The LILAC Study NZ,
Te Puāwaitanga o Ngā Tapuwae Kia Ora Tonu

LILACS NZ

Policy Statement and Code of Practice for Investigators

Version 10
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1 Treaty of Waitangi

The Treaty of Waitangi is the founding document of Aotearoa, New Zealand. The principles of protection, participation, partnership and sharing articulated in the Treaty should be respected by all the investigators associated with LiLACS NZ.

The principles should be incorporated into all health research proposals associated with LiLACS NZ.

The wellbeing and rights of the LiLACS NZ’s participants should be respected in all aspects of the study.

The following documents should be recognised in the conduct of LiLACS NZ:


2 Introduction

This policy statement is written to guide the use of the data and results from LiLACS NZ and from the Feasibility Study, Living to Advanced Age (L2AA).

LiLACS NZ is a longitudinal cohort research study funded by the Health Research Council of New Zealand (HRC) and Ngā Pae o te Māramatanga, New Zealand’s Māori Centre of Research Excellence (Waves 1-3) and the Ministry of Health (Waves 4-6). It is a collaborative initiative involving a number of investigators and associate investigators (see Appendices).

The aims of the longitudinal cohort study are to: Identify predictors of successful advanced ageing by:

- Identifying and recruiting non-Māori and Māori people of advanced age (80 to 90 years old)
- Evaluate the health, social, environmental, psychological, cultural, physiological and biomedical factors
- Ascertain the relevant outcomes

3 Personnel, Roles and Responsibilities

The LiLACS NZ team includes the principal investigator, the leadership group, the co-investigators, the associate investigators, the allied staff based in the university, the project manager, Te RōpūKaitiaki o Ngā Tikanga Māori/The Protectors of Principles of Conduct in Māori Research (hereafter referred to as the RōpūKaitiaki), the sub-contractors, students and collaborators associated with the project.
3.1 Study Leadership

The principal investigator of the study is Professor Ngaire Kerse. The principal investigator leads the study and is supported by the leadership group.

- The leadership group (Appendix 1) should take responsibility for the main decision points in the study.
- The leadership group should reflect the non-Māori and Māori cohort for the study.
- The membership of the leadership group should comprise the principal investigator, research fellows and senior academics and the project manager of the two cohorts.
- The membership may change over time but should at all times represent joint leadership between Māori and non-Māori.
- For matters of major strategic importance and decisions about on-going study design (subsequent waves of follow up) the Leadership Group should consult with the wider investigator group and the RōpuKaitiaki for advice and discussion.

The Principal Investigator should:

- Maintain the scientific and ethical rigour throughout the study.
- Complete reporting requirements for the project including those to HRC, Ngā Pae o te Māramatanga, the Ethics Committees, and the Ministry of Health.
- Account for the funds awarded to the project.
- Monitor the project budget, reporting on variances and approval of invoices for payment.

The Leadership Group and the Principal Investigator should:

- Maintain the integrity and credibility of the study.
- Ensure the scholarly productivity of the study.
- Convene half yearly investigator meetings.
- Maintain positive relationships with funding agencies; clinicians and District Health Boards; General Practices; Māori organisations; the Māori sub-contractors, the users of the research; other stakeholders and others involved with the research team.
- Maintain communication between the investigators, the co-investigators, the clinicians, the Ministry of Health, the subcontractors, and the other organisations involved in the project.
- Facilitate the regulation, control, access to, and security of LiLACS NZ’s data according to the Policy Statement and Code of Practice.
- Liaise with the media to promote the project.
- Review and approve manuscripts for submission for publication.
- Ensure appropriate workforce is working on LiLACS NZ.
- Ensure adequate supervision is in place for PhD and Masters candidates working on LiLACS NZ.
Consult with and seek the opinion of the co-investigators and appropriate advisory groups before making decisions about contentious issues.

3.2 Māori leadership
LiLACS NZ is a partnership between the Māori and the non-Māori investigators.

The Māori leadership is provided by Dr Anna Rolleston and Dr Marama Muru-Lanning. They are supported by the RōpūKaitiaki.

