

# **Introduction to the Electronic Persistent Pain Outcomes Collaboration (ePPOC) - paediatric services**

September 2023

## Introduction to the electronic Persistent Pain Outcomes Collaboration

This document is designed for paediatric pain management services that have recently joined, or are considering joining, the electronic Persistent Pain Outcomes Collaboration (ePPOC). It provides an overview of what ePPOC is, how it works and how your service can use ePPOC. This guide is relevant to all clinicians, managers and staff who will be involved in both setting up and using ePPOC at the service.

### Background

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ePPOC is a program which aims to improve the quality of outcomes and services for people experiencing chronic pain. It is an initiative of the Faculty of Pain Medicine and was established in 2013 with funding from the NSW Ministry of Health.

ePPOC was initially piloted in a small number of services in New South Wales in 2013, and in 2014 all specialist adult pain management services were invited to participate. A separate database (sometimes known as PaedePPOC) was also established in 2014 to address the differing needs of the paediatric pain management sector. The adult and paediatric services currently participating are shown on the ePPOC website at <http://ahsri.uow.edu.au/eppoc/participatingservices>.

### Aims and purpose

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The aims and purpose of ePPOC are to:

- produce information on the effectiveness of pain management interventions through use of standardised assessment tools and measures;
- develop an Australasian benchmarking system to improve pain management outcomes;
- provide comparative data to pain management services using the benchmarks developed;
- develop clinical and management information reports that meet the needs of ePPOC stakeholders;
- provide annual reports that summarise the Australasian data; and
- develop research proposals to address areas of interest within the pain management sector.

### Governance

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ePPOC is part of the Faculty of Science, Medicine and Health faculty at the University of Wollongong, New South Wales and sits alongside other outcome centres in the related fields of rehabilitation (Australasian Rehabilitation Outcomes Centre; AROC), palliative care (Palliative Care Outcomes Collaboration; PCOC) and palliative aged care (Palliative Aged Care Outcomes Program; PACOP).

ePPOC is accountable to the Clinical and Management Advisory Committee (CMAC) whose members include clinicians, key stakeholders, consumers and representatives of major financial contributors.

The CMAC provides advice on matters relating to data, reporting, research and management of ePPOC.

## How does ePPOC work?

The key functions of ePPOC are to facilitate the collection of standardised data from pain management services, analyse and report these data, use the data for benchmarking, and promote research into areas of importance in pain management.

### Data collection

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ePPOC involves collection of standardised information about patients seen in pain management services and the treatment they receive. Patient information is collected via questionnaires completed by patients at defined points within an episode of care. In paediatric services, information is also collected from the patient's parents and/or carers. Information about the type and intensity of treatment is completed by staff of the pain management service. The information is collected according to a standardised process and protocol.

To assist services collect the patient information, ePPOC has developed specialised software called *epiCentre* (ePPOC Patient Information Centre). epiCentre provides a means of collecting and using the data, and at the same time promoting consistent terminology around process and protocol among participating services.

epiCentre features include:

- a user-friendly interface for entering information;
- the option for patients and parents/carers to complete the questionnaires online;
- automatic scoring of the assessment tools;
- patient-level charts to assess clinical change; and
- a 'work flow' and built-in reminders to assist with patient follow-up.

### Reporting

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Pain management services periodically submit information they collect to ePPOC. ePPOC analyses this information and reports the data back to each pain service twice a year. As the information collected is standardised across all pain services, meaningful comparisons to other participating paediatric pain services can be made. Each individual pain management service therefore receives a report that presents their data and also compares this to aggregated data from all other participating paediatric services. In this way, pain management units can compare their patient population, outcomes and service delivery to those seen in other services. An example of a report for a fictitious paediatric pain management service (Enterprise One) can be found on the ePPOC website (<http://ahsri.uow.edu.au/epoc/reports>).

