# Data Policy

**Version 2.2**
**December 2023**

# ePPOC DATA POLICY

| Date approved: | 10 May 2022 | Date Policy will take effect: | 10 August 2022 | Date of Next Review: | 10 August 2025 |
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| Approved by: | ePPOC Clinical and Management Advisory Committee | | | | |
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| Responsible Faculty/Division & Unit: | Australian Health Services Research Institute (AHSRI), Faculty of Business and Law, University of Wollongong | | | | |
| References & Legislation: | IT Security Policy (UOW) IT Server Security Policy | | | | |
| Audience: | Public – accessible to anyone | | | | |
| Supporting documents, procedures & forms: | ePPOC V2 Adult Data Dictionary & Technical Guidelines ePPOC V2 Paediatric Data Dictionary & Technical Guidelines ePPOC Clinical User Guide ePPOC Data Access Application Form ePPOC User Agreement form ePPOC Membership Agreement | | | | |

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## PURPOSE OF THE POLICY

1.  The electronic Persistent Pain Outcomes Collaboration (ePPOC) collects, analyses, reports and benchmarks non-identifiable patient data provided by pain management services. This Policy sets out the guidelines, principles and protocols that govern the data collected and held by ePPOC, and the use of those data.

2.  The policy will assist in communicating the principles and intentions of ePPOC both internally and with ePPOC members and stakeholders within the pain management sector.

3.  Guidelines for the collection of data and submission to ePPOC by data submitting members are to be used in conjunction with this data policy.

## POLICY PRINCIPLES

4.  Non-identifiable data collected and managed by ePPOC will be used for reporting, benchmarking and research into areas of interest within the pain management sector.

5.  The pain services that submit data to ePPOC own the data they supply and the intellectual property related to these data.

6.  AHSRI is the custodian of the non-identifiable data submitted by the pain management services and owns the intellectual property related to this consolidated non-identifiable dataset.

7.  AHSRI will not release any information from the consolidated non-identifiable dataset that could identify an individual pain management service, unless provided with written instruction to do so by that service.

8.  Use of the ePPOC dataset for research purposes is encouraged and the usual procedure is that ePPOC provides researchers with aggregate data in table form for this purpose.

9.  Specific restrictions apply to the reporting and publication of ePPOC data, including submission of pre-publication drafts of any derivative works to the ePPOC CMAC for review and potential advice on data interpretation.

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## DEFINITIONS

10. Terms and definitions used throughout the ePPOC Data Policy are listed in the table below. The terms are defined as they relate to the ePPOC dataset and thus may have a different meaning when applied to other settings.

| Word/Term | Definition (with examples if required) |
| --- | --- |
| Aggregate data | Manipulation of separate sets of data by totalling the number of cases meeting specific criteria, or summing data items for specific subpopulations |
| AHSRI | Australian Health Services Research Institute |
| CMAC | ePPOC Clinical and Management Advisory Committee |
| Non-identifiable Data | The unit record data that has been submitted by the pain management facilities. It includes qualitative and quantitative information about patients, episodes, pathways and service events. It has not been manipulated or processed by ePPOC. It is patient non-identifiable – that is, it does not contain personal identifiers such as name, address or contact details. |
| Data dictionary | The data items, definitions and naming conventions used for the ePPOC dataset. The dictionary is a tool that aids members in applying consistent data definitions. |
| Dataset | A collection of data |
| DAWG | ePPOC Data Access Working Group |
| ePPOC | electronic Persistent Pain Outcomes Collaboration |
| FPM | Faculty of Pain Medicine |
| HREC | Human Research Ethics Committee |
| ITS | Information Technology Services at the University of Wollongong |
| Member | ePPOC members include data submitting and non-data submitting members from the public and private sectors in Australia and New Zealand.<br><br>**Data submitting members** are pain management services who provide data to ePPOC<br><br>**Non-data submitting members** are key stakeholder organisations from across the pain management sector |

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| Word/Term | Definition (with examples if required) |
|---|---|
| Pain management service | A facility staffed by clinicians who specialise in the diagnosis and management of patients with painful conditions. |
| Provider | A pain management service that submits data to ePPOC |
| Purchaser | An organisation which procures health services. Purchasers can be members of ePPOC. |
| Research data | Unit record data received from pain management services that have been rendered non-identifiable to allow access for approved use. Deidentification involves removal of facility identifiers and patient variables of postcode and date of birth that could potentially, or in combination with other variables, identify a patient. |
| Statistics | The statistical measures used to describe the ePPOC dataset, including mean/average, median, percentage and count. |
| Unit record data | Unit record data are records that relate to an individual referred to and/or treated by a pain management service |
| UOW | University of Wollongong |

## EXCEPTIONS

11.  This Policy does not apply to data collected by pain management services that are not part of the ePPOC dataset. For example, identifying information such as given name, family name and street address are routinely collected by pain management services but not submitted to AHSRI as part of the ePPOC dataset.