The Māori as part of the leadership group should take a leading role to:

- Ensure the appropriateness and utility of the research processes for Māori.
- Ensure the appropriateness and utility of the research instruments for Māori.
- Ensure the security and safety of the Māori participants.
- Ensure the security and safety of the data in conjunction with the leadership group and according to the Policy Statement and Code of Practice.
- Review and approve topics for proposed investigations that involve the Māori data either as the sole or partial focus (e.g. Māori /non-Māori comparisons).
- Review and approve the applications for associate investigator status for those intending to analyse and interpret the Māori data.
- Review, analyse and interpret the Māori data and all comparisons with non-Māori.
- Review and approve the manuscripts using the Māori data prior to submission for publication.
- Determine the dissemination processes for the results of the Māori data.
- Review the data and the manuscripts using the non-Māori data to ensure that Māori values, practices, research ethics, and data are not subjugated, and are respected in accordance with the LiLACS NZ methodology and the requirement to at all times uphold te reo Māori me ngā tikanga.
- Ensure that any documents that require translating or use Māori concepts and tikanga/proper conduct are approved at the standard required and in association with the needs and requests of the Māori participants and the collaborators associated with LiLACS NZ.

3.3 Co-Investigators
There are named co-investigators in LiLACS NZ.

The co-investigators should:

- Maintain the integrity and credibility of the study.
- Maintain scientific and ethical rigour throughout the study.
- Contribute to the scholarly productivity of the study.
- Review manuscripts for submission for publication.
- Enlist researchers and students to assist with conducting or analysing research (also known as associate investigators) in line with LiLACS NZ’s...
requirements as approved by the principal investigator (and meeting the requirements outlined under Section 4.3)

A co-investigator wanting access to a LiLACS NZ primary dataset must apply in writing to the Leadership Group (*via the PI*) The application must include:

- A concept paper describing the research aims, methods and significance, the data requested, and publications planned.
- The details of any projected costs of additional research and how these costs will be met.

The proposals will be reviewed initially by the Leadership Group and circulated to the co-investigators and associate investigators.

The proposals to use the LiLACS NZ’s Māori data will be reviewed by the Māori in the Leadership Group.

### 3.4 Associate Investigators

- The associate investigators may or may not have contributed to the initial study design, methodology development or data collection.
- The associate investigators may want to analyse and/or report on the LiLACS NZ data.
- Any costs related to an associate investigator’s proposed research will not be covered by the LiLACS NZ. Funding will need to be sourced externally.
- An associate investigator applicant reports to the Leadership Group directly.
- A proposal by an associate investigator to use the LiLACS NZ data should be in writing and is described in section 4.3.
- The LiLACS NZ subcontractors are associate investigators. The LiLACS NZ subcontractors are listed in Appendix 3.

### 3.5 Other research associates

Other research associates may be other allied staff, a colleague or a student of one of the LiLACS NZ co-investigators. Their role may vary e.g. project coordinator, interviewer or data manager.

In general the research associates may if appropriate:

- Be employed on the project
- Assist the investigators to ensure the project objectives are achieved.
- Assist the investigators to fulfil reporting requirements.
- Contribute to the scholarly productivity of the study.
- Review manuscripts for submission for publication.
- Enlist researchers and students to assist with conducting or analysing research (also known as associate investigators) in line with LiLACS NZ’s requirements as approved by the principal investigator (and meeting the requirements outlined under Section 4.3)
4 Data

- The data must be kept secure and protected from access by unauthorised people.
- Data must be used for authorised purposes only.
- Data must be securely archived, and readily available to current and future investigators.
- Analysis of LiLACS NZ data should only be carried out on unidentifiable data (no names or addresses and only study IDs).
- Any research staff working with identifiable data (e.g. study staff) must sign the LiLACS NZ standard confidentiality agreement.
- The LiLACS NZ master dataset must not leave the School of Population Health building.
- Electronic copies of LiLACS NZ data must be written in a format understood by others who may obtain permission to use them.
- The whereabouts of copies of LiLACS NZ data should be fully documented.

Please see flowchart (Figure 1) of the process for access to data and return of information when completed.

Figure 1: flowchart for access to data and return of information when completed
4.1 Ownership and responsibilities for use of data

- The ownership of the LiLACS NZ data remains with the participant who provided it (primary data).
- The primary data is shared by contractual agreement, between the LILAC NZ and the subcontracting organisation through which the participant was enrolled.
- The Leadership Group has overall responsibility on behalf of the project for the guardianship and safe use of the study data (primary or secondary; as in analysed, recoded, processed).
- No person with approved access to LiLACS NZ data shall at any time provide that data to any other person or party who does not have the prior approval of the Leadership Group through the approved process.