It is important to note that individual pain management units own the data they collect at their service and the intellectual property relating to that information. The ePPOC Director is the data custodian and manager of the de-identified ePPOC dataset supplied by all participating services. More information about how the ePPOC data is stored, collected and used can be found in the ePPOC Data Policy (<http://ahsri.uow.edu.au/epoc/forms>).

### Benchmarking

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Benchmarking is an important function of ePPOC as it:

- enables comparison of performance between services;
- identifies reasons for variation between services;
- allows identification of practices and processes that result in superior outcomes; and
- drives implementation of best practice care to patients.

One benchmark and three indicators have been endorsed for paediatric pain management services to strive to achieve:

Domain	Benchmark
Time from Referral to episode start	70% of episodes starting within 8 weeks of the referral being received.

Domain	Indicators
Average pain	Percentage of patients with at least moderate 'average pain' at referral who make clinically significant improvement at episode end
Pediatric quality of life	Percentage of patients with impaired health related quality of life at referral who make a clinically significant improvement at episode end
Functional disability	Percentage of patients with at least moderate functional disability at referral who make clinically significant improvement at episode end

Each year, ePPOC invites participating pain management services to attend a benchmarking workshop. The purpose of these workshops is to examine the benchmarking data, share information and learn from services who are achieving the best outcomes.

## Research

The de-identified data submitted to ePPOC forms a rich database of information about patients seeking pain management in Australia and New Zealand. This information is available for research into areas of interest within the pain management sector.

## Participating in ePPOC – what's involved?

Services participating in ePPOC receive the following:

- detailed reports twice a year that analyse and present their data;
- comparisons of the service's data to Australasian data;
- real time patient-level information to assist with understanding patients and monitoring their progress;
- information that can be used for refining clinical management and processes, service planning, resource allocation and funding bids;
- a license to use the epiCentre software and training for staff;
- ability to participate in a benchmarking process, aimed at promotion of best practice within a service and throughout the pain sector; and
- ability to access the ePPOC dataset and statistical services for research purposes.

In turn, participating services must commit to:

- collect the required information about their patients and the treatment provided (the ePPOC 'minimum dataset');
- collect this information according to the agreed protocol, which involves administering patient and parent/carer questionnaires at more than one time point in order to measure outcomes. There is little benefit to be gained from participating in the outcomes collaboration if patient and parent/carer outcomes are not collected;
- install and update epiCentre as required;
- participate in workshops; and
- assign and support a team of people to facilitate participation in ePPOC.

Each of these requirements is described in the sections below.

## ePPOC minimum dataset

Paediatric services participating in ePPOC collect a required minimum set of data about their patients, parents/carers and the services they provide. Ensuring that all services collect this information allows standardisation of analysis and reporting, and meaningful comparisons between services.

The minimum dataset includes a broad range of assessment tools and data items that have been selected to encompass the multidimensional nature of chronic pain. They include assessment of pain, physical function and psychological domains. The measures were chosen following wide consultation to ensure they were clinically useful, consistent with information already collected in Australasian paediatric pain management services and, as much as possible, would not impose unreasonable burden on patients, parents/carers and staff.

The standardised assessment tools that make up the minimum dataset are shown in Table 1.

**Table 1 – Paediatric ePPOC assessment tools**

Assessment tool	Data item
<b>Modified Brief Pain Inventory (BPI)</b>	Modified BPI questions are used to assess pain severity in patients aged 8 and over and uses a parent proxy rating of their child's pain for all ages.
<b>Faces of Pain Scale – Revised</b>	The Faces of Pain scale measures pain severity in patients aged 5-7.
<b>Pediatric Quality of Life Inventory (PedsQL)</b>	The PedsQL measures health-related quality of life. Results are reported as four scale scores (physical, emotional, social and school functioning). Parents and all patients complete the age-appropriate version.
<b>Functional disability Inventory (FDI)</b>	The FDI measures the physical functioning and disability of patients aged 8 and over.
<b>Bath Adolescent Pain Questionnaire Section 5 – pain-related worry (BAPQ-S5)</b>	Section 5 of the BAPQ-S5 measures worries or concerns patients over 12 years have about their pain.
<b>Bath Parent Impact Questionnaire</b>	The Bath Parent Impact measures the impact of the child's pain on the parent.

