



Practice Guideline

PG 2019/12 Version No. 1.0

Data Access Request Guidelines

1 Purpose

To provide guidance regarding access to data collected by the Office of Advance Care Planning (ACP) throughout the course of business in accordance with relevant legislation including the National Privacy Principles (NPPs) and Queensland Health data management policies.

2 Scope

These guidelines apply to all parties (internal and external to the Queensland Department of Health) who request identifiable/potentially identifiable and de-identified data contained within the ADVance care planning Reporting Console (AADVARC) which includes the end-of-life preferences database.

Out of Scope

Data that will not be considered for release include patient:

- Name
- Address
- Phone number
- Medicare number
- Co-morbidities
- Unique Reference Number
- Day and month of birth
- Substitute decision-makers and medical practitioner's names and contact details
- Information accessible through other accessible platforms.

3 Related legislation

Multiple legislative instruments govern the use and disclosure of information, including the:

- *Hospital and Health Boards Act 2011*
- *Information Privacy Act 2009*
- *Private Health Facilities Act 1999*
- *Public Health Act 2005*
- *Right to Information Act 2009.*

The NPPs are included in the *Information Privacy Act 2009* and define how personal health information must be managed. In summary, the NPPs cover:

- collection of personal information (NPP 1)
- limits on use or disclosure of personal information (NPP 2)

- quality of personal information (NPP 3)
- security of personal information (NPP 4)
- information about personal information holdings (NPP 5)
- access and amendment of personal information (NPP 6, NPP 7)
- anonymity (NPP 8)
- collection and handling of sensitive personal information (NPP 9).

Identifying data collected by the Queensland Department of Health are protected by confidentiality sections within relevant legislation. These confidentiality sections stipulate the manner and circumstances in which confidential data can be released. For data to be released, legislation demands that this release be done in a manner which is not likely to enable the identification of a particular person or organisation, unless specific exemptions contained in the relevant legislation apply.

Confidential data comprises both identified and potentially identifiable (or 're-identifiable') data. Identified data includes information such as name, address etc. Although removing these key demographic elements may cause the data to be considered 'de-identified', if the data released could be used in combination with other information to identify an individual, or if a researcher knows there is a way of using the remaining information to re-identify an individual uniquely, then the information is still considered potentially identifiable.

Therefore, potentially identifiable information contains a range of items that in combination with each other contain sufficient overall detail that it is possible that some individual could be identified. In this instance, this information would be regarded as confidential, and would be protected by legislation.

4 Data request requirements

The Director of the Office of ACP reserves the right to refuse a request for data.

All applicants should discuss their data requirements with a member of the Office of ACP prior to completing their applications. This should ensure appropriate assessment to help determine whether the data request meets relevant processes.

Requests for de-identified data, such as aggregated and summary data, may not have the same requirement for formal approval as research applications. Therefore, these data may be able to be released at the convenience of the Office of ACP to Queensland Department of Health staff without the need for a formal application.

Please Note:

The Office of ACP routinely provides monthly aggregated data to individual Hospital and Health Service (HHS) ACP representatives regarding ACP document activity specific to that particular HHS.

Release of data for research purposes

When health information is required for formal research purposes, researchers are able to apply to the Queensland Department of Health for this information, via a formal research application.

Requests to access identifiable/potentially re-identifiable data for research purposes require an approval under the *Public Health Act 2005* (PHA).

For the release of confidential health information for the purposes of research, a researcher must obtain:

- Approval from a Human Research Ethics Committee (HREC),
- Approval from the relevant data custodian (to release health information), and
- Approval from under the PHA.

The Health Innovation, Investment and Research Office (HIIRO) is the central point of contact for researchers seeking advice and direction on ethical and governance issues associated with the conduct of research using Queensland Health data. All enquiries should be directed to PHA@health.qld.gov.au.

Further information and the application form can found at https://www.health.qld.gov.au/hiiro/html/regu/aces_conf_hth_info

Data requests for research purposes

Prior to submitting the PHA application to the HIIRO the researcher must email the draft application to the Office of ACP.

The application will be reviewed by the data custodian and comments or requests for more information will be forwarded back to the researcher.

Once the application is signed by the data custodian, a copy will be emailed to the researcher.

The HREC and PHA approvals/certificates should be sent to the Office of ACP.

Release of re-identifiable data

The provision of re-identifiable data will be considered by the data custodian on a case by case basis only.

This may include data for the purpose of conference presentations that don't require any interaction with an ethics committee provided the data custodian approves release of the data in these circumstances.

If there is any doubt, applicants can be directed to a chair of a HREC to seek clarification on a case-by-case basis.

5 How to apply

It is highly recommended that prior to formulating and submitting a data request application, applicants contact the Office of ACP to discuss. This will help reduce delays or rejections in the application process, which can be caused by incomplete or out of scope applications.

Researchers must consult with the Office of ACP prior to applying for ethics approval to ensure that relevant data items are available and permissible for release.