4.2 Access to data by the Leadership Group and Co-Investigators

- The Leadership Group and the Co-investigators have access to secondary LiLACS NZ data managed and produced by the Data Manager, by direct request. Ie tables prepared for a publication, output from statistical analyses.
- Access to a dataset of primary data for analysis must follow the data release guidelines as stated in 4.3

4.3 Access to primary data

Any person wanting access to a LiLACS NZ primary dataset must apply in writing to the Leadership Group (via the PI). The application must include:

- The applicant's curriculum vitae (other than leadership group).
- A concept paper describing the research aims, methods and significance, the data requested, and publications planned.
- The details of any projected costs of additional research and how these costs will be met.

The proposals will be reviewed initially by the Leadership Group and circulated to the co-investigators and associate investigators.

The proposals to use the LiLACS NZ’s Māori data will be reviewed by the Māori in the Leadership Group.

All other co-investigators will be notified of any such proposals and invited to review or comment.

If the proposal is accepted the applicant must read the Policy Statement and Code of Practice for Investigators (this document) and the Data Release Agreement (Appendix 4) and agree to abide by the terms and conditions specified.

Data release agreement

The Data Release Agreement (Appendix 4) must be completed in all situations where LiLACS NZ data are requested by or need to be accessed by those not listed as co-investigators or if the data need to be sent to an external body; for example, any data for analysis by Masters or PhD students. The Data Release Agreement describes the
purpose for which the data extract is sought, it defines what is required, and provides the applicant’s assurance that they will act professionally and ethically. Furthermore:

- The form must be signed by both the principal investigator and the party who will be receiving the data.
- LiLACS NZ data must not be released until both parties have signed the form.
- Once signed, the original form should be given to the Principal Investigator for filing.
- A copy of the form should also be provided to the party receiving the data.

After a proposal to use the LiLACS NZ data is accepted the applicant will be allocated a study liaison person by the leadership group who should:

- Be fully involved in planning the applicant’s project, the selection and interpretation of data, and the production of report/s.
- Ensure the applicant provides brief three monthly progress reports to the research team on progress in analysis, preparation of articles, reports, newsletters or presentations.
- Ensure the applicant provides a copy of all statistical coding used in the analysis in an agreed appropriate format prior to any publication from the work.
- Ensure the applicant (and liaison person) does not have on-going access to the dataset on completion of the project, and destroys or returns the dataset to LiLACS NZ investigators.

4.4 Access to data by other users, or for purposes beyond those included in LiLACS NZ

The Leadership Group may approve access to LiLACS NZ data by other suitably qualified researchers, clinicians, teaching staff, primary care providers and international or national collaborators. The process will be that set out in Section 4.3 of this Code of Practice.

4.5 Public access to data

The LiLACS NZ data is not publicly accessible except through the procedures set out in section 4.3 of this Code of Practice.

5 Publication

There is an expectation that research that is carried out using the LiLACS NZ data will result in publications in scholarly journals, monographs, books or other appropriate report formats

- For publication, the Lead Author will refer to the Framework for the interpretation of LiLACS NZ (appended) and then circulate an abstract or summary of the manuscript to the Co-investigator and Associate Investigator group to invite co-authorship.
- A potential co-author should make a direct approach to the Lead Author and clarify the proposed contribution.
- The Lead Author is expected to consider the proposed contribution from a co-author but s/he is under no obligation to accept the input.
The interested group will then work on the paper together as appropriate.

A progress report should be submitted to the research Leadership Group regularly so that projects are completed.

The progress report will be used to provide on-going information for reports and newsletters as part of the requirements of dissemination to study participants and sponsors of outcomes achieved.

Once publication dates are known to the first author then advice of this date must be given to the principal investigator.

5.1 Authorship

LiLACS NZ upholds the international accepted Vancouver convention for authorship which emphasises that authorship credit should be based only on substantial contribution.

Participation in the acquisition of funding, the collection of data, or general supervision of the research does not justify authorship.

