

Data Access Application

Please complete this form to request information and data from the PCOC data collection.

Guidelines for application:

- Prior to completing and submitting the application, ensure that you have read the following documents, which are both available on the [PCOC website](#)
 - *PCOC Data Policy* for information regarding use of and access to the PCOC dataset, custodianship and co-authoring arrangements
 - *PCOC Data Dictionary and Technical Guidelines* for a description of individual data items
- Determine whether you require unit record data for analysis or aggregated (summary) data
- After completing this application form please email a copy to pcoc@uow.edu.au
- Receipt of your application will be acknowledged within 10 working days
- You may be contacted by PCOC staff for clarification of your request
- If approved, data will be released following receipt of a signed User Agreement

To request aggregated data:

- Complete Sections A, B and C
- Requests for aggregated data will be reviewed initially by PCOC staff and forwarded to the PCOC Executive Directors Group for further consideration

To request unit record data:

- Complete Sections A, B, D and E
- Requests for unit record data will be reviewed initially by PCOC staff and forwarded to the PCOC Executive Directors Group for further consideration

Office use only

Application reference:

Date received:

Action required:

Section A – Project title and applicant details

1. Project Title

2. Applicants

Include details for all project personnel, including their role in the project. Attach additional pages if necessary.

Chief Investigator

Name & title:

Organisation:

Position:

Role in project:

Project Contact

Name & title:

Organisation:

Position:

Role in project:

Phone:

Work:

Mobile:

Email:

Co-Investigators

Name & title:

Organisation:

Position:

Role:

Name & title:

Organisation:

Position:

Role:

Name & title:

Organisation:

Position:

Role:

Name & title:

Organisation:

Position:

Role:

Name & title:

Organisation:

Position:

Role:

Section B – Project details

5. Does your data access application require complete project details?

Answer Yes only if your project requires access to unit record data and/or if the PCOC team has advised you to provide full project details

Yes - *please complete all questions in Section B*

No – *you only require aggregate data and have been advised that it is not necessary to provide full project details. You do not need to answer any more questions in this Section. Please complete Section C.*

6. Project Description

Please provide a concise and simple description of the project in not more than 400 words

Background

Aims

Research Design

Methods

7. Duration of project

Provide the start and finish dates for the study, including data analysis

Anticipated start date:

Anticipated finish date:

8. Cohort Description

Please describe your cohort, specifying any exclusion/inclusion criteria (e.g. "all patients in the PCOC data collection" or "patients aged over 50 years referred to a specialist palliative care service in 2015")

9. Dissemination plan

Detail how you intend to report the results of the study (e.g. publications, reports, presentations)

10. Ethics approval

Has ethical approval for this project been obtained?

Yes - *please attach the application and approval letter.*

No - *please explain below why ethical approval is not required.*

Section C – Application for aggregated data

11. Data description

Please provide draft tables of the information you require, including headings, selection criteria and statistical analyses (see example below). Attach additional pages as required.

Example table:

Referrals by age

<i>Age group</i>	<i>2014</i>		<i>2015</i>	
	<i>Female</i>	<i>Male</i>	<i>Female</i>	<i>Male</i>
18-25	No. (%)	No. (%)	No. (%)	No. (%)
26-35	No. (%)	No. (%)	No. (%)	No. (%)
36-45 etc...	No. (%)	No. (%)	No. (%)	No. (%)

12. Intended use of the information

If you did not provide full project details in Section B, please provide details here of how this information will be used and where it will be reported

Section D – Application for unit record data

13. PCOC data items: Please indicate the variables required for your study and provide relevant selection criteria where necessary. Refer to the PCOC Data Dictionary and Technical Guidelines for further information.

Variable	Tick if required	Selection criteria
Patient level data items		
Sex	<input type="checkbox"/>	
State/Territory	<input type="checkbox"/>	
Indigenous Status	<input type="checkbox"/>	
Preferred Language	<input type="checkbox"/>	
Country of Birth	<input type="checkbox"/>	
Diagnosis	<input type="checkbox"/>	
Episode level data items		
Referral Date	<input type="checkbox"/>	
Referral Source	<input type="checkbox"/>	
First Contact Date	<input type="checkbox"/>	
Date Ready for Care	<input type="checkbox"/>	
Episode Start Date (Year or Month)	<input type="checkbox"/>	
Episode Type	<input type="checkbox"/>	
Episode Start Mode	<input type="checkbox"/>	
Accommodation at Episode Start	<input type="checkbox"/>	
Episode End Date (Year or Month)	<input type="checkbox"/>	
Episode End Mode	<input type="checkbox"/>	
Accommodation at Episode End	<input type="checkbox"/>	
Place of Death	<input type="checkbox"/>	
Age group (at beginning of episode)*	<input type="checkbox"/>	
Length of episode*	<input type="checkbox"/>	
Phase level data items		
Phase Start Date	<input type="checkbox"/>	
Phase Type	<input type="checkbox"/>	
Phase End Date	<input type="checkbox"/>	
Phase End Reason	<input type="checkbox"/>	
Length of phase*	<input type="checkbox"/>	
Clinical assessments (reported at start of episode, at change in phase and at discharge)		
RUG-ADL: Mobility	<input type="checkbox"/>	
RUG-ADL: Toileting	<input type="checkbox"/>	
RUG-ADL: Transfer	<input type="checkbox"/>	
RUG-ADL: Eating	<input type="checkbox"/>	
RUG-ADL: Total*	<input type="checkbox"/>	
SAS: Insomnia	<input type="checkbox"/>	
SAS: Appetite Problems	<input type="checkbox"/>	
SAS: Nausea	<input type="checkbox"/>	
SAS: Bowels	<input type="checkbox"/>	
SAS: Breathing	<input type="checkbox"/>	
SAS: Fatigue	<input type="checkbox"/>	
SAS: Pain	<input type="checkbox"/>	
PCPSS: Pain	<input type="checkbox"/>	
PCPSS: Other Symptoms	<input type="checkbox"/>	
PCPSS: Psychological /Spiritual	<input type="checkbox"/>	
PCPSS: Family/Carer	<input type="checkbox"/>	
AKPS	<input type="checkbox"/>	

Section E - Storage and retention of data

14. Location

List all locations where the data will be stored and analysed

15. Storage of data

Please describe how the data will be stored during and after the research project

16. Security Plan

Specify the measures taken to ensure the security of information from misuse, loss or unauthorised access

17. Retention and disposal plan

Specify the period of retention of the data after completion of the project and how the information will be destroyed
