## Data policy

<table>
<thead>
<tr>
<th><strong>Date approved:</strong></th>
<th>31 October 2017</th>
<th><strong>Date Policy will take effect:</strong></th>
<th>1 November 2017</th>
<th><strong>Date of Next Review:</strong></th>
<th>1 November 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Approved by:</strong></td>
<td>PCOC Executive Directors Group</td>
<td><strong>Custodian title:</strong></td>
<td>Australian Health Services Research Institute (AHSRI)</td>
<td><strong>Author:</strong></td>
<td>Palliative Care Outcomes Collaboration (PCOC)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td><strong>Contact:</strong></td>
<td>Karen Quinsey, PCOC Director (<a href="mailto:kquinsey@uow.edu.au">kquinsey@uow.edu.au</a>)</td>
</tr>
<tr>
<td><strong>Responsible Faculty/Division &amp; Unit:</strong></td>
<td>Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, Faculty of Business, University of Wollongong</td>
<td><strong><a href="mailto:pcoc@uow.edu.au">pcoc@uow.edu.au</a></strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>References and Legislation:</strong></td>
<td>IT Security Policy (University of Wollongong) v4</td>
<td>IT Server Security Policy v6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Audience:</strong></td>
<td>Public access</td>
<td><strong>Supporting documents</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• PCOC V3.0 Data Dictionary and Technical Guidelines v1.2.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• PCOC Clinical Manual</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• PCOC Application for access and use of PCOC data for research purposes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Australian Code of Responsible Conduct of Research (2007)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• National Statement on Ethical Conduct in Human Research (2007, Updated May 2015)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Privacy Act (1988)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Table of Contents

Terms and definitions.......................................................................................................................... 1  
Context of PCOC ............................................................................................................................... 2  
Purpose of the policy........................................................................................................................... 3  
Policy principles................................................................................................................................. 3  
Exceptions .......................................................................................................................................... 3  
Application and scope ....................................................................................................................... 3  
Ownership .......................................................................................................................................... 4  
Requirements of services participating in PCOC ............................................................................. 4  
Data custodianship and management ............................................................................................... 4  
Confidentiality and privacy ............................................................................................................... 5  
Ethical requirements .......................................................................................................................... 5  
Data items .......................................................................................................................................... 6  
Data collection .................................................................................................................................... 6  
Data submission ................................................................................................................................. 6  
Data quality ........................................................................................................................................ 7  
Data storage and security .................................................................................................................. 7  
Analysis and reporting ...................................................................................................................... 8  
Data access ......................................................................................................................................... 9  
  Scope of PCOC data available for requests ................................................................................. 9  
  Principles guiding release and use of PCOC data ......................................................................... 9  
  Process for requesting aggregated data ...................................................................................... 10  
  Process for requesting unit record data ..................................................................................... 11  
Data agreements ............................................................................................................................... 11  
Reporting and publication of released data .................................................................................... 12  
Data destruction and disposal .......................................................................................................... 12  
Version control and change history ................................................................................................. 12
**Terms and definitions**

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

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggregate data</td>
<td>Manipulation of separate sets of data by totalling the number of cases meeting specific criteria, or summing data items for specific subpopulations.</td>
</tr>
<tr>
<td>Data Dictionary and Technical Guidelines</td>
<td>A document that outlines the data items, their definitions and validation rules to be collected as part of the PCOC dataset.</td>
</tr>
<tr>
<td>Dataset</td>
<td>A collection of data.</td>
</tr>
<tr>
<td>PCOC longitudinal database</td>
<td>All data submitted by services participating in PCOC since PCOC commenced up to the present.</td>
</tr>
<tr>
<td>PCOC staff</td>
<td>All staff employed by the PCOC program. These include the Director, Data Manager, Statistician(s), Clinical Director, Education and Quality Manager(s), Quality Improvement Facilitators and Chief Investigators.</td>
</tr>
<tr>
<td>Research data</td>
<td>Non-identifiable extracts of either unit record data or aggregate data taken from the PCOC longitudinal database for use in research. Before release, data is de-identified by removing facility identifiers and patient variables that could potentially, or in combination with other variables, identify a patient. Release of research data can only be provided after approval of a formal data access request.</td>
</tr>
<tr>
<td>Services participating in PCOC</td>
<td>Palliative care services in Australia who are registered with PCOC and are submitting data for outcome reporting.</td>
</tr>
<tr>
<td>Unit record data</td>
<td>Records that relate to an individual who has commenced an episode of care (according to the PCOC definition in the PCOC Data Dictionary and Technical Guidelines) with a service participating in PCOC.</td>
</tr>
</tbody>
</table>
Context of PCOC

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care.

