



**Centre of
Research Excellence**
Intervention Research in Chronic Disease
Kanyini Vascular Collaboration

Data Access and Publication Policy

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KVC Data Access and Publication Policy

Executive Summary

The Kanyini Vascular Collaboration (KVC) is a program of research which aims to improve health outcomes for Indigenous Australians with chronic disease. The KVC comprises a range of national and international projects of varying scope and size. The objectives of the KVC are to:

1. Identify systemic barriers to health care for Aboriginal and Torres Strait Islander (ATSI) people with cardiovascular disease (CVD), chronic kidney disease (CKD) and diabetes, from the perspective of the patient, their community and health care providers;
2. Use rigorous methods to develop, implement and evaluate relevant health systems and service interventions across the continuum of care for CVD, CKD and diabetes in collaboration with community-controlled primary health services;
3. Build capacity within community-controlled health services and mainstream health services to meet chronic disease needs; and
4. Establish a coherent policy agenda and strategy for dissemination.

The KVC is jointly managed by the George Institute for Global Health (The George) and Baker IDI Heart and Diabetes Institute (Baker Institute) and is collectively overseen by an Executive Steering Committee. KVC research projects are funded through a number of grants and have been conducted in partnership with Aboriginal Community Controlled Health Services (ACCHS) in urban, rural and remote NSW, QLD, NT and SA.

Data collected for KVC research projects are held in trust by the KVC, which acts as a custodian of the data. As such, the KVC recognises that Indigenous people have rights and responsibilities of ownership regarding their health and health-related information, including the right to protect and care for the use of this information, the right to determine culturally appropriate form of its reporting, and the right to grant or withhold permission from other agencies or organisations for its use. All partner ACCHS sites retain unrestricted access to data collected at their sites.

Data collected from KVC research projects may be accessed by researchers and is encouraged. This document details the KVC data access policy, which outlines the protocol of access to data by researchers and publication of data, reports and scientific papers. **Please note that some KVC projects have their own data access and publication protocols that align those projects with relevant requirements and standards specific to each project.** Further information about each of the KVC research projects and access to data for those projects is available on the KVC website www.kvc.org.au.

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KVC Data Principles

Access to KVC data is based on six principles relating to access, purpose, researchers, quality, security and dissemination, and agreement to a set of general terms and conditions.

1. Access

- 1.1 Data from all KVC research projects may be accessed by staff of KVC partner ACCHS sites, KVC partner organisations, students, researchers and collaborators who have been or are currently involved with KVC research activities to conduct analyses of KVC data with the intent to publish findings;
- 1.2 Datasets will be supplied to researchers on a CD or through a secure electronic file format.
- 1.3 Datasets will be made available within a reasonable timeframe following data collection.
- 1.4 A list of datasets available for access will be kept up to date on the KVC website.
- 1.5 Researchers will not be granted ownership of KVC datasets.

2. Purpose

- 2.1 The proposed research must be consistent with the purposes for which the data were collected and overall KVC aims and objectives.
- 2.2 The proposed research must be in line with Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, available from the NH&MRC website www.nhmrc.gov.au.
- 2.3 KVC datasets may not be accessed for any research that stands to make commercial gain.
- 2.4 The proposed research must:
 - i. be achievable using the dataset;
 - ii. be based on scientifically sound methodology; and
 - iii. satisfy any appropriate research ethics requirements.

3. Researchers

- 3.1 Researchers may apply for access to KVC datasets, subject to the following criteria:
 - i. the person has a proven history of research; or
 - ii. the person is supervised by someone with a proven history of research;
 - iii. the person has appropriate support people such as statisticians and/or analysts to help with analysis of qualitative and/or quantitative datasets, as relevant.
- 3.2 All researchers must agree to accept these obligations by adhering to the Terms and Conditions of data access outlined in this policy.
- 3.3 Researchers are required to comply with the Australian Code for the Responsible Conduct of Research, available from the NH&MRC website www.nhmrc.gov.au.

