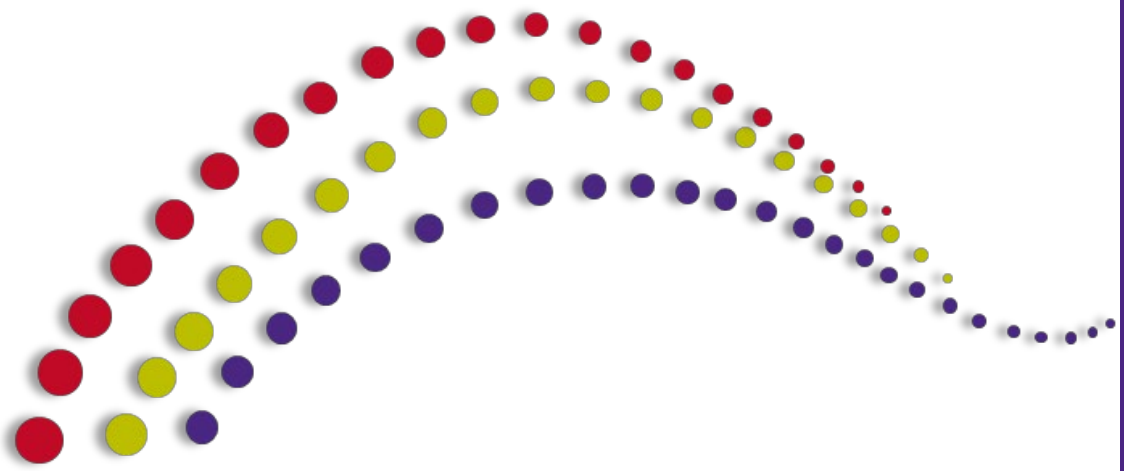
PaedePPOC Clinical Reference Manual

New Zealand
Version 2 Dataset



ePPOC
electronic persistent pain outcomes collaboration

UNIVERSITY OF WOLLONGONG AUSTRALIA

TABLE OF CONTENTS

INTRODUCTION

The Paediatric 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 Paediatric 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- and carer-rated outcome measures.

Excluded from the Paediatric Clinical Reference Manual are the technical items required for data entry and extraction purposes. This information is contained in the Paediatric ePPOC 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 such as name, address and contact details.

Contacts

For queries regarding this document or for further information about ePPOC, please contact us at eppoc@uow.edu.au, phone (02) 4221 4411 or visit our webpage: http://ahsri.uow.edu.au/eppoc

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 state 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:	The patient's G*ender* is used in demographic analysis of ePPOC data, 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.

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.

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* is 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 services 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)

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.

Pain cause

Description: This question asks how the patient's main pain began.

Document: One of the following:

Injury
After surgery
Illness
No known cause
Other (please specify)

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
More than 12 months

Compensation

Description: Records whether there is a current or potential legal case relating to the child's pain problem (e.g. compensation/public liability claim).

Document: One of the following:

Yes
No

Previous pain episode

Description: Records whether the patient has previously attended a specialist pain service at a children's hospital.

Document: One of the following:

Yes
No

Comorbidities – health conditions

Description: A record of whether the patient has other health conditions

Document: One or more of the following:

A chronic disease (e.g. arthritis, inflammatory bowel disease, rare disease of childhood)
A mental health condition (e.g. depression, anxiety, eating disorder, ADHD)
Cancer, now or in the past

Disabilities

Description: A record of whether the patient has pre-existing disabilities.

Document: One or more of the following:

Sight impairment
Hearing impairment
Intellectual disability
Physical disability

Comorbidities and disabilities - detail

Description: Optional additional information regarding the child's comorbid health conditions or disabilities.

Document: Additional free text information provided by the carer/parent.

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 complete – 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 delivery mode

Description: A description of the mode by which each treatment pathway within an episode is delivered.

'Care plan only' refers to development of a management plan and/or recommendations to the family, referrer and/or allied health providers, where the expectation is that ongoing care will be provided entirely outside the specialist team's resources.