Participation of services in PCOC is voluntary and can assist palliative care service providers to improve practice. This is achieved via the PCOC patient outcome improvement framework which is designed to:
- provide clinicians with the tools to systematically assess individual patient experiences using validated clinical assessment tools,
- define a common clinical language to streamline communication between palliative care providers,
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking,
- provide service-to-service benchmarking reports and opportunities to discuss sector results at benchmarking workshops, and
- support research using the PCOC longitudinal database (2006-ongoing).

The PCOC dataset includes the clinical assessment tools: Palliative Care Phase, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-Modified Karnofsky Performance Status (AKPS) scale and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

PCOC is a national collaboration delivered by a partnership of four university research centres including: the University of Wollongong (UOW), Queensland University of Technology (QUT), University of Western Australia (UWA) and the University of Technology (UTS) Sydney.
Purpose of the policy

1. The Palliative Care Outcomes Collaboration (PCOC) collects, analyses, reports and benchmarks data provided by palliative care services. This policy sets out the principles, guidelines and procedures that govern the data collected and held by PCOC and the use of those data.

2. The policy assists in communicating the principles and intentions of PCOC, with services participating in PCOC and stakeholders within the palliative care sector.

Policy principles

3. Data submitted to and managed by PCOC is used for reporting, benchmarking and research into areas of importance to the palliative care sector.

4. Services participating in PCOC are the original custodians of the data they supply to PCOC and retain ownership of the intellectual property relating to those data.

5. The Australian Health Services Research Institute is the custodian of the PCOC longitudinal database and owner of the intellectual property relating to the PCOC longitudinal database.

6. The Australian Health Services Research Institute does not release any information that could identify an individual service participating in PCOC, unless provided with written consent from the service.

7. Non-identifiable extracts from the PCOC longitudinal database can be released for use in research after approval of a formal application to PCOC (Application for access and use of PCOC data for research purposes).

8. Specific conditions apply to the reporting and publication of PCOC data, including submission of pre-publication drafts of any derivative works to the PCOC Director for review by members of the PCOC team and potential advice on data interpretation.

9. This policy should be read in conjunction with the supporting documents listed previously.

Exceptions

10. This Policy does not apply to data that are not part of the PCOC dataset. For example, identifying information such as given name, family name and street address are routinely collected by palliative care services but are not submitted to PCOC as part of the dataset.

Application and scope

11. All PCOC staff and services participating in PCOC are required to comply with the policy and be familiar with its content and aware of their responsibilities and obligations.

12. This policy may assist other key stakeholders within the palliative care sector.
Ownership
13. Services participating in PCOC are the original custodians of the data they supply to PCOC and retain ownership of the intellectual property relating to those data.

14. The Australian Health Services Research Institute is the custodian of the PCOC longitudinal database and owner of the intellectual property relating to the PCOC longitudinal database.

Requirements of services participating in PCOC
15. Services participating in PCOC sign a registration form where they agree to:

   a) Allow the data they submit to be used for reporting, benchmarking and research purposes.

   b) Ensure that the data they collect are complete, accurate and meet definitions outlined in the PCOC Data Dictionary and Technical Guidelines document, which outlines the data items, their definitions and validation rules.

   c) Take responsibility for ensuring that the data they submit to PCOC is collected in accordance with relevant Commonwealth, State or Territory legislation (including privacy legislation) designed to protect the privacy of individuals. It is the responsibility of the services participating in PCOC to keep track of relevant legislation.

   d) Absolve PCOC of any responsibility in relation to the way that data are collected or stored by the service participating in PCOC.

Data custodianship and management
16. The Australian Health Services Research Institute is the data custodian and manager of the PCOC longitudinal database. As such, the Australian Health Services Research Institute is responsible for the operational management of PCOC.

17. PCOC program activities, including management, use and release of PCOC data, are governed by the following groups:

   a) PCOC Management Advisory Board - PCOC’s governance committee which provides strategic oversight of the PCOC project.

   b) PCOC Executive Directors Group - PCOC’s governance committee which provides operational oversight of the PCOC project.

18. The PCOC Director is responsible for operational management of the PCOC program.

19. PCOC staff are responsible for the administration and maintenance of the PCOC longitudinal database.
Confidentiality and privacy

20. As custodian and manager of the PCOC longitudinal database, the Australian Health Services Research Institute protects the privacy and confidentiality of individuals (the patient) and services participating in PCOC by adhering to the codes of practice stipulated by the University of Wollongong, the PCOC Management Advisory Board\(^1\) and the University of Wollongong Human Research Ethics Committee and relevant Acts of Parliament including the Privacy Act.

