

PACOP Data Policy



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PACOP data policy

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Supporting documents	<ul style="list-style-type: none"> • PACOP IT Specifications • PACOP Profile Collection Data Dictionary • PACOP Outcomes Collection Data Dictionary • PACOP registration form • PACOP Profile Collection Clinical Guide • PACOP Outcomes Collection Clinical Guide • PACOP Data Access Application form • PACOP Data User Agreement • Australian code for the responsible conduct of research (NHMRC, 2018) • Principles for accessing and using publicly funded data for health research (NHMRC, 2016) • Australian Health Services Research Institute (AHSRI) policy for seeking ethical approval for research • National statement on ethical conduct in human research (NHMRC 2007, Updated 2018) 				

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Terms and definitions

Terms and definitions used throughout the PACOP Data Policy are listed in the table below. The terms are defined as they relate to PACOP and may have a different meaning when applied to other programs or contexts.

Terms	Definitions
Aggregate data	Manipulation of separate sets of data by totalling the number of cases meetingspecific criteria, or summing data items for specific subpopulations
ACH	An individual residential aged care home or facility, usually managed through a largerprovider residential aged care organisation
AHSRI	Australian Health Services Research Institute
Data custodian	The entity that collects or generates data for any purpose, and is accountable and responsible for the governance of that data
Data dictionary and clinical reference guide	Documents that outline the data items, their definitions (with included clinical reference guide for relevant data items) and validation rules to be collected as part of the PACOP dataset. There is a version for the Profile Collection and a separate version for the Outcomes Collection
Dataset	A collection of data
Data linkage	The joining of one or more data sets through key variables common to each of the data sets being linked. Also referred to as data integration
Data release	Making data publicly available with no or few restrictions on who may access the data and what they may do with it
Data sharing	Data sharing is making data available to another agency, organisation or person under agreed conditions
Data sharing agreement	A formal arrangement between a data custodian and another entity, organisation or individual that details conditions under which data is shared and used
Disclosure risk	The combination of likelihood and consequence that information about an individual, organisation or other entity is revealed or provided to an unauthorised person or entity
HREC	Human Research Ethics Committee
PACOP longitudinal database	All data submitted by ACHs participating in PACOP
PACOP staff	All staff employed and collaborating with PACOP either in a paid, honorary or voluntary manner. This includes PACOP’s executive director, director, quality and education staff, data and statistical staff, improvement facilitators and administrative staff.
Research data	Following an approved research application these include non-identifiable extracts of either unit record data or aggregate data taken from the PACOP longitudinal database for use in research
Organisations participating inPACOP	Residential aged care organisations and aged care homes who are registered withPACOP
Unit record data	Records that relate to an individual who has commenced care in an aged care home (according to the PACOP definition in the PACOP Data Dictionary and PACOP IT specifications) participating in PACOP

About the PACOP data policy

Background to PACOP data policy

1. PACOP is a national program that uses standardised clinical assessment tools to measure resident outcomes in aged care homes (ACHs). PACOP aims to systematically improve the care and outcomes of residents' including improvements in distress related to pain, other symptoms and psychosocial/spiritual wellbeing, and in the outcomes of residents' families and carers. Participation in PACOP is voluntary and assists ACHs/organisations to improve practice. Central to the program is a framework and protocol for routine clinical assessment and response. This works in parallel with a routine point-of-care data collection, capturing clinically meaningful information which is used to inform quality improvement. The items in the PACOP data collection:
 - Provide clinicians and others with an approach to systematically assess individual resident experiences,
 - Include routine resident-reported outcome measures (PROMs) and clinician-rated measures,
 - Define a common clinical language to allow ACHs/organisations to communicate with each other, and,
 - Facilitate the routine collection of consistent palliative aged care data for the purpose of reporting and benchmarking to drive quality improvement at ACH, organisation, state/territory, and national/international levels.

PACOP is a national, integrated outcomes program delivered by the Australian Health Services Research Institute (AHSRI) at the University of Wollongong.