'Remotely supported care' refers to support of ongoing care by the specialist team via telecommunication (e.g. telehealth, telephone, email)

'In clinic care' refers to care delivered at the pain management service.

Document: One of the following:

Care plan only
Remotely supported care
In clinic care

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 is only used during Pathway 3, where a group program occurs 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 are required. 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 is only used during Pathway 3, 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 end dates of both the pathway as a whole and the group program are required. 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. 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 of patient time, 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- and carer-reported outcome measures

These items are completed by the patient and parent/carer in the 'referral and 'follow-up' questionnaires. The primary collection points are:

- 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.

Questionnaire completion date

Description:	The date the questionnaire was completed by the patient and/or carer. This is labelled as 'Today's date' on the paper questionnaires.
Condition:	Completed by the patient and parent/carer.
Document:	The questionnaire completion date.

Parent/carer gender

Description:	The gender of the parent or carer who completed the parent/carer questionnaire.
Condition:	Completed by the parent/carer
Document:	One of the following:

Male
Female
Not stated/Inadequately described

Parent/carer relationship

Description:	The relationship to the patient of the parent/carer completing the questionnaire.
Condition:	Completed by the parent/carer
Document:	One of the following:

Parent/step-parent
Relative (e.g. grandparent, kinship carer)
Foster carer
Other

Communication assistance required

Description:	Identification of whether the parent/carer of the patient requires assistance with written or spoken communication.
Document:	One of the following:

Yes
No

Height

Description:	Records the height of the patient in centimetres. *Height* is used with *Weight* to calculate *Body Mass Index.*
Condition:	Completed by the parent/carer
Document:	Height in centimetres.

Weight

Description:	Records the weight of the patient in kilograms. *Weight* is used with *Height* to calculate *Body Mass Index.*
Condition:	Completed by the parent/carer
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 meters x height in meters)
Document:	This item is calculated by epiCentre.
Interpretation:	The AIHW recommend that for children and adolescents, self-reported or parentally-reported height and weight data should be used cautiously if at all. In addition, BMI for children and teenagers is generally calculated taking age and sex into account. This calculator can be found at: https://nccd.cdc.gov/dnpabmi

Current school level

Description: Records the patient's current level of school.

Condition: Completed by the parent/carer

Document: One of the following:

Preschool
Primary school
Secondary school
Other

School days missed

Description: Records an estimate of the number of days of school the patient has missed in the previous two weeks due to the patient's pain and/or pain-related appointments or treatment.

Condition: Completed by the parent/carer

Document: Number of days missed, including whole and part days.

Work status and productivity - patient

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

Condition: For patients completing an Adolescent Questionnaire (13-18 years)

Document: One of the following:

Yes
No

If Yes, record one of the following:

Working full time
Working part time /casually

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
Seeking employment (I consider myself able to work but cannot find a job)
Too young to work

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

Work status and productivity – parent/carer

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

Condition: Completed by the parents/carer

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 child's pain?
During the past 7 days, how many hours did you actually work?
During the past 7 days, how much did your child's pain affect your productivity while you were working?

If No, record one of the following:

Unable to work due to reasons associated with your child's pain
Not working by choice (student, retired, homemaker)
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)

Pain description

Description: This question asks the patient and parent/carer to select the statement that best describes the frequency of the pain.

Condition: Completed by the parent/carer and patients aged 8-18 years

Document: For parent/carers and patients aged 13-18, 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*

For patients aged 8-12, one of the following:

I always have pain
I always have pain but the amount changes
I often have pain
I sometimes have pain but not all day
I sometimes have pain but not every day
I no longer have any pain*

**These response options are not available in referral questionnaires*

Health service usage

Description:	These questions ask the parent/carer about their child's utilisation of health services over the past three months *(other than the child's visits to the pain clinic).*
Condition:	Completed by the parent/carer
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. paediatrician, surgeon) in regard to their pain • seen health professionals other than doctors (e.g. physiotherapist, psychologist) in regard to their pain • seen other therapists (e.g. naturopath, chiropractor) 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

Pain site – ALL pain

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

Condition: Completed by the patient and the parent/carer

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.