21. The PCOC longitudinal database does not contain patient details such as name and address. Potentially identifying items, such as patient date of birth and postcode, are submitted to PCOC by services participating in PCOC. These items are used to derive other variables (e.g. patient age). Such items are only reported or released to the service that provided the data on request by the service or in support of quality processes.

22. PCOC staff who have access to the PCOC longitudinal database do not have access to any other datasets which might reasonably enable re-identification of individual patients whose data is held by PCOC (for example, hospital IT systems).

23. Information identifying the results of a specific service will not be distributed to another party unless requested and formal, written consent is provided by that service.

24. Within PCOC, participating services are identified according to a unique provider code. This code is not distributed to another party unless it is agreed to in writing by the service participating in PCOC.

Ethical requirements

25. PCOC is responsible to the University of Wollongong Human Research Ethics Committee. PCOC has responsibility to comply 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. PCOC is required to:
   a) Obtain ethical approval from the University of Wollongong Human Research Ethics Committee for the collection, maintenance, analysis and reporting of data from the services participating in PCOC; and provide annual reports to the University of Wollongong Human Research Ethics Committee for continuation.
   b) Obtain approval from the University of Wollongong Human Research Ethics Committee for any changes to PCOC protocols and data items which may affect the conduct of the data collection, analysis or reporting.

\(^1\) PCOC Management Advisory Board (MAB) is the PCOC governance committee which provides strategic oversight of the PCOC project.
c) Ensure all appropriate ethical approvals have been sought and approved prior to any release of research data \(^2\) from the longitudinal database.

27. Researchers are required to obtain their own ethical approval to cover the conduct of their research.

Data items

28. The data items in the PCOC dataset have been chosen and defined in consultation with stakeholders.

29. The current data items are listed and described in the PCOC Data Dictionary and Technical Guidelines.

30. Changes to data items are communicated to services participating in PCOC and documented in updated versions of the PCOC Data Dictionary and Technical Guidelines.

Data collection

31. All items in the PCOC dataset are collected and submitted by the services participating in PCOC.

32. Services participating in PCOC may enter data into their own software or software supplied by PCOC.

33. Services using their own software are required to:
   a) Liaise with the software developers to ensure the software is capable of collecting all data items in the PCOC dataset.
   b) Ensure that the software can generate a PCOC data extract in the format required by PCOC, outlined in the PCOC Data Dictionary and Technical Guidelines.
   c) Update their software when required. For example, following modifications to the PCOC dataset.

Data submission

34. Data is submitted electronically via a secure file upload facility hosted by the University of Wollongong.

35. Services participating in PCOC submit data to PCOC on a biannual basis (at a minimum) for the six month reporting periods ending June and December each year.

36. Services participating in PCOC submit records of all phases of palliative care during the reporting period.

37. Data received by PCOC are screened for missing values, errors and inconsistencies.

\(^2\) Non-identifiable extracts of either unit record data or aggregate data taken from the PCOC longitudinal database for use in research. Before release, data is de-identified by removing facility identifiers and patient variables that could potentially, or in combination with other variables, identify a patient. Release of research data can only be provided after approval of a formal data access request.
38. Data fields are not altered or adjusted by PCOC unless specifically requested / or agreed to by the service submitting the data.

39. Data quality reports are sent to services participating in PCOC for them to correct and resubmit the data.

40. Guidelines for the submission of PCOC data are provided to services participating in PCOC. These guidelines include detailed instructions regarding the file format required, the methodology for submitting data, and the error and quality checking processes for submitted data.

Data quality

41. PCOC develops and maintains guidelines and procedures to ensure the quality of the data and the meaningfulness of reports provided to services participating in PCOC. These include:
   a) Providing data quality reports to services which detail errors, inconsistencies and missing data.
   b) Providing clear timelines for data submission.
   c) Maintaining and disseminating a PCOC Data Dictionary and Technical Guidelines document to reduce the variability in content and quality of the data obtained from each service participating in PCOC.
   d) Ongoing support for and communication with services participating in PCOC.

42. The ability to provide quality and meaningful reports to services participating in PCOC is aided where palliative care services:
   a) Undertake quality checks prior to the submission of data to PCOC to reduce the number of errors and missing variables.
   b) Submit data according to the PCOC timelines.
   c) Correct and resubmit data where PCOC’s data validation process identifies errors or inconsistencies.

Data storage and security

43. All data received by PCOC are stored in electronic format.

44. Storage of the data is on a secure password-protected server located in a physically secure computer room at the University of Wollongong.

