

# DE-IDENTIFIED DATA USE AGREEMENT

<b>Project title</b>	
<b>ANZOD request ID</b>	
<b>Chief investigator</b>	

This data use agreement is between the Australia and New Zealand Organ Donation (“ANZOD”), and the investigator named above (“Recipient”), for the purposes of conducting the above research project (“Project”). It describes the conditions of use of a de-identified Limited Data Set, extracted from the Registry’s database, exclusively for the conduct of the Project.

## Permitted Uses and Disclosures

The Recipient agrees:

- To use the Limited Data Set solely for the purpose of conducting the Project
- Not to conduct additional analyses using the Limited Data Set without ANZOD’s written permission
- Not to attempt to re-identify, nor permit others to attempt to re-identify individuals or units/facilities represented in the Limited Data Set
- Not to attempt to link the Limited Data Set to any other datasets from any source without ANZOD’s written permission
- Not to release the Limited Data Set to a third party, except with the written approval of ANZOD
- To use appropriate administrative, physical and technical safeguards to prevent the use or disclosure of the Limited Data Set, other than as provided for by this Agreement
- Not to present or publish information contained in the Limited Data Set that might make an individual or unit identifiable
- To notify ANZOD immediately of any known or suspected breach of privacy arising from the use of the Limited Data Set
- To ensure that any agent, including a subcontractor, to whom it provides the Limited Data Set, agrees to the same restrictions and conditions that apply through this Agreement to the Recipient with respect to the Limited Data Set

## Publications

- The Recipient agrees to send ANZOD a copy of any publication arising from the use of the Limited Data Set
- All publications or graphic presentations using the Limited Data Set will comply with the following attribution guidelines:
  - The source of the data must be acknowledged, along with a statement that the analysis and interpretation are those of the author, not ANZOD.
  - Where a member of a participating unit has analysed data provided by ANZOD and subsequently prepared a manuscript, then "ANZOD Registry" should be acknowledged as a secondary institution in addition to the author’s Hospital or University. This applies whether the primary data analysis is performed by the author or by ANZOD staff.
  - Where the author is an ANZOD office holder or staff member then the primary attribution should be "ANZOD Registry".
  - Where ANZOD data is only a minor portion of the work, then it may be more appropriate to acknowledge the source explicitly in the "Acknowledgements" section.



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- The following disclaimer should be included in any written publication:

*The data reported here have been supplied by the Australia and New Zealand Organ Donation. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of the Australia and New Zealand Organ Donation.*

- In all cases the source and treatment of the data should be made clear in the "Methods" section. The abstract (and keywords if applicable) should preferably also include "ANZOD" to facilitate searching for Registry publications.

## Term and Termination

- The terms of this Agreement shall be effective as of the date ANZOD Registry Delegate signature below, and shall remain in effect until all data within the Limited Data Set, provided to the Recipient, are destroyed or returned to the ANZOD
- ANZOD will take reasonable steps to ensure that other investigators will not conduct analyses addressing the same research question(s) as the Project
- In return the Recipient agrees to provide ANZOD with a progress report within 12 months of data provision. The Recipient further agrees that after 6 months, if no publication has been submitted based on the Limited Data Set, ANZOD may provide other investigators with similar data. Extensions to the 6 month timeframe may be granted at ANZOD's discretion.
- The Recipient agrees to destroy, or return to ANZOD, the Limited Data Set when it is no longer required

**Signature below indicates agreement to comply with the above stated provisions**

Recipient Signature \_\_\_\_\_ Date \_\_\_\_\_

Recipient Name \_\_\_\_\_ Organisation \_\_\_\_\_

ANZOD Signature \_\_\_\_\_ Date \_\_\_\_\_

ANZOD Name \_\_\_\_\_ ANZOD Request ID \_\_\_\_\_