Others contributing to the work should be recognised in the acknowledgments, or as contributors (see for example BMJ advice for authors).

It is expected that all the authors will satisfy the authorship requirements. All papers written predominantly about the LiLACS NZ Māori data are required to appoint a Māori co-author.

The requirement does not preclude Māori co-authorship on papers focused on the non-Māori cohort.

Order of authors

The first/lead author is the person who prepares the initial draft and takes responsibility for submitting it for publication. The lead author is responsible for the final quality and content of the submission, and shall determine the order of authorship. The co-authors should be included, in order, according to the amount of their input.

Each additional author should have participated sufficiently in the work to take public responsibility for the content. For example:

- Conception and design or analysis and interpretation of data and
- Drafting or critically revising the article and
- Final approval of the version to be published.

In the event that the Lead Author is unable to take the paper through to publication, then a mutually agreeable arrangement should be made between the Lead and co-authors to complete the publication process.

5.2 Final approval of publications

All manuscripts will be circulated to the named subcontractors for information sharing and comment as appropriate. This will be done through study administrator who will circulate to the study sites and the Leadership Group.

Any paper prepared from this project for publication must be approved by the Principal Investigator. This will aid in the provision of consistency with previous and
subsequent study publications. Papers involving LiLACS NZ Māori data should in addition be approved by the Māori members of the Leadership group as set out in section 3.2.

A copy of the successful publications should be provided to the study administrator to enable the development of a collection of LiLACS NZ papers and theses for future researchers and establishment of an archive of advanced ageing research.

5.3 Presentations

It is important that LiLACS NZ is promoted and the results presented to wide audiences.

Presenting the LiLACS NZ study and associated studies at conferences or other meetings requires notification and approval the Leadership Group.

If the presentation includes results that are yet to be published, then prior approval for the use of this data from the Leadership Group is required.

5.4 Acknowledgments

When any material from the project is submitted for publication or is presented, the advisory groups, funding agencies, subcontracting organisations, individuals that supported the research and participants must be acknowledged. For example:

LiLACS NZ has been funded by the Health Research Council of New Zealand (HRC) and Ngā Pae o te Māramatanga, New Zealand’s Māori Centre of Research Excellence (Waves 1-3) and the Ministry of Health (Waves 4-6).

If appropriate the Oakley Mental Health Foundation provided a project grant for blood analyses, the Heart Foundation provided a project grant for study of cardiological aspects, the Auckland Medical Research Foundation provided a project grant for Vitamin D analyses, the Rotorua Energy Trust provided funds to promote the study.

Due acknowledgement should be made to all participants for their commitment to this study and to community organisations that facilitated the study (name of organisations) as well as those who participated, to co-authors, to subcontractors and other members of the research team as appropriate.

As long as the above acknowledgements are appropriately included, the exact wording of acknowledgements is left to the discretion of the publication or presentation’s first author.

6 Disputes

When disagreements and disputes arise in LiLACS NZ, the dispute should be referred to the Leadership Group for clarification.

Disputes involving Māori specific issues should be directed to the Māori Leadership Group who will dialogue kanohi kitea/face to face, until the dispute is resolved.

Te reo Māori me ngā tikanga will prevail in resolving disputes involving Māori.

Any dispute concerning the subject matter of this document will be settled by full and frank discussion and negotiation between the parties.
Should the dispute not be resolved satisfactorily by these means, the parties will engage in mediation conducted in accordance with the terms of the LEADR New Zealand Inc. Standard Mediation Agreement.

The principal investigator or a designated other must document, in detail, an account of the dispute and the rationale for related decisions.
Appendix 1: Leadership group

The Leadership Group should reflect joint leadership between Māori and non-Māori. The membership may change from time to time depending on project co-ordination and research fellow positions. The Leadership Group should meet frequently and, as needed, to oversee the study processes.