The PACOP data policy was developed as a modification of the Palliative Care Outcomes Collaboration (PCOC) data policy in consultation with ACHs participating in PACOP, data analysts, researchers and other stakeholders, and with reference to other national outcome centres, including the Australasian Rehabilitation Outcome Centre (AROC) and the electronic Persistent Pain Outcomes Collaboration (ePPOC) operating within AHSRI.

Purpose of the policy

2. This policy sets out the principles, guidelines and procedures that govern the data collected and held by PACOP and the use of those data.
3. The policy is instrumental in communicating the principles and intentions of PACOP both internally and with ACHs/organisations participating in PACOP, members and other stakeholders.
4. PACOP guidelines, agreements and forms, and technical documents regarding the collection and use of data are to be used in conjunction with this data policy.

Policy principles

5. Data submitted to and managed by PACOP is used for reporting, benchmarking and research into areas of importance to the aged care sector.
6. ACHs participating in PACOP are the original custodians of the data they supply to PACOP and retain ownership of the intellectual property relating to those data.
7. The Australian Health Services Research Institute (AHSRI) is the custodian of the PACOP longitudinal database and owner of the intellectual property relating to the PACOP longitudinal database.
8. AHSRI does not share any aggregated or unit record data from an individual ACH participating in

PACOP, unless provided with written consent from the ACH/organisation to do so.

9. Non-identifiable extracts from the PACOP longitudinal database can be released for use in research after approval of a formal research application to PACOP (*Data Access Application* form) and, where required, supply of evidence of ethical approval for the research or confirmation that a formal ethical approval is not required.
10. The value of data lies in its use. Use of datasets for research and quality improvement should be promoted, encouraged and maximised for public benefit, while also protecting privacy and confidentiality.
11. Research and quality improvement is an important endeavour to drive improvements for the benefit of individuals requiring palliative aged care, their families, society and systems.
12. The provision of data to PACOP and the sharing of the PACOP data is done with the intent to contribute to the improved practice and policy, and generation of knowledge.
13. Linking PACOP data can enable valuable information for policy and research into the health and wellbeing of the population.
14. The sharing of high-quality data supports high-quality outputs. Only data items of a sufficiently high-quality are shared.
15. PACOP is committed to ensuring privacy principles. PACOP releases the least sensitive level and number of data items practicable to fulfil the requirements of any research proposal.
16. PACOP's data policy will be revised in order for it to remain contemporaneous in line with advances in palliative aged care, and data, research and health technologies.
17. Specific conditions apply to the reporting and publication of PACOP data, including submission of pre-publication drafts of any works derivative of a PACOP data access application to the PACOP National Director for review by PACOP before its external release or publication.
18. This policy should be read in conjunction with the supporting documents listed previously.

Application and scope

19. All PACOP staff, ACHs participating in PACOP and those who have access to PACOP data are required to comply with this policy, be familiar with its content and be aware of their responsibilities and obligations.

Exceptions

20. This policy does not apply to data that are not part of the PACOP dataset.

Governance and ownership in relation to the data policy

PACOP's governance

21. PACOP's Executive Leadership Group (ELG) is responsible for the management and oversight of the operational functions of PACOP on day-to-day management, financial reporting and other accountability requirements. This includes ensuring the collection, analysis, reporting and development of PACOP data; the support to ACHs/organisations to collect and use PACOP information; the review and approval of data requests; and the promotion of research and development opportunities with the data collected, and helping to marshal resources to deliver

these opportunities. The ELG is responsible for the day to day governance of PACOP.

22. The PCOC/PACOP Management Advisory Board (MAB) is responsible for the strategic advice to PCOC and PACOP, including comment and oversight of their clinical and scientific governance and for compliance with the terms of the Funding Agreements.
23. PACOP's ELG, participating ACHs and other committees and groups provide advice and feedback in order to improve PACOP's data policy. This may include, and is not limited to, matters regarding data collection, maintenance and security, reporting and access.
24. PACOP's National Director (or another nominated by the National Director) maintains and updates PACOP's data policy.
25. PACOP staff are responsible for the administration and maintenance of the PACOP longitudinal database.