Pain site – MAIN pain

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

Condition: Completed by the patient and the parent/carer

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 and parent/carer are asked to rate the intensity of the patient's pain 1. at its worst in the last week 2. at its least in the last week 3. at its usual level 4. right now
Condition:	Completed by the patients and parents/carers
Document:	*For parents/carers and patients 8-18 years:* For each of the four questions above, pain is rated on a Likert scale of 0 to 10, where 0 = 'No pain' and 10 = 'Pain as bad as you can imagine' *For patients 5-8 years:* For each of the four questions above, pain is rated using a series of faces showing varying levels of pain. The six faces represent the numbers 0, 2, 4, 6, 8, 10.
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.
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.
Validity:	All items must be completed to compute an average pain severity rating
Reference:	Modified Brief Pain Inventory, reproduced with acknowledgement of the Pain Research Group, University of Texas, MD Anderson Cancer Centre, USA Faces Pain Scale – Revised, ©2001, International Association for the Study of Pain. www.iasp-pain.org/FPSR 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

Functional Disability Inventory

Description:	The Functional Disability Inventory is a measure of function and disability in young people with chronic pain. Patients are asked to rate the physical trouble or difficulty they had performing a range of activities over the past two weeks.
Conditions:	Completed by patients aged 8-18 years.
Document:	For each of the fifteen activities, the patient indicates how much physical trouble or difficulty they experienced, according to the following scale: 0 – no trouble 1 – a little trouble 2 – some trouble 3 – a lot of trouble 4 – impossible
Scoring:	A total disability score is calculated by summing the scores for the fifteen items to give a score out of 60.
Interpretation:	Higher scores equal more severe disability <13 = no/minimal disability 13-29 = moderate disability 30+ = severe disability Clinically significant change is indicated where there is a change of 5 or more points coupled with a change to a different severity category
Reference:	Functional Disability Inventory (FDI), Walker and Greene. Journal of Pediatric Psychology, 1991; 16(1): 39-58

Bath Adolescent Pain Questionnaire – Section 5

Description: The Bath Adolescent Pain Questionnaire (BAPQ) is a tool used to assess the impact of chronic pain on social functioning, physical functioning, depression, general anxiety, pain specific anxiety, family functioning and development. ePPOC uses Section 5 of this tool to assess pain specific anxiety in adolescents.

The patient is asked to read the following statements and indicate how often they experienced each in the last two weeks:

1. I worry about my pain problem
2. I avoid activities that cause pain
3. When I think about pain, it makes me upset
4. Pain scares me
5. I worry that I will do something to make my pain worse
6. When I have pain, I think something harmful is happening
7. I am afraid to move due to pain

Condition: Completed by patients aged 13-18 years

Document: For each of the statements, the patient selects one of the following:

0 – never
1 – hardly ever
2 – sometimes
3 – often
4 – always

Scoring: The pain related worry score is calculated by summing the BAPQ items to give a score out of 28, with higher scores reflecting greater worry.

Reference: Bath Adolescent Pain Questionnaire, Bath Centre for Pain Research

Pediatric Quality of Life Inventory

Description:	The Pediatric Quality of Life Inventory (PedsQL) measures health-related quality of life in children and adolescents. ePPOC uses the Generic Core Scales and includes self-report and parent proxy-report for young children (5-7 years), children (8-12 years) and adolescents (13-18 years). The patient (aged 8-18 years) and parent/carer is asked to read a list of items that might be a problem for the child in the areas of physical, emotional, social and school functioning. The PedsQL for patients aged 5-7 years is administered by a clinician.
Condition:	Completed by the patient and parent/carer
Document:	For each of the statements, the patient and parent/carer selects one of the following: 0 – Never 1 – Almost never 2 – Sometimes 3 – Often 4 – Almost always Patients aged 5-7 years choose between the options of: 0 – Never 2 – Sometimes 4 – Almost always
Scoring:	Scores are computed for each of the four dimensions: Physical Functioning, Emotional Functioning, Social Functioning and School Functioning. Each item is firstly reverse scored and transformed to a 0-100 scale where: 0 = 100 1 = 75 2 = 50 3 = 25 4 = 0 A mean score for each dimension is computed, by summing the scores for each item in the dimension and dividing by the number of items answered. If more than 50% of the items in the scale are missing, the dimension scores should not be computed. A **Psychosocial Health Summary Score** is computed – this equals the sum of the items over the number of items answered in the Emotional, Social and School Functioning Scales The **Physical Health Summary Score** = Physical Functioning Scale (Dimension) score.