## APPLICATION AND SCOPE

12.  This Policy and associated requirements applies to all ePPOC staff and members

13.  All ePPOC staff and members are required to comply with the Policy and should be familiar with its content and aware of their responsibilities and obligations.

## OWNERSHIP

14.  Member services are the owners of the data they collect at their pain service and the intellectual property relating to the data.

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15. AHSRI is the custodian of the non-identifiable data submitted by the pain management services, and owns the intellectual property related to this consolidated non-identifiable dataset

16. Non-data submitting members include Commonwealth, state, territory and regional health authorities, health insurers and third-party payers. These organisations may participate in ePPOC without submitting data. They have no ownership of the data provided to ePPOC by the pain management services.

## REQUIREMENTS OF DATA SUBMITTING MEMBERS

17. Pain management services submitting data to ePPOC must:

    a)   sign and return the ePPOC membership form prior to submission of data

    b)   agree that the non-identifiable data they submit will be used for reporting, benchmarking and ethically approved research purposes

    c)   ensure that the data they collect are complete and accurate and meet the ePPOC Data Dictionary and Technical Guidelines definitions

    d)   conform with privacy legislation and other measures designed to protect the confidentiality of individuals

    e)   accept responsibility for ensuring that the data they submit to ePPOC will be collected in accordance with relevant Commonwealth, State or Territory legislation designed to protect the privacy of individuals

    f)   absolve ePPOC of any responsibility in relation to the way that data are collected or stored by the pain management service.

## DATA CUSTODIANSHIP AND MANAGEMENT

18. AHSRI is the data custodian and manager of the non-identifiable ePPOC dataset. As such, AHSRI is responsible for the day-to-day operations of ePPOC.

19. ePPOC staff are responsible for the administration and maintenance of the dataset, communication with ePPOC members, supporting pain management service staff in their participation in ePPOC, and conducting education and benchmarking workshops.

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## CONFIDENTIALITY AND PRIVACY

20. As custodian and manager of the ePPOC dataset, AHSRI is bound to protect the privacy and confidentiality of individuals (the patient), providers (data submitting members) and purchasers by adhering to:

    a) codes of practice stipulated by UOW, the ePPOC CMAC and the UOW HREC

    b) relevant Acts of Parliament including Privacy Acts

    c) relevant Australian and New Zealand data and information standards

    d) regulations of the jurisdiction within which members operate.

21. The ePPOC dataset does not contain patient details such as name and address, however potentially identifying items (patient date of birth and postcode) are submitted to ePPOC by pain management services. These items will be used to derive other variables (e.g. patient age) but will not be reported or released in their raw form, except to the pain management service that provided the data.

22. Within ePPOC, data submitting pain management services are identified according to a unique provider code. This code will not be distributed to another party unless it is:

    a) a regulation or condition of funding, a copy of which is held by ePPOC

    b) agreed to in writing by the parties

    c) in accordance with an existing contract between the parties, e.g. a data submitting member and an insurer or other third-party payer

    d) a requirement of any other entity nominated in writing by the data submitting member.

23. Information in which a purchaser is identified will not be distributed to another party unless requested and formal consent is provided by the purchaser.

24. ePPOC, which functions within the University of Wollongong, collects de-identified patient information as part of its service delivery. Member services are reminded to ensure that any personally identifiable patient information is excluded when emailing ePPOC, in accordance with the service organisational privacy obligations.

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## ETHICAL REQUIREMENTS

25.    As a university research centre, AHSRI is responsible to the UOW HREC. The HREC complies with obligations under the Privacy Act and guidelines including the Australian Code for Responsible Conduct of Research and the National Statement on Ethical Conduct in Human Research.

26.    As a sub-centre of AHSRI, ePPOC is required to:

a)    obtain ethical approval from the UOW HREC for the collection, maintenance and reporting of data from the pain management sector and provide annual reports to the UOW HREC for continuation

b)    obtain approval from the UOW HREC for any changes to ePPOC protocols and data items which may affect the conduct of the data collection or processing

c)    ensure all appropriate ethical approvals have been sought and approved prior to any release of aggregated or research data from the ePPOC dataset.