In addition to these standardised assessment tools, the ePPOC minimum dataset also includes demographic and other data. These items are shown in Table 2.

**Table 2 – Additional information**

Domain	Data item
<b>Demographic information</b>	Age, gender, postcode, indigenous status/ethnic origin and country of birth, referral information, comorbidities, work status and productivity, school days missed due to pain
<b>Medication use</b>	Types of medications patients use and the frequency of their use
<b>Healthcare utilisation</b>	Patient pain-related utilisation of health care services over the last three months
<b>Episode information</b>	Waiting time, how the episode started and ended, episode duration, treatment type and services provided.

**Please note:** these assessment tools and data items represent the **minimum** data set.

## Protocol for collection of the data

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To ensure that the ePPOC reports compare 'like with like' it is important that pain management services collect data at consistent and defined points within a patient's episode of care. This requires firstly defining the 'elements' in an episode.

These elements are:

**1. Referral** – the date the referral is received at the pain management service.

**2. The episode** – this refers to the period of care at a pain service. It is defined as the time from the first clinical contact to when the patient completes active treatment at your service.

The episode **start** could therefore be:

- an education/orientation group program that includes clinical content and is delivered by a clinician(s); or
- an appointment or assessment conducted by one or more clinicians.

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 the end of an episode include when a group pain program ends and there is no intention to continue *active* treatment at the pain service, or when the treating clinician begins to taper individual appointments.

**Please note:** a patient may have more than one episode of care during their lifetime, however there should be only one episode occurring at any one time for each patient.

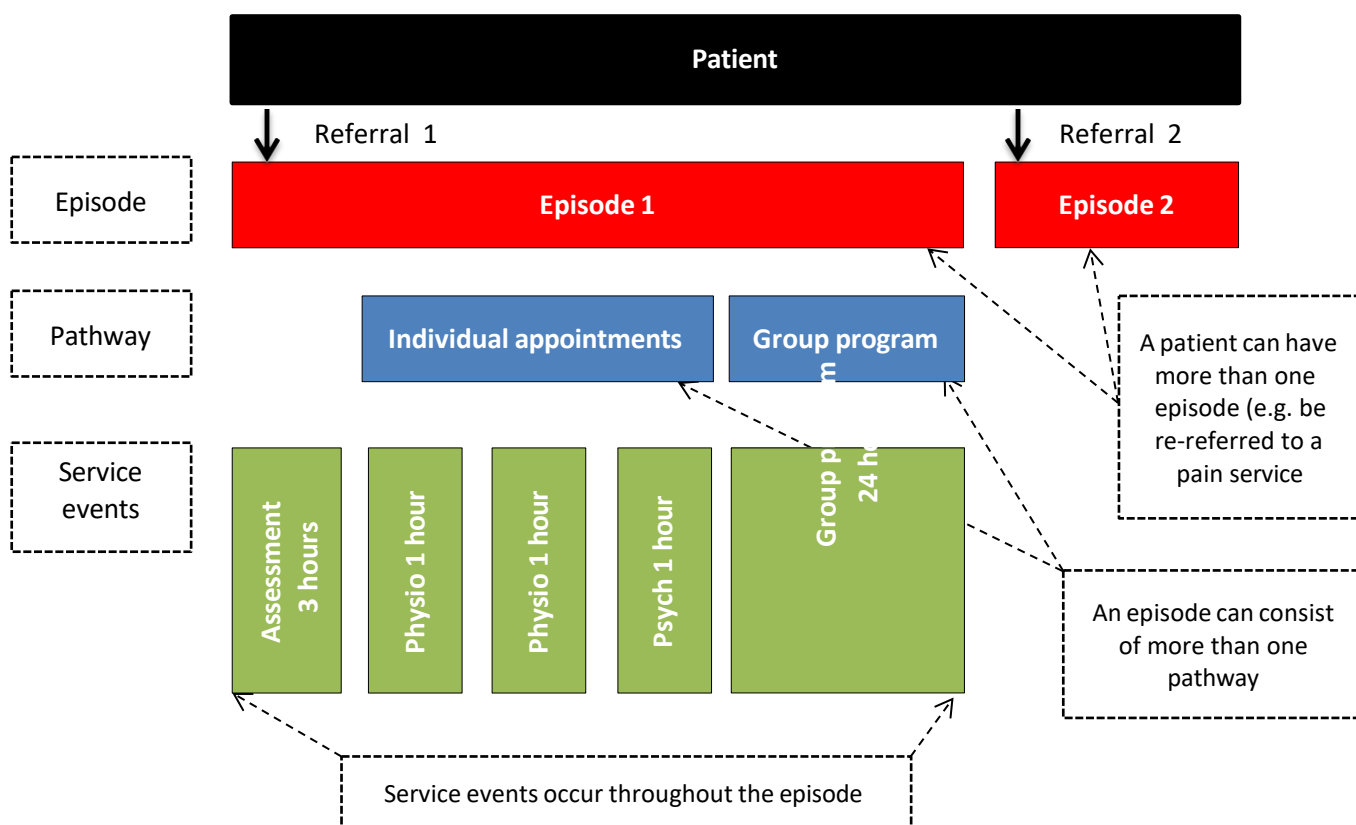
**3. The pathway** – this describes the **type** of treatment delivered within the episode. An episode can consist of one or more pathways, delivered sequentially.