45. Access to PCOC data on the server is limited to staff involved in administration, management and analysis of PCOC data.

46. User accounts and IT infrastructure for PCOC are managed according to the University of Wollongong Information Technology Server Security Policy, ensuring appropriate levels of access, and password and username control (i.e. password strings, password ageing, password expiry dates).
47. PCOC stores working copies of data submissions on local desktop computers temporarily as required for analysis. These computers are password protected and have automatic screen locking.

48. Backup procedures for PCOC data are the responsibility of Information Technology Services (ITS). Backup requirements are documented and coordinated by ITS according to the Minimum Server Security Standards outlined in the Information Technology Server Security Policy.

49. Disaster recovery procedures, including failover and redundancy are in accordance with the University of Wollongong policy for data security and the Information Technology Intrusion Response Plan outlined in the University of Wollongong Information Technology Server Security Policy.

Analysis and reporting

50. PCOC analyses the data provided by services participating in PCOC to routinely provide a number of different types of reports. These include:

a) Regular reports to individual services participating in PCOC containing:
   i) analysis of the service’s data, with some data reported against the national data or a benchmark group
   ii) achievement against benchmarks developed and agreed upon by the PCOC Management Advisory Board
   iii) tables showing the frequency with which each item of the PCOC dataset is collected by the service (to summarise data completeness).

b) A national PCOC bi-annual report describing the data submitted for a six month period by all services participating in PCOC. This includes demographic details of the population of people receiving palliative care services, outcomes for this group of patients as a result of treatment by services and service-related information.

c) Bi-annual reports describing the data submitted for a six month period in Australian states (at a state level), where applicable. These reports include similar information to that presented for services participating in PCOC, but reported at the state level. These reports do not identify the results of individual palliative care services and therefore are only provided in states large enough that individual services cannot reasonably be identified.

d) Bi-annual reports to specific consortia of services participating in PCOC. These reports identify specific services and are provided at the formal request of each of the services participating in PCOC who are part of the consortia.

e) Reports containing analysis of data collected through periodic surveys.

f) Reports containing results from research studies and ad hoc analysis.

51. PCOC staff may use information held in the PCOC longitudinal database to compile one-off reports to facilitate improvement in palliative care services, inform governance bodies
or for quality purposes. These reports may be presented at conferences or submitted for publication in journals. Results of individual services participating in PCOC will not be identifiable in any reports, publications or presentations.

52. All reports contain aggregated data to ensure that the confidentiality of individuals and services participating in PCOC are maintained. PCOC ensures that results are not 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 services participating in PCOC, reporting at the jurisdictional level may identify individual services. In these instances one of the following occurs:
   a) 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.
   b) Following discussion and agreement with the PCOC Director, PCOC seeks formal agreement with the affected services participating in PCOC. The agreement highlights the fact that only a small number of services will be included.

53. PCOC reports include only valid data items, such that:
   a) If data items are submitted with values in error and these are not corrected as part of the data validation process, these values are not included in reports.
   b) Low data item completion may lead to values being excluded from reporting.

Data access

Scope of PCOC data available for requests

54. Data regarding patients, episodes and phases are provided to PCOC by services participating in PCOC throughout Australia. Each patient record contains demographic items as well as assessment level items. The PCOC longitudinal database also contains a number of derived items.

Principles guiding release and use of PCOC data

55. There are two purposes for which data from PCOC data may be released:
   a) **Quality improvement**: unit record data or aggregate data may be released to PCOC services to assist in their own quality improvement activities. Release of data for the purpose of quality improvement to a particular service will not include data which might enable identification of any other service, or patients from any other service.
   b) **Research**: The use of the PCOC longitudinal database is encouraged for research whose objective is likely to strengthen the research evidence base for palliative care.
56. PCOC services who wish to use PCOC data for the purpose of quality improvement may contact the PCOC team directly. The PCOC team will advise regarding how to progress this request.

57. Researchers who wish to use PCOC data for the purpose of research must complete the form ‘PCOC Application for Access and use of PCOC data for research purposes’. The conditions and processes outlined in points 54-68 apply to this use.

58. Projects requesting extracts of data from the PCOC longitudinal database must meet appropriate standards of scientific merit and public health importance, as determined by the PCOC Executive Directors Group.

59. Applicants are required to make the results of their research using data from the PCOC longitudinal database publicly available and accessible to the wider community. Proposed dissemination strategies are requested and listed on the ‘PCOC Application for access and use of PCOC data for research purposes’ form.