Data ownership

26. ACHs participating in PACOP are the original custodians of the data they supply to PACOP and retain ownership of the intellectual property relating to those data.
27. AHSRI is the custodian of the PACOP longitudinal database and owner of the intellectual property relating to the PACOP longitudinal database.
28. PACOP reserves the right to negotiate ownership of data once integrated and or to establish a formal agreement regarding use and ownership of data that is integrated with another dataset.

Requirements of ACHs participating in PACOP

29. ACHs participating in PACOP sign a registration form where they agree to:
 - a. Allow the de-identified 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 *PACOP's Profile and Outcome Data Dictionaries* and *PACOP IT Specifications* documents which include an outline of data items, their definitions and validation rules.
 - c. Take responsibility for ensuring that the data they submit to PACOP is collected in accordance with relevant Commonwealth, State or Territory or other jurisdiction legislation (including privacy legislation) designed to protect the privacy of individuals. It is the responsibility of the ACHs participating in PACOP to keep track of relevant legislation.
 - d. Absolve PACOP of any responsibility in relation to the way that data are collected or stored by the ACH participating in PACOP.

Confidentiality and privacy

30. As custodian and manager of the PACOP longitudinal database, AHSRI protects the privacy and confidentiality of individuals (the resident or another) and ACHs/organisations participating in PACOP by adhering to the codes of practice stipulated by the University of Wollongong, the PACOP ELG and MAB, and the University of Wollongong Human Research Ethics Committee (HREC) and relevant Acts of Parliament, including Australia's Privacy Act.
31. The PACOP longitudinal database does not contain residents' details such as names and

addresses. Potentially identifying items, such as resident date of birth and postcode, are submitted to PACOP by ACHs/organisations participating in PACOP. These items are used to derive other variables (e.g. age) but are only reported to the ACH/organisation that provided the data or shared on request by the ACH/organisation or in support of quality processes.

32. Information identifying the results of a specific ACH/organisation will not be distributed to another party unless formal, written consent is provided by that ACH/organisation.
33. Within PACOP, participating ACHs 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 ACH/organisation participating in PACOP.

Ethical requirements

34. PACOP has ethical approval from the University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical Human Research Ethics Committee (HREC) (Ref # 2021/ETH12021) for the collection, maintenance, analysis, research and reporting of data from the ACHs/organisations.
35. PACOP 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. Australian state and territory health departments have signed a Memorandum of Understanding for mutual acceptance of ethical and scientific review of multi-centre human research projects undertaken in public health organisations. The University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical HREC is jointly registered and certified (EC00150) with the National Health and Medical Research Council of Australia.
36. PACOP is required to:
 - a. Provide annual reports to the University of Wollongong and Illawarra Shoalhaven Local Health District Health HREC for continuation.
 - b. Obtain approval from the University of Wollongong HREC for any changes to PACOP protocols and data items which may affect the conduct of the data collection, analysis or reporting.
 - c. Ensure all appropriate ethical approvals have been sought and approved prior to any release of research data from the longitudinal database.
37. Researchers are required to obtain their own ethical approval to cover the conduct of their research.

Data items

38. The data items in the PACOP dataset have been chosen and defined in consultation with stakeholders.
39. The current data items are listed and described in *PACOP's Profile* and *Outcomes Data Dictionaries*.
40. Changes to data items are communicated to ACHS participating in PACOP and documented in

updated versions of the *PACOP Data Dictionaries* and *PACOP IT Specifications*.

Data collection

41. All items in the PACOP dataset are collected and submitted by the ACHs participating in PACOP.
42. ACHs participating in PACOP may enter data into their own software or software supplied by PACOP.
43. ACHs 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 PACOP dataset according to the PACOP protocol.
 - b. Ensure that the software can generate a PACOP data extract in the format required by PACOP, outlined in the *PACOP Profile* and *Outcomes Data Dictionaries* and *PACOP IT Specifications*.
 - c. Update their software when required. For example, following modifications to the PACOP dataset.