## DATA ITEMS

27.    The data items in the V2 ePPOC dataset have been chosen and defined in consultation with many stakeholder groups, including the Faculty of Pain Medicine, Australian Pain Society, ePPOC CMAC and individual pain physicians and clinical staff from pain services throughout Australia and New Zealand.

28.    The current data items are listed and described in the ePPOC V2 Adult Data Dictionary and Technical Guidelines and the ePPOC V2 Paediatric Data Dictionary and Technical Guidelines documents.

29.    Requests for changes to data items or extension of the ePPOC data collection will be sent to AHSRI for consideration by an ePPOC V3 Dataset Working Group. The recommendations of this group will be presented to the ePPOC CMAC for endorsement. The endorsed revisions to the dataset will be implemented in the release of ePPOC Version 3.

30.    Version 3 changes to the data items will be communicated to all members and reflected in updated versions of the data dictionaries.

31.    All items in the ePPOC dataset must be collected and submitted by the data submitting member. An exception to the completion of items may be where a

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patient is unwilling or unable to complete items in the patient-rated assessment tools.

## DATA COLLECTION

32. Data submitting members choose how they wish to collect the ePPOC dataset and may use their own software, the software purpose built for ePPOC (epiCentre), or a hybrid of the two.

33. Services using their own software are required to:

    a) liaise with their developers to ensure the software is capable of collecting all variables in the ePPOC dataset

    b) ensure that the software can generate an ePPOC data extract in the format required by ePPOC specifications

    c) update their software when there are modifications to the ePPOC dataset.

## DATA SUBMISSION

34. Data will be submitted electronically via a secure file upload facility.

35. Pain management services will submit data to ePPOC biannually, for the periods ending June and December each year. Services that have recently joined ePPOC may be asked to submit data every quarter for the first year of their membership.

36. Members have a four-week period from the end of the data collection period to submit their data to ePPOC (i.e. data will be submitted in July and January each year).

37. Pain management services must submit records of all pain management episodes during the reporting period.

38. All data received by ePPOC are screened for missing variables, errors and inconsistencies. Data fields are not altered or adjusted by ePPOC, rather, quality reports are sent to data submitting members so that they have the opportunity to correct and resubmit the data.

39. Guidelines for the submission of ePPOC data will be developed and provided to members prior to the first submission period. These guidelines will include detailed instructions regarding the file format required and the mechanism for securely uploading data.

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## DATA QUALITY

40. ePPOC develops and maintains guidelines and procedures for submitting data to ensure the quality of the data and the meaningfulness of reports provided to members. These include:

    a) data validation checks built into epiCentre at the point of data entry to minimise the type and number of errors and missing fields in the data

    b) providing quality reports to services which detail errors, inconsistencies and missing data

    c) providing clear timelines for data submission

    d) maintaining a data dictionary for the adult and paediatric services to reduce the variability in content and quality of the data obtained from each provider

    e) validation checks of the source data which are undertaken by ePPOC at its discretion and with the approval of the provider

    f) ongoing support for, and communication with, members

    g) provision of education workshops, seminars and conference presentations describing how to collect the ePPOC data and how to make the best use of the benchmarking information provided by ePPOC.

41. The ability to provide quality and meaningful reports to data submitting members will be aided where pain management services:

    a) undertake quality checks prior to the submission of data to ePPOC to reduce the number of errors and missing variables

    b) submit data according to the ePPOC timelines

    c) correct and resubmit data where ePPOC's data validation process identifies errors or inconsistencies.

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## DATA STORAGE AND SECURITY

42. Storage and security of data collected by pain management services is the responsibility of the pain service

43. Storage and security of the non-identifiable data sent by pain management services to ePPOC is the responsibility of ePPOC, with the following safeguards in place:

    1. All data received by ePPOC are stored in electronic format.

    2. Storage of the data is on a secure password-protected server located in a physically secure computer room of the UOW.

    3. Access to ePPOC data on the server is limited to staff involved in management and analysis of ePPOC data.

    4. User accounts are managed according to the ITS Server Security Policy, ensuring appropriate levels of access, and password and username control (i.e. password strings, password ageing, password expiry dates).

    5. ePPOC stores working copies of datasets on local desktop computers temporarily as required for analysis. These computers are password protected and have automatic screen locking.

