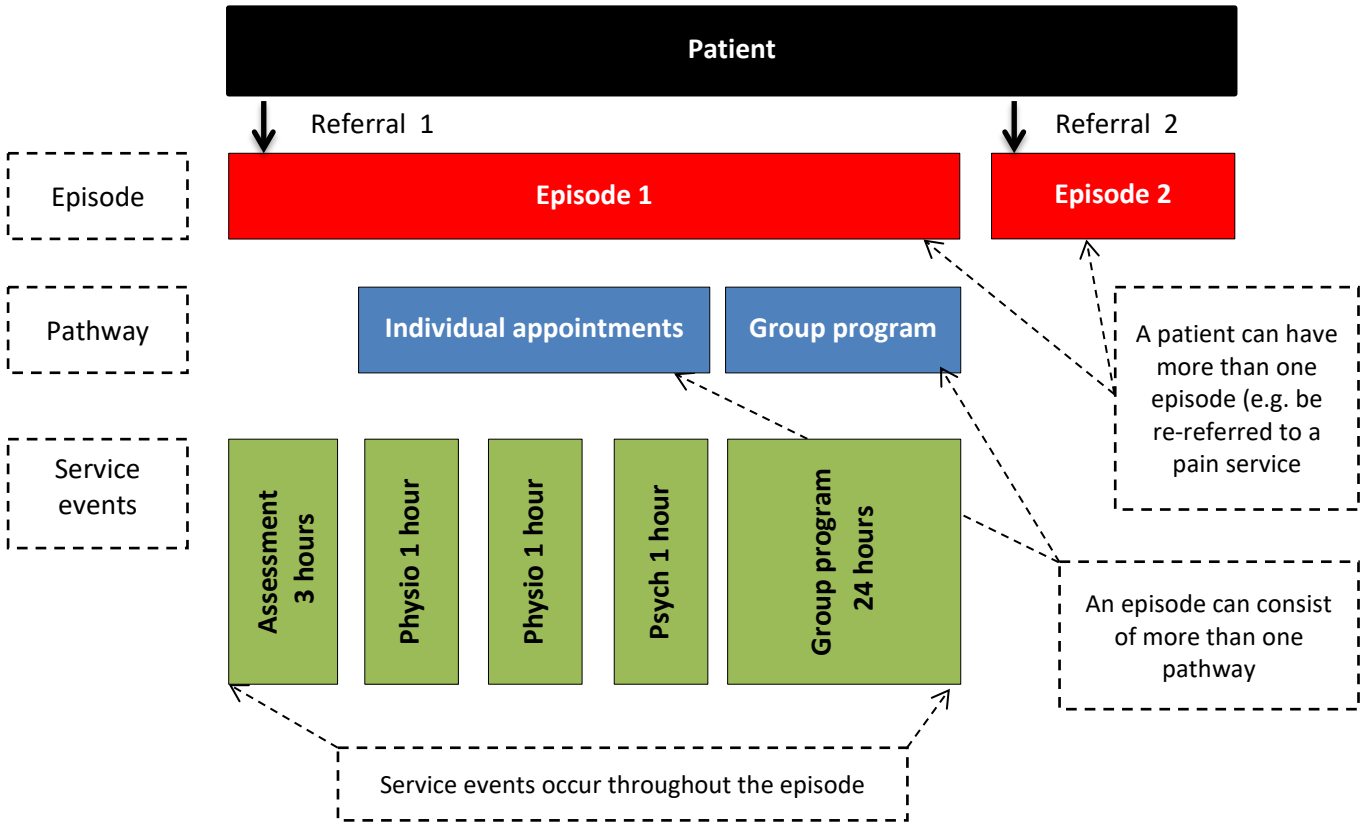
Description: This item records whether or not the patient is on an opioid replacement/substitution program. This information may be contained in the referral information or provided by the patient.

Document: One of the following:

Yes
No

APPENDIX – EPISODE ELEMENTS AND EPPOC COLLECTION PROTOCOL

The diagram below shows the relationship of the referral, episode, pathways, and service events.



Collection

The patient questionnaires should be collected at:

- **Referral** (to obtain baseline patient data)
- **At the start of the pathway** (pre-treatment data)[1]
- **At the end of the pathway** (end of treatment data)
- **3 to 6 months after the episode of care has ended** (to determine whether any changes have been maintained)

These time points have been chosen as they coincide with clinically meaningful time points in a patient's journey through a pain management clinic, rather than fixed time periods which may not be meaningful. Note that services can also collect additional patient questionnaires at any other time throughout or after the episode to monitor and review patient progress.

[1] If the pathway begins soon after the referral questionnaire is completed (e.g. within 3 months) the pathway start questionnaire does not need to be collected

Reporting

Collection of patient information at the time points above allows ePPOC to report patient outcomes reflecting:

1. Change from pathway start to pathway end (to examine the effect of a particular treatment)
2. Change from referral to the end of the episode (to assess change that occurred as a result of completing treatment at a pain service)
3. Change from referral to a point 3-6 months after the episode has ended (to assess whether change as a result of treatment has been maintained)

The ePPOC benchmarks are also based on the referral to end of episode outcomes.

The relationship between collection points and reporting of information is shown in the figure below.