Data submission

44. Data are submitted electronically via a secure file upload facility hosted by the University of Wollongong.
45. ACHs participating in PACOP submit data to PACOP on a biannual basis (at a minimum) for the six-month reporting periods ending June and December each year.
46. ACHs participating in PACOP submit records of all resident admissions and episodes of care within the Profile and Outcomes collections, and clinical/palliative care assessments during the reporting period.
47. Data received by PACOP are screened for missing values, errors and inconsistencies.
48. Data fields are not altered or adjusted by PACOP unless specifically requested or agreed to by the ACH/organisation submitting the data.
49. Data quality reports are sent to ACHs participating in PACOP for them to correct and resubmit the data.
50. Guidelines for the submission of PACOP data are provided to ACHs/organisations participating in PACOP. 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

51. PACOP develops and maintains guidelines and procedures to ensure the quality of the data and the meaningfulness of reports provided to ACHs participating in PACOP. These include:
 - a. Providing data quality reports to ACHs which detail errors, inconsistencies and missing data.
 - b. Providing clear timelines for data submission.

- c. Maintaining and disseminating the *PACOP Data Dictionaries (Profile and Outcomes)* and the *PACOP IT Specifications* documents to reduce the variability in content and quality of the data obtained from each ACH/organisation participating in PACOP.
 - d. Ongoing support for and communication with ACHs/organisations participating in PACOP.
52. The ability to provide quality and meaningful reports to ACHs/organisations participating in PACOP is aided where ACHs/organisations:
- a. Undertake quality checks prior to the submission of data to PACOP to reduce the number of errors and missing variables.
 - b. Submit data according to the PACOP process and timelines.
 - c. Correct and resubmit data where PACOP's data validation process identifies errors or inconsistencies.

Data storage and security

53. All data received by PACOP are stored in electronic format.
54. Storage of the data is on secure, password-protected servers located in the University of Wollongong's physically secured data centre.
55. Access to PACOP data on the server is limited to staff involved in administration, management and analysis of PACOP data.
56. User accounts and IT infrastructure for PACOP 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).
57. PACOP 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.
58. Backup procedures for PACOP data are the responsibility of the University of Wollongong Information Management & Technology Services (IMTS). Backup requirements are documented and coordinated by IMTS according to the Minimum Server Security Standards outlined in the *Information Technology Server Security Policy*.
59. 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

60. PACOP analyses the data provided by ACHs participating in PACOP to routinely provide a number of different types of reports. These include:
- a. Regular reports to individual ACHs participating in PACOP 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 PACOP Executive Leadership Group.
 - iii. Tables summarising data completeness.
- b. A national PACOP bi-annual report describing the data submitted for a six-month period by all ACHs participating in PACOP. This includes demographic details of the population of people in ACHs, assessments of residents 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 sufficient ACHs participate to maintain anonymity), where applicable, and elsewhere as identified by PACOP. These reports include similar information to that presented for ACHs/organisations participating in PACOP but reported at the state level. These reports do not identify the results of individual ACHs/organisations and therefore are only provided in states large enough that individual ACHs/organisations cannot reasonably be identified.
 - d. Bi-annual reports to specific consortia of ACHs/organisations participating in PACOP. These reports identify specific ACHs and are provided at the formal request of each of the ACHs/organisations participating in PACOP who are part of the consortia.
 - e. Bi-annual reports to specific consortia involved in supporting ACHs/organisations to implement the PACOP program and/or in the delivery of palliative aged care. In this instance, participating ACHs' data will only be included with the explicit written permission of the ACH.
 - f. Reports containing analysis of data collected through surveys.
 - g. Reports containing results from research studies and ad hoc analyses. PACOP staff may use information held in the PACOP longitudinal database to compile one-off reports to facilitate improvement in ACHs/organisations, inform governance bodies or for quality purposes. These reports may be presented at conferences or submitted for publication in journals. Results of individual ACHs/organisations participating in PACOP will not be identifiable in any reports, publications or presentations unless written permission has been received by PACOP from that ACH/organisation.
61. All reports contain aggregated data to ensure that the confidentiality of individuals and ACHs/organisations participating in PACOP are maintained. PACOP ensures that results are not reported for small groups ($n < 5$) to avoid the inadvertent disclosure of information from which characteristics of an individual, ACH/organisation or a small distinctive population can be inferred. For example, where a jurisdiction has only a small number of ACHs participating in PACOP, reporting at the jurisdictional level may identify individual ACHs/organisations. In these instances, one of the following occurs:
- a. Data for the ACH/organisations may be combined with those of other jurisdictions to ensure confidentiality. Other (consequential) cells may also be suppressed to ensure data cannot be derived through deduction from the information available.
 - b. Following discussion and agreement with the PACOP National Director (or another nominated by PACOP's Executive Director or Director), PACOP seeks formal agreement with the affected ACH/organisation participating in PACOP. The agreement highlights the

fact that only a small number of ACHs/organisations will be included.