    6. Backup procedures for ePPOC data are the responsibility of ITS. Backup requirements are documented and coordinated by ITS according to the Minimum Server Security Standards outlined in the IT Server Security Policy.

    7. Disaster recovery procedures, including failover and redundancy are in accordance with the UOW policy for data security and the University's IT Intrusion Response Plan outlined in the IT Security Policy UOW.

## ANALYSIS AND REPORTING

43. ePPOC analyse the data provided by pain management services to routinely provide a number of different types of reports. These include:

    a) Regular reports to individual data submitting members containing:

        i) analyses of the member's data, with comparisons to Australasian data

        ii) achievement against benchmarks developed and agreed upon by the members and the CMAC

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      iii)   tables showing the frequency with which each item of the ePPOC data set is collected by the provider (a proxy for data quality), and the number of referrals and service events provided each month (a proxy for data completeness).

   b)   An ePPOC annual report describing the state of pain management in Australasia.  This will include demographic details of the population of people seeking pain management services (e.g. age of patients, duration of pain), outcomes for this group of patients as a result of treatment by pain management services (e.g. change in pain severity, self-efficacy, work status), and service-related information (e.g. time from referral to treatment).

   c)   Regular reports to funders (e.g. State government departments funding the participation in ePPOC of the pain management services within their jurisdiction).  These reports will include similar information to that presented for individual pain services but reported at the jurisdictional level. These reports will not identify individual pain management services and therefore will only be provided in jurisdictions large enough that individual services cannot reasonably be identified.

44. ePPOC staff may use information held in the non-identifiable ePPOC dataset to compile reports to facilitate improvement in pain management services, inform governance bodies or for quality purposes. These reports may be presented at conferences or submitted for publication in journals. No individual pain management services will be identified in any reports.

45. All reports will contain aggregated data to ensure that the confidentiality of individuals, providers and purchasers are maintained. ePPOC will ensure that:

   a)   results will not be reported for small groups (n < 5) to avoid the inadvertent disclosure of information from which characteristics of an individual, service or a small distinctive population can be inferred. For example, where a jurisdiction has only a small number of participating services, reporting at the jurisdictional level may identify individual services. In these instances, data for the services may be combined with those of other jurisdictions to ensure confidentiality. Other (consequential) cells may also be supressed to ensure data cannot be derived through deduction from the information available

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    b)    no group will be dominated by or contain one provider, as this could constitute a breach of confidentiality.

46.    ePPOC reports will include only valid data items, such that:

    a)    if data are submitted with fields in error and these are not resubmitted as part of the data validation process, these fields will not be included in reports

    b)    scores for patient self-assessment tools will not be included in ePPOC reports if there are more than the recommended number of missing items.

## DATA ACCESS

## Scope of ePPOC information available for requests

47.    ePPOC receives data detailing patient episodes provided by pain management services throughout Australia and New Zealand. Each patient record contains items completed by the pain management service along with assessment tools and clinical outcome measures completed by the patient. The ePPOC dataset also contains a number of derived items. Full details of the ePPOC data items are provided in the ePPOC V2 Adult Data Dictionary and Technical Guidelines and ePPOC V2 Paediatric Data Dictionary and Technical Guidelines documents.

## Principles guiding access to ePPOC data

48.    The use of the ePPOC dataset is encouraged for bona fide research whose objective is likely to strengthen the research evidence base for pain management.

49.    Projects requesting access to the ePPOC dataset must meet appropriate standards of scientific merit and public health importance, as determined by the ePPOC CMAC or DAWG.

50.    Applicants will make the results of their research using the ePPOC dataset publicly available and accessible to the wider community.

51.    Only data items of a sufficiently high quality will be released.

52.    Access to the ePPOC dataset will be on a non-exclusive basis.

53.    ePPOC will release the least sensitive level and number of data items practicable to fulfil the requirements of the research proposal.

54.    ePPOC will maintain a register of data access requests.

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## PROCESS FOR REQUESTING AGGREGATED DATA

Requests by members, non-members, consumers and other interested parties for ad hoc statistical extracts from the ePPOC datasets may be met where the information requested requires an aggregated output and does not directly or indirectly disclose information about a single episode, patient, pain management service or purchaser.