Interpretation: Higher scores indicate better health-related quality of life.

Minimal clinically meaningful difference is indicated with a:

- 4.4 change in the child self-report total score
- 4.5 change in adult proxy-report total score

"At risk status" for impaired HRQOL is indicated where:

- Total scores below 69.7 for child self-report
- Total scores below 65.4 for adult proxy-report

Reference: Pediatric Quality of Life Inventory, Copyright © 1998 JW Varni, Ph.D. All rights reserved

Varni, J. W., et al. (2005). "The PedsQL as a Pediatric Patient-Reported Outcome: Reliability and Validity of the PedsQL Measurement Model in 25,000 Children " Expert Review of Pharmacoeconomics Outcomes Research **5**(6): 705-718

Bath Adolescent Pain - Parent Impact Questionnaire

Description: The Bath Adolescent Pain – Parent Impact Questionnaire (BAP-PIQ) is a measure of the way caring for a young person with chronic pain affects the life of the parent. The BAP-PIQ includes eight sub scales measuring depression, anxiety, child-related catastrophising, self-blame and helplessness, partner relationship, leisure functioning, parental behaviour and parental strain.

Condition: Completed by the parent/carer only

Document: For the 62 statements, the patient indicates how often they have experienced each in the last two weeks, according to the following scale:

0 – never
1 – hardly ever
2 – sometimes
3 – often
4 – always

Scoring: The BAP-PIQ is scored separately for all eight subscales by summing the score for the items in each subscale. Note that a number of the items must be reverse scored (see www.bath.ac.uk/pain/assessment-tools/ for details).

Interpretation: For all scales, a higher score indicates more impaired functioning. The authors note that while it is possible to calculated a total BAP-PIQ score by summing the totals of all eight subscales, they do not believe that this is a clinically useful exercise.

Reference: Bath Adolescent Pain – Parent Impact Questionnaire, Bath Centre for Pain Research

Medication use

Description: A record of how often in the last month the patient has used the following types of medication:

- Paracetamol-only medicines
- Anti-inflammatory medications not requiring a prescription
- Anti-inflammatory medications requiring a prescription
- Complementary or alternative medicines
- Opioid medication containing codeine
- Opioid medication other than codeine
- Medication given for nerve pain.

Condition: Completed by the parent/carer

Document: For each medication type, the parent/carer indicates the frequency of use, selecting one the following options:

Daily
Often
Sometimes
Rarely
Never

Questionnaire completion

Description: Record of whether the patient was able to complete his or her questionnaire.

Condition: Completed by the parent/carer

Document: One of the following:

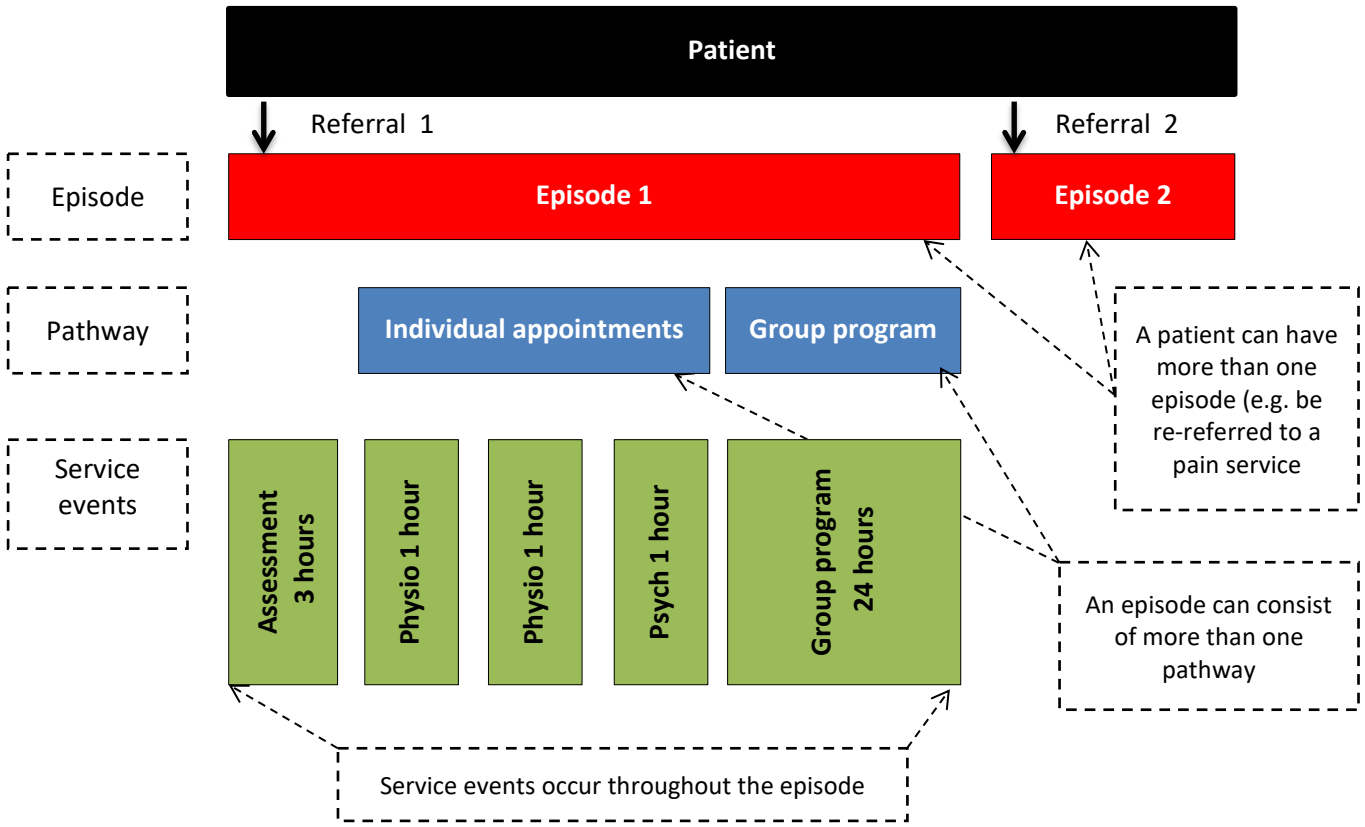
Yes
No

If NO, record one of the following reasons for non-completion:

Refused
Cognitively unable to complete
Physically unable to complete
Too young
Non-English speaking
Other (please specify)

APPENDIX – EPISODE ELEMENTS AND EPPOC COLLECTION PROTOCOL

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



Assessment tool summary

Age group	Assessment tools
5-7 years	Pain source, Faces of Pain Scale - Revised, Paediatric Quality of Life Inventory
8-12 years	Pain source, pain severity and description, Functional Disability Inventory, Paediatric Quality of Life Inventory
13-18 years	Pain source, pain severity and description, Functional Disability Inventory, Bath Adolescent Pain Questionnaire (Section 5 – pain-related worry), Paediatric Quality of Life Inventory
Parent/carer	Pain source, pain severity and description, Paediatric Quality of Life Inventory, Bath Parent Impact Questionnaire

Collection

The patient and parent carer questionnaires are 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)

In addition, the Bath Parent Impact Questionnaire is collected at:

- Referral
- Every 12 months following the start of the pathway
- Pathway end/episode end
- 3-6 months after the episode has ended

These time points have been chosen as they coincide with clinically meaningful events 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.