62. PACOP reports include only valid data items, such that:
- c. 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.
 - d. Low data item completion may lead to values being excluded from reporting.

Data access

Scope of PACOP data available for requests

63. Data regarding residents, admissions to the ACH, episodes of palliative care, phases and assessments are provided to PACOP by ACHs participating in PACOP throughout Australia. Each resident record contains demographic items. Admission records contain information about how the resident enters and departs the ACH and a secondary level related to the episode of palliative care within the Outcomes Collection, and assessment-level items. Additional items are collected periodically. The PACOP longitudinal database also contains a number of derived items. For example, age is derived from the resident's reported date of birth.

Principles guiding the sharing and use of PACOP data

64. There are four purposes for which data from PACOP data may be shared:
- a. *Quality improvement*: unit record data or aggregate data may be released to PACOP participating ACHs to assist in their own quality improvement activities. Release of data for the purpose of quality improvement to a particular ACH/organisation will not include data which might enable identification of any other ACH/organisation, or residents from any other ACH/organisation.
 - b. *Research*: The use of the PACOP longitudinal database is encouraged for research whose objective is likely to strengthen the research evidence base for palliative aged care.
 - c. *Policy*: PACOP data can be used to help influence and improve policy.
 - d. *Service Planning*: PACOP data can be used within individual ACHs and their organisation to plan their approach to care. Data may also be used by health services and governments to plan or modify approaches to palliative and end of life care in the residential aged care sector.
65. ACHs who wish to use their own PACOP data for the purpose of quality improvement may contact the PACOP team directly. The PACOP team will advise regarding how to progress this request.
66. Researchers who wish to use PACOP data for the purpose of research must complete the *PACOP Data Access Application* form.
67. Projects requesting extracts of data from the PACOP longitudinal database must meet appropriate standards of scientific merit and public health importance, as determined by the PACOP ELG.
68. Applicants are required to make the results of their research using data from the PACOP longitudinal database publicly available and accessible to the wider community. Proposed dissemination strategies are requested and listed on the *PACOP Data Access Application* form.

69. Only data items of a sufficiently high-quality are released. This is determined in collaboration with the PACOP data and statistical staff, and the PACOP National Director.
70. PACOP releases the least sensitive level and number of data items practicable to fulfil the requirements of the research proposal.
71. There are two categories of data which PACOP may release for use:
 - a. *Aggregated data*: manipulation 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 ACH admission (according to the PACOP definition in the *PACOP Data Dictionaries (Profile & Outcomes)* and *PACOP IT Specifications* with an ACH/organisation participating in PACOP. Before data sharing occurs, facility identifiers and resident variables that could potentially, or in combination with other variables, identify a resident are removed.
72. PACOP maintains a register of data access requests, which is tabled at the PACOP ELG.
73. PACOP reserves the right to dissociate itself from conclusions drawn from the data by researchers if it deems necessary.

Process for requesting aggregated data

74. Requests are made in writing using the *PACOP Data Access Application* form.
75. The application is reviewed by the PACOP National Director, data team and the PACOP ELG for approval.
76. Cell sizes of less than five are suppressed to avoid identification of an individual or ACH/organisation participating in PACOP. 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

77. In exceptional cases, where provision of aggregated data is not sufficient to answer a research question, ACHs participating in PACOP and stakeholders may request access to unit record data from the longitudinal database.
78. Unit record data will not be made available to any entities outside of the ACH or their organisation without written approval from the ACH who owns the data.
79. Requests are made in writing using the *PACOP Data Access Application* form and submitted to the PACOP National Director.
80. These requests are reviewed by the PACOP National Director, data team and the PACOP ELG for scientific merit, risk and potential to contribute to the research priorities. 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. On occasion, a fee-for-service may be requested to process the data access request and share the data.
81. Approved applications are prioritised for actioning by the PACOP leadership group.
82. Applications must include evidence of compliance with relevant ethical requirements.