4. Quality

- 4.1 Datasets provided to researchers will be high quality, containing as much detail as possible, without compromising individual identification information.
- 4.2 Researchers must produce good quality outputs that are subject to acceptable quality assurance processes, as determined by the KVC Executive Steering Committee.
- 4.3 Researchers must have relevant ethics approvals to conduct appropriate analyses.
- 4.4 Researchers must follow any quality rules and statistical obligations stipulated in the dataset documentation supplied by the KVC.

5. Security

- 5.1 Researchers are required to maintain the security of KVC datasets by complying with relevant terms and conditions with regard to access, use, storage and disposal of datasets.

6. Dissemination

- 6.1 Researchers are required to commit to completing and disseminating research findings in a timely manner.
- 6.2 Research findings must be made publicly available and researchers are required to inform and provide copies of relevant documents to the KVC prior to dissemination of any results. This includes presentations, posters and publications.

General Terms and Conditions

Researchers who apply for access to KVC datasets are required to agree to and comply with the following general terms and conditions.

1. Agreement

- i. The Lead Researcher on the application is responsible for the research team and must enter into a Data Access and Publication Agreement with the KVC Executive Steering Committee.
- ii. The KVC dataset must only be used for the research proposal described in the Data Access and Publication Agreement.

2. Confidentiality and Security

- i. All researchers should ensure safe storage of any part of the KVC dataset. Safe storage means that data are protected from accidental or deliberate access by unauthorised people (physically or electronically). For example, datasets should be locked in a secure cabinet and passwords should be used to protect electronic data.
- ii. Researchers should not attempt to identify individuals in KVC datasets.
- iii. The Lead Researcher is responsible for informing the KVC Executive Steering Committee of any breaches in security or confidentiality.

3. Quality

- i. Researchers are responsible for the quality of all analytical outputs.
- ii. Researchers must follow any statistical obligations and quality rules stipulated in the dataset files.
- iii. Researchers are responsible for obtaining the relevant ethics approvals to conduct analyses on KVC datasets. Where researchers have been named on ethics application forms, no further action is required.

4. Outputs

- i. The Lead Researcher must agree to a reasonable timeframe for completing the research and publishing the results.
- ii. All results must clearly acknowledge the source of datasets.
- iii. The Lead Researcher must send copies of any results, publications and presentations to the KVC Executive Steering Committee within a reasonable timeframe prior to public dissemination.

5. **Progress reporting** – the Lead Researcher must provide updates of progress as stipulated by the KVC Executive Steering Committee. The frequency of progress updates will be determined on a case-by-case basis and will be dependent on the scope of the research. Each progress report must outline what was achieved over the required period of reporting, what results were disseminated, what is planned for the next required period of reporting and any changes to the current research and support team.

6. **Compliance**
 - i. In the event where researchers have not complied with aspects of the Data Access and Publication Agreement, a report will need to be submitted outlining the reasons for non-compliance.
 - ii. The KVC Executive Steering Committee will consider this report in discussion with the relevant researchers, supervisors and/or managing bodies to address the issues raised in the report and find a mutually agreeable solution.

7. **KVC website updates**
 - i. The KVC will publish a summary of the proposed research, progress updates and anticipated timeframe of completion on its website.
 - ii. The KVC will publish links to the completed research and results on its website.

Applying for Access to KVC Data

Researchers are required to complete an application process to access KVC data. It is the Lead Researcher's responsibility to ensure that the full process is followed. Access to KVC data is subject to:

- the application being approved by the KVC Executive Steering Committee;
- relevant ethics approvals being obtained; and
- a Data Access and Publication Agreement being signed between the KVC Executive Steering Committee and the Lead Researcher.

Use the checklist below to ensure that you have completed the application process before submitting.