Reporting

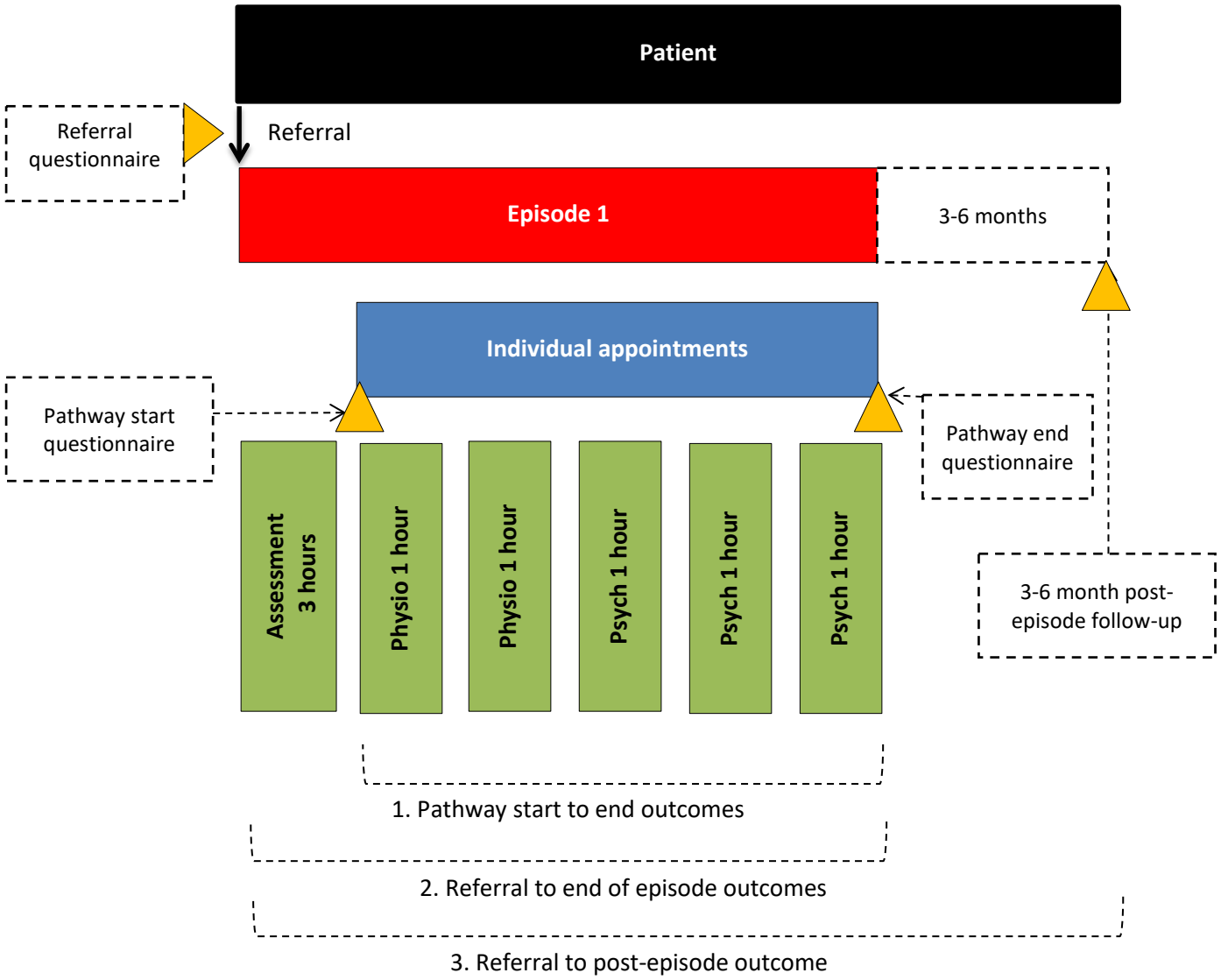
Collection of patient information at the time points above allows ePPOC to report patient outcomes reflecting:

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.

[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


Patient
Referral questionnaire
Referral
Episode 1
3-6 months
Individual appointments
Pathway start questionnaire
Pathway end questionnaire
Assessment 3 hours
Physio 1 hour
Physio 1 hour
Psych 1 hour
Psych 1 hour
Psych 1 hour
3-6 month post-episode follow-up
1. Pathway start to end outcomes
2. Referral to end of episode outcomes
3. Referral to post-episode outcome