Research projects that are deemed to be in the public interest, have appropriate merit and align with the strategic direction of the Office ACP will be considered, with final approval by the data custodian and in some cases, the Director- General of Department of Health.

All applications for Office of ACP data for the purposes of research will be reviewed by the data custodian prior to approval and submission.

An Office of ACP Data Access Request form can be completed and sent to the Office of ACP email address acp@health.qld.gov.au . The application form can be found at [Appendix 1](#).

If applicable, a copy of the consent/s obtained from each re-identifiable agency e.g. individual, Residential Aged Care Facility, care provider, hospital etc must be attached to the request form.

The Office of ACP will then contact the applicant to discuss further.

6 Application and Evaluation Process

The Office of ACP has limited resources and must integrate all data request activities with normal operational requirements. This results in the prioritisation of activities and may mean that data request processing is delayed.

Depending on the nature of the request, turn-around time will vary, as data extraction can be complex and time consuming, with most requests taking a couple of weeks.

Processing Times

Notification of outcome of data request should be provided within 20 business days of receipt of application.

Provision of data for successful applications will occur according to Office of ACP schedules and workloads and the completion of all necessary approvals e.g. HREC/PHA. Reasonably requested data will be provided within 2 months from date of provision of all required fields.

The Office of ACP accepts no responsibility for any late releases of requested data.

A staff member from the Office of ACP will remain contactable for the applicant throughout the evaluation process.

7 Conditions of release of data

All data requests are considered by the Office of ACP with final authorisations provided by the data custodian. The data custodian may consult with and/or seek external advice as required.

For research projects, it is expected that at least one approved Office of ACP staff member is included as a co-investigator. The Office of ACP may choose to nominate an appropriate staff member.

The release of data will be approved only for the specific purpose stated in the request. The data custodian has the authority to approve data release with or without conditions including the right to comment on the use and interpretation of data prior to publication or to veto its use.

For any research outputs (e.g. articles, reports, conference presentations), the Office of ACP must be included in a consultative process and provided with draft documents prior to publication, with sufficient time to allow provision of feedback.

The Office of ACP must be provided with advanced notice of media releases and/or aspects that may receive media attention in relation to research that includes reference to the Office of ACP and/or its data.

Office of ACP data must only be used for the research purposes outlined in the research protocol and proposal that has been approved by the Office of ACP. Separate approval must be sought to use the data for research purposes not described in the original data request(s).

It should be noted, that where a request results in an outcome that is less than ten (<10), the result will be reported as this (<10) to avoid possibility of identification.

The data shall not be shared/presented or made public in their original or manipulated form, such as publications or presentations, without explicit consent.

Use of the same data set for a different purpose will require further approval from the data custodian or the authorised delegate.

Security Plan

Upon receipt of the requested data, the applicant must agree to:

- Not disclose or share the data to third parties or to another person who has no authority to have the data.
- Take caution in relation to the provision of data items that pose a high risk of identification because they may be used to identify specific individual, HHS, community health service or Residential Aged Care Facility.
- Protect the information and save it in a safe location to prevent unauthorised access of the data.

8 Definitions

AADVARC	An ADVance care planning Reporting Console is a custom Access database designed to support the Office of Advance Care Planning, in the consistent and efficient receipt, review and upload of advance care planning (ACP) documents to The Viewer. It provides a secure, searchable repository of patient and document data.
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Advance Health Directive	An Advance Health Directive is a legally binding document completed when a person has capacity. It provides directions about treatment in specific circumstances, general wishes and can appoint a substitute decision-maker.
Data Custodian	A position designated with overall accountability and responsibility for decision making in relation to the data set, data collection and/or application allocated and the ongoing capture, compliance, development, management, care and maintenance of data to support business needs.
End-of-life preferences database	The End of life preferences database is a de-identified central database of Queenslanders' preferences for end-of-life care, as they appear on the Statement of Choices and directions as they appear on the Advance Health Directive. This is a custom Access database designed to support the Office of Advance Care Planning, in the consistent and efficient receipt, review and upload of advance care planning (ACP) documents to The Viewer. It provides a secure, searchable repository of patient and document data.
Identifiable data	Data, whether recorded in a material form or not, that will enable a person to establish the identity of a person.
Potentially Identifiable/re-identifiable data	Data containing variables other than name and address can still be potentially identifiable if indirect identification of an individual or organisation is possible. For example data including a combination of date of birth, sex, and postcode may be identifiable if this combination of variables can uniquely identify an individual. In particularly small data sets, even a single variable such as a postcode may be an indirect identifier. If only one or more of the persons or organisations are potentially identifiable, then the full data set is considered potentially identifiable.
Statement of Choices (SoC)	The Statement of Choices (SoC) is a values-based ACP document that provides a framework for ACP discussions and a standardised tool for a person to record their wishes and choices for health care into the future. There is a Form A which is used by people who can make health care decisions for themselves and a Form B which is used for people who cannot make health care decisions on their own. This document is used in Hospital and Health services, community and residential aged care services across Queensland.