There are four pathways types:

- **Group** - group pain management programs;
- **Individual** – individual appointments with clinicians (e.g. medical/nursing/allied health);
- **Concurrent** - where group programs and individual appointments are provided at the same time; and
- **Other** – these might include a procedural intervention with no further individual appointments planned, or a single appointment with a medical specialist.

**4. Service events** – are the actual services provided to the patient during an episode of care at a 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.

The diagram below shows how these elements of referral, episode, pathways and service events fit together.



These elements are important to define and standardise as they determine when the information is collected by pain management services and how results are reported by ePPOC, as detailed below.

### Collection

The patient and parent/ carer questionnaires should be collected at:

- **referral** (to obtain baseline patient data)
- **start of the pathway** (pre-treatment data)<sup>1</sup>
- **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.

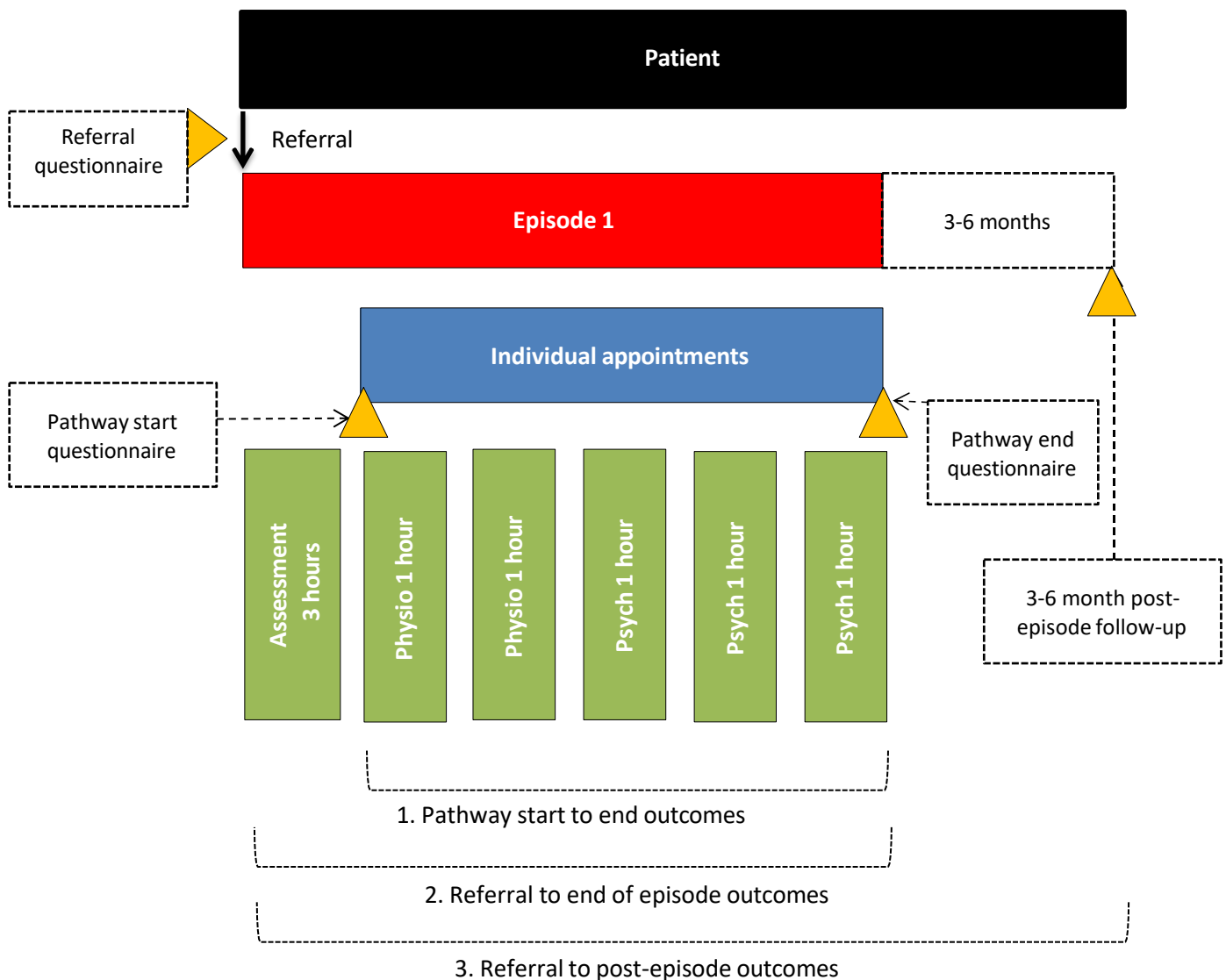
<sup>1</sup> If the pathway begins soon after the referral questionnaire is completed (e.g. within 3 months) the pathway start questionnaire does not need to be collected

## Reporting

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

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

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





A further example using a ‘typical’ patient episode is shown in the table below.