55. Requests must be made in writing to ePPOC using the ePPOC Data Access Application Form.
56. The application will initially be reviewed by ePPOC staff and the ePPOC Data Access Working Group (DAWG), and if necessary, forwarded to the ePPOC CMAC for further review.
57. Cell sizes of less than 5 will be suppressed to avoid identification of an individual or provider. Other (consequential) cells may also be supressed to ensure data cannot be derived through deduction from the information available.
58. ePPOC may charge a fee to non-member applicants who apply for and are granted access to aggregated data. For-profit entities will be charged a fee for access to aggregated ePPOC data.

## PROCESS FOR REQUESTING RESEARCH (NON-IDENTIFIABLE UNIT RECORD) DATA

59. In those cases where provision of aggregate data is not sufficient to answer a research question, ePPOC members and stakeholders may request access to ePPOC research data. Research data will not be made available to for-profit, commercial entities.
60. Requests must be made in writing using the ePPOC Data Access Application Form and submitted to ePPOC.
61. These requests will be reviewed by the ePPOC DAWG and/or CMAC for scientific merit and potential to contribute to the research priorities determined by the CMAC. The amount of resources necessary to fulfil the request, the source of the request, and intended use of the requested information will also be taken into consideration in reviewing the application.
62. Approved requests may be prioritised for actioning by the ePPOC CMAC.
63. Requests must include evidence of compliance with relevant ethical requirements.

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64. ePPOC may charge a fee to non-member applicants who apply for and are granted access to research data.

## DATA AGREEMENTS

65. ePPOC will formally specify any restrictions on the use of aggregated and research data where appropriate.

66. Data will only be released on receipt of a User Agreement signed by all applicants in which they undertake to:

    a) use the information only for the research purpose stated in their application

    b) store the data in a secure manner and only for an agreed time period related to the purpose of the research

    c) not provide the data to any person who is not named on the User Agreement

    d) not link the data to any other dataset

    e) not attempt to identify individuals or providers by any process, including by linkage with another dataset

    f) submit a Research Progress Report to ePPOC every six months for the life of the project. These reports will be reviewed by the ePPOC DAWG and reported to CMAC. If Progress Reports are not completed or indicate limited progress, the CMAC reserves the right to revoke approval for a project, and/or to refuse access to ePPOC data for further projects. This will help to ensure timely availability of the outcomes of research using ePPOC data.

## REPORTING AND PUBLICATION OF RELEASED DATA

67. While ePPOC expects that applicants will make the results of their research accessible in the public domain, specific restrictions apply to the reporting and publication of ePPOC data released to users. These restrictions are listed below.

    a) To ensure that the data and any limitations in scope or quality of the data provided has been properly understood by the user, pre-publication drafts of any derivative works must be submitted to the ePPOC CMAC for review and potential advice on data interpretation.

    b) ePPOC must be acknowledged as the source of the data

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c) Results must never be presented at a level where pain management services could be identified

d) Where appropriate, ePPOC may negotiate with the applicant for co-authorship on a publication utilising ePPOC data

e) Where the ePPOC data is the sole or predominant source of information on which the results are based, the publication should consider including 'ePPOC' in the title.

f) Where a journal requires authors to provide a data availability statement, the following statement should be adopted:

    *"Data are available upon reasonable request. All data are available to bona fide researchers through the electronic Persistent Pain Outcomes Collaboration through their standard operating procedures and data policy, which can be accessed at: https://www.uow.edu.au/ahsri/eppoc/resources".*

68. ePPOC reserves the right to dissociate itself from conclusions drawn from the data if it deems necessary.

## DATA DESTRUCTION AND DISPOSAL

69. There are no provisions for the destruction or disposal of the non-identifiable data forwarded by the pain services to ePPOC. ePPOC is an ongoing collaboration with the pain management sector with the aim to maintain a collection of information that will be used to create sector-specific benchmarks and measure outcomes for patients receiving pain management services. This collection of information will grow over time to provide a valuable resource for these purposes and for the wider scientific community to conduct research into pain management.

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# VERSION CONTROL AND CHANGE HISTORY

| Version Control | Date Effective | Approved By | Amendment |
|---|---|---|---|
| V1 | 1 November 2013 | ePPOC National Reference Group | New Policy Document |
| V2 | August 2018 | ePPOC Clinical and Management Advisory Committee | Amended Policy Document |
| V2.1 | August 2022 | ePPOC Clinical and Management Advisory Committee | Amended Policy Document |
| V2.2 | June 2023 | ePPOC Clinical and Management Advisory Committee | Guidance on data availability statement added to clause 67 |