9 Associated documents

- [Data Access Request form](#)

10 Amendment History

Version	Date	Updated by	Amendments
1	Sept 2020	J Caldwell	N/A – version 1
2			

11 Practice guideline details

Practice Guideline Number

PG 2019/12

Practice Guideline Name

Data Access Request Guidelines

Policy Reference

https://www.health.qld.gov.au/_data/assets/pdf_file/0025/396052/gh-pol-279.pdf

https://www.health.qld.gov.au/_data/assets/pdf_file/0032/859604/gh-pol-469.pdf

https://qheps.health.qld.gov.au/_data/assets/pdf_file/0025/2044195/custodianship-list.pdf

Supersedes

Nil

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Approving Date

Date

Effective From

Date

Date of Last Review

N/A

Date of Next Review

Date (within next 3 year)

Data Access Request Form

Purpose

This form is to be completed when requesting data from the Office of Advance Care Planning (ACP).

Please refer to the Office of ACP "*Data Access Request Guidelines*" prior to completing this form.

The completed request form and any required supplementary material should be sent to acp@health.qld.gov.au

Applicant Contact Details	
Name:	
Position:	
Organisation:	
Email:	
Phone:	
Address:	

Type of Research
<p><i>Please indicate the purpose of the data request</i></p> <p><input type="checkbox"/> A new stand-alone project</p> <p><input type="checkbox"/> A sub-component of or related to, a previously approved project</p> <p><input type="checkbox"/> A student project (<i>e.g. forms part or all of an Honours or PhD thesis</i>) Please specify: <i>e.g. Clinical Masters, or PhD</i></p> <p><input type="checkbox"/> Other Please provide brief details:</p>
<p><i>Name of Principal Investigator</i></p>
<p>Sites or agencies involved in the research:</p> <p><i>e.g. Metro South Hospital and Health Service; Prince Charles Hospital; University of Queensland; Queensland Police Service</i></p>



Study Outline

Please provide a description of the project in plain language including background, aims, design and methodology.

Background

*Please include a hypothesis **Word limit: 250***

Aims

*Please list the aims of the study and how they relate to ACP **Word limit: 200***

Design *Word limit: 250*

Methodology *Word limit: 300*

Research Timeline

Expected Start Date:

Expected Completion Date:



Describe any ethical considerations (if applicable)

Issues may include privacy, confidentiality **Word limit: 250**

Has your project received approval from a Human Research Ethics Committee (HREC)?

- YES** If 'Yes', please attach a **copy of the ethics application** and **approval letter** from the relevant committee(s)
- NO**

HREC number

Are you applying for the release of Identifiable and/or Re-Identifiable data from the Office of ACP?

Have you completed or do you intend to complete a PHA application?

- YES** If 'Yes', please attach a **copy of the consent/s** obtained from each Identifiable and/or Re-Identifiable agency e.g. *Individual, HHS, RACF, etc*
- NO**

Benefit to the Public

Provide a brief description of how the research will directly benefit the community **Word limit: 250**

Data Request Details

Regional Scope of request

Which specific Hospital and Health Service/Hospital/Agency/RACF etc do you require information for. Have these agencies consented to the release of this information? **Word limit: 200**



Date range of request
<i>What are the earliest and latest dates of data being requested? (e.g. 1 July 2019 – 30 June 2020) Word limit: 100</i>
Data security
<i>Where will the data be stored and how will security be maintained? Word limit: 100</i>
Data Items
<i>Please Specify the Data that will be provided to the Office of ACP Word limit: 200</i>
<i>Please specify the Data that is being requested Word limit: 200</i>
Other data to be linked
<i>Outline which other databases are being accessed as part of this application Word limit: 200</i>
Is it planned to publish or present the data in the public domain?
<input type="checkbox"/> YES If 'Yes', please specify <input type="checkbox"/> NO
What are the anticipated impacts, for the Office of Advance Care Planning, of publishing/presenting the data?
<i>Specify the risks and benefits Word limit: 200</i>

Office of ACP Use ONLY

Data Custodian authorisation	
Data Access Request	Comments/Conditions
Authorised	<p>The release of data as requested above is approved subject to:</p> <ul style="list-style-type: none"> <input type="checkbox"/> right of comment by the Data Custodian on use of data and interpretation prior to publication <input type="checkbox"/> right of approval or veto of data and interpretation by the Data Custodian prior to publication <input type="checkbox"/> the conditions listed in the Office of ACP "Data Access Request Guidelines" <input type="checkbox"/> further information required (<i>specify</i>) <ul style="list-style-type: none"> <input type="checkbox"/> the following steps being completed (<i>e.g. HREC approval, PHA application/approval</i>) <ul style="list-style-type: none"> <input type="checkbox"/> other (<i>specify</i>)
Not Authorised	<p>Release of data as requested above is <u>not</u> approved. <i>Reason why the data is not authorised to be released</i></p>
Data Custodian Details	
Name	
Position	
Signature	
Date	