Patient Journey	Episode element	Questionnaire Process
A patient is referred to your service	<b>Referral</b> (= add new patient & add new episode in epiCentre)	Patient and carer/parent complete a <b>referral (initial) questionnaire</b>  Carer/parent completes a <b>Parent Impact questionnaire</b>
The patient is triaged based on the returned referral questionnaire		
The patient attends a multidisciplinary team assessment	<b>Episode start + Service event</b> (= MDT team assessment)	
The team discusses the patient’s case and recommends a series of sessions with a psychologist and physiotherapist	<b>Service event</b> (= MDT panel discussion)	
The patient attends the first treatment appointment with the psychologist/physiotherapist	<b>Pathway start + Service event</b> (= individual appointment with psychologist/physiotherapist)	Patient and carer/parent complete a <b>pathway start questionnaire</b>
Patient attends further appointments with the clinician(s)	<b>Service events</b> (= e.g. individual appointment/s with psychologist/nurse physiotherapist)	
The patient attends the last appointment with the clinician(s)  It is decided the patient needs no further treatment at your service or is discharged	<b>Service event + Pathway end + Episode end</b> (= individual appointment with psychologist/physiotherapist)	Patient and carer/parent complete a <b>pathway end questionnaire</b>  Carer/parent completes a <b>Parent Impact questionnaire</b>
Pain management service follows up the patient 3 to 6 months after ending the episode		Patient and carer/parent complete a <b>3 to 6 month follow up questionnaire</b>

