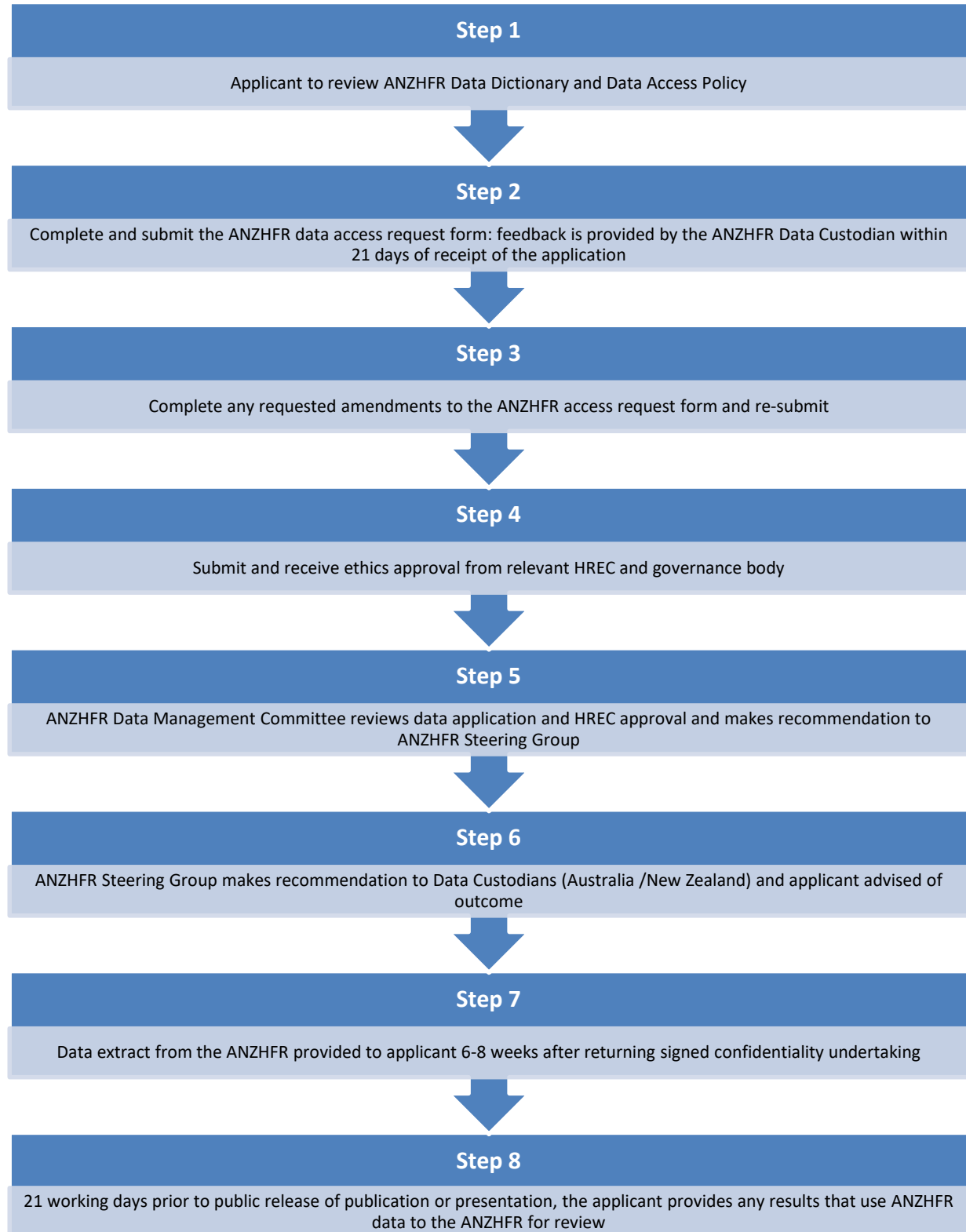


Step-by-Step Guide to Application for ANZHFR Data



Step 1: Review Data Dictionary and Data Access Policy

The current versions of the ANZHFR Data Dictionary (version 14, October 2021) and ANZHFR Data Access Policy (version 5.1, March 2021) are available from the ANZHFR website <http://www.anzhfr.org> Alternatively, they can be requested from the ANZHFR, Neuroscience Research Australia. Review both of these documents prior to submitting the request for data.

Step 2: Submit Data Access Request form

The Data Access Policy includes the ANZHFR Data Access Request Form. The form includes the list of ANZHFR variables that can be requested. Complete the form and the checklist of variables being requested and return to the ANZHFR Data Custodian, 139 Barker Street, Randwick NSW 2031 or via email clinical@anzhfr.org. The request will be reviewed and the ANZHFR Data Custodian will provide feedback to the applicant within 21 working days of receipt of the request.

Step 3: Amend the application

Based on the feedback provided by the ANZHFR Data Custodian, make any changes and re-submit the application.

Step 4: HREC and Governance approvals

All research projects must undertake appropriate applications for ethics and governance approval and provide copies of the approved documentation and approval letter(s) prior to ANZHFR data being released. Commencement of the HREC and governance applications early in the application process will help keep to a minimum the timeline for the request and data release.

Step 5: Review of request to access data

Once the application has been accepted by the Data Custodian, it will be submitted to the ANZHFR Data Management Committee for review at its next scheduled meeting. The Data Management Committee meets four (4) times per year one month prior to Steering Group meetings. Data Management Committee recommendations will be tabled at the subsequent Steering Group meeting.

Step 6: Steering Group recommendation

The ANZHFR Steering Group will make recommendation to Data Custodians (Australia/New Zealand) and will contact the applicant with the outcome of the review. At that time the ANZHFR will be able to provide a more definitive timeline for provision of the ANZHFR data. Usually, aggregated data requests take 6-8 weeks to complete after Data Custodian sign-off.

Step 7: Provision of data

Data variables will be extracted into a csv or excel file. The file will be encrypted and the file protected with a password. The file will be sent electronically to the applicant using a secure data transfer mechanism. The password to access the file will be delivered separately, via the telephone person-to-person. The applicant will use the password to open the file and then unencrypt the data in the file.

Step 8: Review by ANZHFR Steering Group

At least 21 working days prior to any publication or presentation of results that use the ANZHFR data, the applicant will provide the information to be released to the ANZHFR Steering Group. The ANZHFR must be acknowledged and there must be inclusion of a statement within the publication/presentation that the analysis and interpretation of the data is that of the applicant and not the ANZHFR.