60. Only data items of a sufficiently high quality are released. This is determined by a minimum of one of the PCOC Chief Investigators, in collaboration with the PCOC Data Manager and PCOC Director.

61. PCOC releases the least sensitive level and number of data items practicable to fulfil the requirements of the research proposal.

62. There are two categories of data which PCOC may release for use:
   a) Aggregated data - manipulation of separate sets of data by totalling the number of cases meeting specific criteria, or summing data items for specific subpopulations.
   b) Unit record data - records that relate to an individual who has commenced an episode of care (according to the PCOC definition in the PCOC Data Dictionary and Technical Guidelines) with a service participating in PCOC. Before release, data is de-identified by removing facility identifiers and patient variables that could potentially, or in combination with other variables, identify a patient.

63. PCOC maintains a register of data access requests, which is tabled at the Management Advisory Board meetings.

64. PCOC reserves the right to dissociate itself from conclusions drawn from the data if it deems necessary.

**Process for requesting aggregated data**

65. Requests are made in writing using the ‘PCOC Application for access and use of PCOC data for research purposes’ form.

66. The application is initially reviewed by the PCOC Director, and forwarded to the Executive Directors Group for approval.

---

3 PCOC Executive Directors Group is PCOC’s governance committee which provides operational oversight.
67. Cell sizes of less than five are suppressed to avoid identification of an individual or service participating in PCOC. Other (consequential) cells may also be suppressed to ensure data cannot be derived through deduction from the information available.

**Process for requesting unit record data**

68. In exceptional cases, where provision of aggregated data is not sufficient to answer a research question, services participating in PCOC and stakeholders may request access to unit record data\(^4\) from the longitudinal database. Unit record data is not be made available to for-profit, commercial entities.

69. Requests are made in writing using the PCOC ‘Application for access and use of PCOC data for research purposes’ form and submitted to the PCOC Director.

70. These requests are initially reviewed by the PCOC Director, and forwarded to the Executive Directors Group for review of scientific merit and potential to contribute to the research priorities (as determined by the PCOC Management Advisory Board.) The amount of resources necessary to fulfil the request, the source of the request, and intended use of the requested information is also taken into consideration in reviewing the application.

71. Approved applications are prioritised for actioning by the PCOC Executive Directors Group.

72. Applications include evidence of compliance with relevant ethical requirements.

**Data agreements**

73. PCOC formally specifies any additional restrictions on the use of aggregated and unit record data where appropriate.

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

   a) Use the information only for the 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 request\(^5\).

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

   d) Not attempt to identify individuals or services by any process, including by linkage with another dataset.

---

\(^4\) Unit record data are records that relate to an individual who has commenced an episode of care (according to the PCOC definition in the PCOC Data Dictionary and Technical Guidelines) with a service participating in PCOC.

\(^5\) User agreement point 6 and Data Policy Doc p14 72b): In accordance with the Australian Code for the Responsible Conduct of Research (2007), data will be retained for an appropriate period following completion of the project. Data will be stored in a safe and secure storage environment for the designated minimum period, after which it will be securely destroyed (e.g. hard copies will be shredded into confidential waste, electronic copies will be irretrievably deleted). NHMRC, 2007. Australian Code for the Responsible Conduct of Research, Section 2 Management of Research Data and Primary Materials. Australian Government, Canberra.
Reporting and publication of released data

75. While PCOC expects that applicants make the results of their research accessible in the public domain, specific conditions apply to the reporting and publication of PCOC aggregated data released to users:

   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 are submitted to the PCOC Director for review and potential advice on data interpretation from the PCOC team.

   b) PCOC is acknowledged as the source of the data.

   c) Results are not to be presented in such a way that individuals and/or services participating in PCOC could be identified.

   d) PCOC reserves the right to negotiate with the applicant for co-authorship on any publication utilising PCOC data.

76. PCOC reserves the right to withdraw permission to publish the data as per the conditions of the User Agreement.

Data destruction and disposal

77. There are no provisions for the destruction or disposal of the data submitted by palliative care services to PCOC. PCOC is an ongoing collaboration with the palliative care sector with the aim to maintain the longitudinal database that is used to create sector-specific benchmarks and measure outcomes for patients receiving palliative care services. This longitudinal database has grown over time to provide a valuable resource for these purposes and for the wider scientific community to conduct research into palliative care.

Version control and change history

<table>
<thead>
<tr>
<th>Version Control</th>
<th>Date Effective</th>
<th>Approved By</th>
<th>Amendment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0</td>
<td>1 November 2017</td>
<td>Executive Directors Group</td>
<td>-</td>
</tr>
</tbody>
</table>