

PACOP Data Policy in Brief

Background

PACOP uses standardised clinical assessment tools to measure resident outcomes in aged care homes (ACHs). PACOP aims to systematically improve palliative and end of life care and outcomes of residents and their families. Central to the program is a framework for routine clinical assessment and a protocol to guide appropriate clinical response. This works in parallel with the opportunity for ACHs to receive feedback about outcomes from resident care for quality improvement purposes.

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

Requirements of ACHs participating in PACOP

ACHs participating in PACOP sign a registration form where they agree to:

1. Allow the de-identified information they submit to be used for reporting, benchmarking and research purposes;
2. Ensure that the data they collect are complete, accurate and meet definitions outlined in the *PACOP Data Dictionaries (Profile & Outcomes) /PACOP IT specifications*; and,
3. 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 designed to protect the privacy of individuals.

Data collection and submission

ACHs participating in PACOP may enter data into their own software or software supplied by PACOP (i.e., palCentre). If the ACHs is using their own software it is important to:

1. Ensure the software is capable of collecting all PACOP items and generating extracts in the format required by PACOP; and,
2. Update their software when required. For example, following modifications to the PACOP dataset.

The data collection protocol and information about the data items are available in the *PACOP IT specifications*.

Data are submitted to PACOP on a six monthly basis for reporting periods ending in June and December each year. Submission is via a secure file upload facility hosted by the University of Wollongong. PACOP provides guidelines for the data submission process, including timelines, detailed instructions regarding the file format required, the methodology for submitting data, and the error and quality checking processes.

Initial education about the PACOP process for entering data into the IT system and submission is provided by PACOP, with ongoing support as required.

Data ownership

ACHs are the custodians of the original data they supply to PACOP and retain ownership of those data. De-identified information submitted to PACOP is integrated into the PACOP longitudinal database under the custodianship of the Australian Health Services Research Institute (AHSRI).

Confidentiality and privacy

As custodian of the PACOP longitudinal database, AHSRI protects the privacy and confidentiality of individuals (i.e. the resident) and ACHs/organisations participating in PACOP by adhering to the codes of practice stipulated by the University of Wollongong and relevant Acts of Parliament, including Australia's Privacy Act and the Aged Care Act.

The PACOP longitudinal database does not contain resident details such as name and address but does contain date of birth and postcode—used to derive other variables (e.g., age, SEIFA¹). Items such as date of birth and postcode are only ever reported, on request, in support of quality improvement processes to the ACH/organisation that provided the data.

Information identifying a specific ACH/organisation will not be distributed to another party unless requested and formal, written consent is provided by that ACH/organisation.

Data storage and security

Storage of PACOP data is on secure, password-protected servers located at the University of Wollongong and is managed according to the University's Information Technology Server Security Policy. Access to data is limited to staff involved in administration, management and analysis of PACOP data.

PACOP Reports

PACOP analyses the data provided by ACHs to produce a number of different reports. These include bi-annual reports to individual ACHs, a national PACOP report and state reports. State reports are only provided where sufficient ACHs are participating to ensure that individual ACHs cannot reasonably be identified.

Individual ACHs/organisations will not be identifiable in any reports, publications or presentations, unless written permission has been received by PACOP from that ACH/organisation. All reports contain aggregated data to ensure confidentiality. 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.

Research

The provision of data to PACOP and the sharing of the PACOP data is done with the intent to contribute to the generation of knowledge, improved practice and policy and is promoted, encouraged and maximised for public benefit, while also protecting privacy and confidentiality of individual residents and ACHs/organisations. The principles of security, anonymity and confidentiality are applied to all research and to requests for PACOP data for research purposes.

Information submitted to PACOP ACHs will be retained indefinitely, given that 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.

Non-identifiable extracts from the PACOP longitudinal database can be released for use in research after approval of a formal application to PACOP. The least sensitive level and number of data items practicable are released for the research.

Any reports or publications of PACOP data are reviewed by PACOP prior to submission of pre-publication drafts.

¹ Socio-Economic Indexes for Areas (SEIFA) was developed by the Australian Bureau of Statistics and ranks areas in Australia according to relative socio-economic advantage and disadvantage. The indices use information from the five-yearly Census.

Ethical Requirements

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. PACOP must provide annual reports to the HREC for continuation. Approval is required for any changes to PACOP protocols and data items which may affect the conduct of the data collection, analysis or reporting.

For more information please see the full PACOP Data Policy v1.0 available on our website [Palliative Aged Care Outcomes Program - University of Wollongong – UOW](#)