Checklist:	
1. Read the KVC Data Access and Publication Policy.	<input type="checkbox"/>
2. Check the availability and content of the KVC dataset of interest.	<input type="checkbox"/>
3. Check whether the proposed research fits the purposes for which the data were collected (see Principle 2 – Purpose).	<input type="checkbox"/>
4. Check that the criteria for researcher access to KVC datasets are met (see Principle 3 – Researchers).	<input type="checkbox"/>
5. Contact the KVC Program Manager with any queries.	<input type="checkbox"/>
6. Complete a KVC Data Access Application Form with supporting material attached, including: <ol style="list-style-type: none"> a. CV of the Lead Researcher and the wider research team (if appropriate); b. Any relevant Ethics Committee documentation; and c. Any other relevant background material. 	<input type="checkbox"/>
7. Send the completed application form and supporting material to the KVC Program Manager.	<input type="checkbox"/>

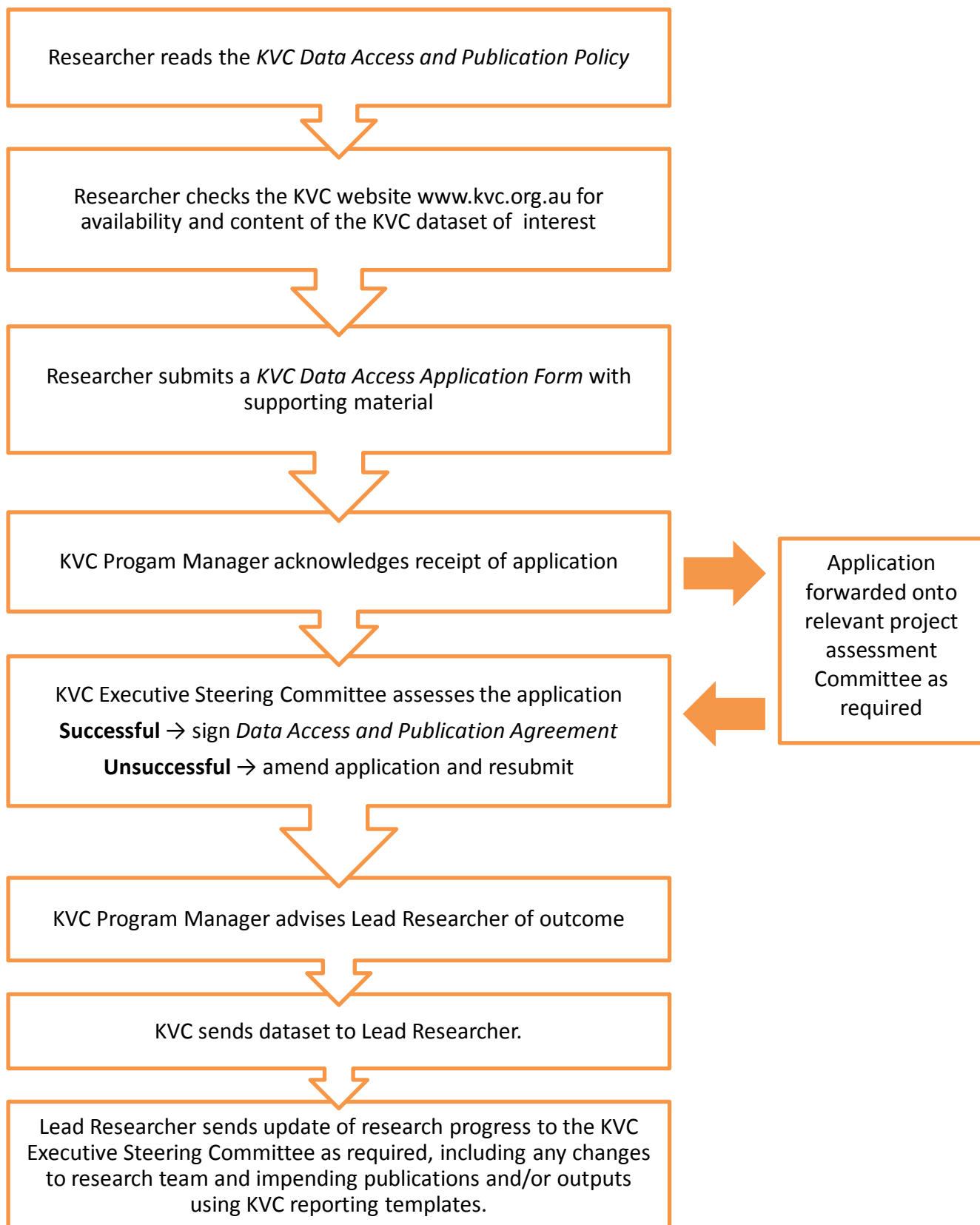
Evaluating Data Access Applications

The KVC Executive Steering Committee evaluates and assesses all applications for access to KVC data. Once an application is received:

1. The KVC Programme Manager will acknowledge receipt of application.
2. If approval is required from another body (certain data sets will require approval from a project-specific data assessment committee) the application will be forwarded to that Committee in the first instance.
3. The KVC Executive Steering Committee will assess the application against the availability of the dataset and compliance with the overall KVC data access principles.
4. The KVC Programme Manager will advise the Lead Researcher of the outcome.
5. If the application is successful, the Lead Researcher will be required to sign a Data Access and Publication Agreement with the KVC Executive Steering Committee that outlines specific terms and conditions.
6. If the application is unsuccessful, the Lead Researcher may resubmit an amended application or send a submission to the KVC Executive Committee for consideration.

A summary of the data access protocol is outlined in the flowchart below.

KVC Data Access Protocol



Submission Forms and Templates

The forms you will need to complete to access KVC data are enclosed in the following pages. The table below outlines when these forms generally need to be submitted in the process.

Data Access Application Form	To be completed when applying for access to KVC data.
Data Access and Publication Agreement	To be signed once approval for access has been gained from the KVC Executive Steering Committee.
Progress Update Template	To be completed on a regular frequency as determined by the KVC Executive Steering Committee.

KVC Data Access Application Form

There are two pages to this form. Please ensure that you have read the KVC Data Access and Publication Policy and checked the KVC website www.kvc.org.au for relevant information about the dataset(s) that you are applying for.

Lead Researcher Details (attach lead researcher's CV)

Name:			
Organisation:			
Position:			
Address:			
Email:			
Phone:		Mobile:	

Other Researcher Details (enter as relevant)

Name	Organisation	Position	Email

KVC dataset(s) this application is for (tick as relevant)

<input type="checkbox"/>	<input type="checkbox"/>	Kanyini Qualitative Study	<input type="checkbox"/> Unavailable	<input type="checkbox"/> Chronic Care Model
<input type="checkbox"/>	<input type="checkbox"/>	Kanyini Vascular Audit	<input type="checkbox"/> Unavailable	<input type="checkbox"/> HOME Study
<input type="checkbox"/> Unavailable	<input type="checkbox"/>	Kanyini Polypill Study	<input type="checkbox"/> Unavailable	<input type="checkbox"/> Stress, Depression and Chronic Disease Study

Relevant Ethics Approval (tick as relevant)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	This research has approval from an Ethics Committee
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	This research requires approval from an Ethics Committee

Please provide details of relevant Ethics Committee approval e.g. name of committee and approval number OR details of pending Ethics Committee application as relevant below.

Summary of Proposed Research

Summary of Proposed Research

Other Information (provide as relevant)

Other Information (provide as relevant)

Checklist

<input type="checkbox"/>	The Lead Researcher's CV is attached to this form.
<input type="checkbox"/>	Any relevant Ethics Committee details and documents have been attached to this form.
<input type="checkbox"/>	Any additional supporting information for this research has been attached to this form.

Please send the completed application form to the KVC Program Manager, Sharon Ponniah via email: sponniah@georgeinstitute.org.au

KVC Data Access and Publication Agreement

Researchers who apply for access to KVC datasets are required to agree to and comply with the General Terms and Conditions outlined in the KVC Data Access and Publication Policy Document. By signing the Agreement below, you confirm that you have read and understand the principles outlined in the KVC Data Access and Publication Policy Document and the General Terms and Conditions under which your research must be undertaken.

Details of your research

Lead Researcher:	
Organisation:	
Position:	
Title/Overview of Proposed Research:	
Ethics Details:	
Date of approval:	
Frequency of Progress Updates:	

Agreement

Lead Researcher Signature:	
Date:	
KVC Representative Signature:	
Date:	

KVC Progress Update Template

Please provide a one page update on the progress of your research below.

Summary of progress since last progress report

Planned progress until next progress report

Changes to original research or researchers