Data agreements

83. PACOP formally specifies any additional restrictions on the use of aggregated and unit record data where appropriate.
84. Data are only released on receipt of a PACOP *Data User Agreement* signed by all applicants in which they undertake to:
- Use the information only for the purpose stated in their application.
 - Store the data in a secure manner and only for an agreed time period related to the purpose of the request.¹
 - Not provide the data to any person who is not named on the *Data User Agreement*.
85. Applicants provided with PACOP data may be requested to submit a progress report to PACOP every six months (or at another timeframe nominated by PACOP) for the life of the project. These reports will be reviewed by PACOP, and if necessary, referred to the PACOP ELG if progress reports are not completed or indicate limited progress, PACOP reserves the right to revoke approval for a project, and/or to decline access to PACOP data for further projects. This will help to ensure timely availability of the outcomes of research and the availability of PACOP data to those that may make full and optimal use of this valuable resource.

Data linkage

86. All data linkage projects are to be preceded by a discussion between the PACOP National Director and PACOP data and statistical staff, and representatives of the secondary dataset and or research team to be linked to the PACOP data (or research project leader), to confirm that data linkage is feasible based on the data held in the datasets to be linked.
87. Where data linkage is considered feasible, approval for linkage must be obtained by the researcher from all data custodians.
88. Projects involving the use of linked data also require a project-specific HREC approval. The project-specific HREC approval considers all issues related to the project, including the specific process used for that data linkage, any issues related to identifiability of the linked dataset and the risks and benefits of the project to people whose data will be used.
89. A data sharing arrangement is then to be established, indicating:
- Which variables will be disclosed to facilitate data linkage (by whom and to whom);
 - Which variables will be included from each dataset in the linked research dataset;
 - The scope of records to be included from each dataset (based on date range and/or resident characteristics);
 - Which party will conduct the probabilistic linkage;

¹In accordance with the *Management of Data and Information in Research A guide supporting the Australian Code for the Responsible Conduct of Research* (National Health and Medical Research Council, 2019), 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. hardcopies will be shredded into confidential waste, electronic copies will be irretrievably deleted). NHMRC, 2019. *Management of Data and Information in Research A guide supporting the Australian Code for the Responsible Conduct of Research*. Australian Government, Canberra

- Which of the parties will hold the linked research dataset, or the process for disclosing each party's component of the linked research dataset to the research team;
- The conditions of use for the linked research dataset—i.e., will the linked research dataset be used in one research project only, or used initially in a research project and preserved for use in future projects;
- Any additional requirements identified by PACOP; and,
- Agreement on authorship of any resultant outputs.

Reporting and publication of released data

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

- a. To ensure that the data and any limitations in scope or quality of the data provided has been sufficiently understood by the user, pre-publication drafts of any derivative works are submitted to the PACOP National Director and data team for review and potential advice on data interpretation from the PACOP team.
- b. PACOP is acknowledged as the source of the data.
- c. Results are not to be presented in such a way that individuals and/or ACHs/organisations participating in PACOP could be identified unless written consent has been provided to PACOP by participating ACHs/organisations.
- d. PACOP reserves the right to negotiate with the applicant for co-authorship on any publication utilising PACOP data.

91. PACOP reserves the right to withdraw permission to publish the data as per the conditions of the *Data User Agreement*.

Data destruction and disposal

92. There are no provisions for the destruction or disposal of the data submitted by ACHs/organisations to PACOP. PACOP is an ongoing collaboration with the aged care sector with the aim to maintain the longitudinal database that is used to create sector-specific benchmarks and measure outcomes for residents receiving aged care services. This longitudinal database will grow over time to provide a valuable resource for these purposes and for the wider scientific community to conduct research into palliative aged care.

Version control and change history

Version Control	Date Effective	Approved By	Amendment
1.0	21 September 2022	PCOC/PACOP MAB	N/A

[end]