## Installing and updating epiCentre

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epiCentre is the software purpose built for ePPOC. It consists of two integrated systems: a desktop application (epiCentre) and a web application (REDCap). The epiCentre application provides a user friendly 'front-end' for staff at pain management services to enter and use data relating to their patients, episodes, pathways and service events. REDCap (Research Electronic Data Capture) is used for the creation and management of the patient questionnaires, allowing these to be completed online by patients and securely transmitted to your pain service.

A document providing a technical overview of the system and options for installation is available at <http://ahsri.uow.edu.au/eppoc/epicentre/resources>.

While epiCentre is a small program and relatively easy to install, the time taken to install the software is very much dependent on your IT department's policies, processes and responsiveness, and/or the IT support that is available to you. We recommend that prior to joining ePPOC, you ensure your IT staff are aware of epiCentre's technical specifications and agree to install the software at your service.

epiCentre is updated periodically to incorporate enhancements, new features and bug fixes. Participating pain services are expected to install the updates in a timely manner.

## Participating in benchmarking workshops

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There is an expectation that services participating in ePPOC will participate in the benchmarking workshops. These workshops are an opportunity to network and collaborate with clinicians from other pain services, share ideas and learn from each other about what works (or doesn't) in the management of persistent pain. These workshops are held annually and are attended by pain management services and key stakeholder bodies.

## Assigning and supporting a team of people to facilitate participation in ePPOC

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It is important to have a project team at your service that has the skills and leadership to champion the project and initiate and embed change. ePPOC works best where there is support and leadership from management, clinical expertise and a small team that takes ownership of ePPOC. It is important that the roles listed below are identified prior to PaedePPOC being implemented at your service to ensure that ePPOC is accepted, implemented and supported within the service.

### **ePPOC Executive Lead** – e.g. Director of pain service

- Champions the implementation of ePPOC membership and epiCentre at the service
- Ensures local procedures and workflows are in place to support ePPOC membership and epiCentre
- Leads system changes including resolution of systemic barriers.

### **ePPOC Primary contact** – e.g. clinical coordinator, clinic manager

- Acts as the primary point of contact for the ePPOC team
- Leads implementation of ePPOC membership and epiCentre at the service
- Ensures local procedures and workflows are implemented to support ePPOC membership and epiCentre
- Facilitates attendance at ePPOC training and support sessions, including benchmarking workshops
- Provides leadership in reviewing the individual service ePPOC report and identifying opportunities for improvement
- Provides feedback to the leadership team on clinical and service outcomes including opportunities for improvement.

**ePPOC Data Coordinator** – e.g. research staff, administrative staff

- Leads data entry in epiCentre including ensuring data is entered on time and accurately at the service
- Ensures data extraction is submitted to ePPOC on time and data quality reviews undertaken
- Ensures patient questionnaires are being sent and completed
- Works closely with the Primary contact.

### Next steps – to complete ePPOC membership

1. Complete a Membership Agreement form and forward to ePPOC
2. Indicate approval of the Membership Fee quote so that an invoice can be provided (ePPOC will confirm when the membership has been paid)
3. Install epiCentre (details will be sent when items 1 & 2 above are confirmed as completed)
4. Advise ePPOC when epiCentre installation is complete

Once the above steps have been confirmed, ePPOC will be in contact to progress epiCentre training and service support.

**For further information please:**

- visit the ePPOC website at <http://ahsri.uow.edu.au/eppoc>
- contact us on +61 (02) 4221 4411
- email [eppoc@uow.edu.au](mailto:eppoc@uow.edu.au)