The 2009-2011 group that represented the principal investigator, the Māori leadership, the research fellows and the project manager roles for both the Māori and the non-Māori cohorts were:

- Professor Ngaire Kerse
- Dr. Lorna Dyall
- Dr. Mere Kēpa
- Ms. Karen Hayman

The 2012 – 2014 group that represents the joint leadership and management roles for both the Māori and the non-Māori cohorts are:

- Professor Ngaire Kerse
- Dr. Lorna Dyall
- Dr. Mere Kēpa
- Dr. Ruth Teh

The 2014 – 2016 group that represents the joint leadership and management roles for both the Māori and the non-Māori cohorts are:

- Professor Ngaire Kerse
- Dr. Anna Rolleston
- Dr. Marama Muru-Lanning
- Dr. Ruth Teh
## Appendix 2: Project Co-Investigators

<table>
<thead>
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### Appendix 3: Research Investigators

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<td>Whakatane area</td>
<td>027 738 8434</td>
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<td></td>
<td>Hine Loughlin</td>
<td>Te Rūnanga o Ngāti</td>
<td>027 755 6182</td>
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**International collaborators**

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<tr>
<th></th>
<th>Prof Tom Kirkwood</th>
<th>Newcastle University Institute for Ageing and Health</th>
<th><a href="mailto:Tom.Kirkwood@newcastle.ac.uk">Tom.Kirkwood@newcastle.ac.uk</a></th>
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<tr>
<td></td>
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<td></td>
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**Indigenous collaborators**

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<th></th>
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<th><a href="mailto:mecashk@alulike.org">mecashk@alulike.org</a></th>
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<tr>
<td></td>
<td>Dr Turner Goins</td>
<td>Native American Indian</td>
<td><a href="mailto:rtgoins@email.wcu.edu">rtgoins@email.wcu.edu</a></td>
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<tr>
<td></td>
<td>Dr Jordan Lewis</td>
<td>Aleut</td>
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<tr>
<td></td>
<td>Dr Sela Panapasa</td>
<td>Tongan/Rotuman/Pacific Islander</td>
<td><a href="mailto:panapasa@umich.edu">panapasa@umich.edu</a></td>
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<tr>
<td></td>
<td>Dr Sarah Llanque</td>
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**Research associates**

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<th></th>
<th>Project Manager</th>
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<tr>
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<td>Data Quality Personnel</td>
<td>Kinny Kepa, Dale Cormack-Pearson</td>
<td><a href="mailto:k.kepa@auckland.ac.nz">k.kepa@auckland.ac.nz</a></td>
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<td></td>
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<td><a href="mailto:d.cormack-pearson@auckland.ac.nz">d.cormack-pearson@auckland.ac.nz</a></td>
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<tr>
<td></td>
<td>Study Administrator</td>
<td>Ruth Speck</td>
<td><a href="mailto:r.speck@auckland.ac.nz">r.speck@auckland.ac.nz</a></td>
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Appendix 4: Data Release Agreement

Agreement

The parties below agree that in return for the provision of data from the LiLAC Study NZ (Life and Living in Advanced Age: A Cohort Study in New Zealand) Te Puāwaitanga o Ngā Tapuwae Kia Ora Tonu, the recipient of such data,

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<th>Name of Applicant</th>
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<td>University department or organisation</td>
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agrees to keep such data in strict confidence, use them only for the purposes specified below and under the terms and conditions described herein in accordance with the LiLAC Study NZ, Te Puāwaitanga o Ngā Tapuwae Kia Ora Tonu Policy Statement and Code of Practice for Investigators.

Purposes of Data Release

It is understood and agreed that the data will be accessed only for the purposes outlined as follows:

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Please attach a brief research proposal outlining: Aims of the research, Methods, Data needed, Timeline, Significance (proposed outputs e.g. publications)
Attach your CV.
Terms and Conditions

The Applicant undertakes:

1. Not to distribute, disclose or reveal individually or group identifiable data for any reason whatsoever, to any outside party, except as provided below;
2. To disclose to LiLACS NZ any potential conflict of interest (such as a funder with commercial interests in the project);
3. To store LiLACS NZ data and documentation in a secure environment protected from access by any unauthorised person(s);
4. To follow LiLACS NZ ethical guidelines in the use of these data, including the approval from an appropriate Ethics Committee;
5. To receive approval from the Principal Investigator before making any written or verbal presentation of the results;
6. To provide regular (at least 6 monthly depending on the duration of the project) reports to LiLACS NZ on progress in analyses and preparation of articles, reports or presentations;
7. In any written or verbal presentation, to acknowledge the source of LiLACS NZ’s data and the role of LiLACS NZ, funders and/or sponsors;
8. To offer co-authorship to LiLACS NZ’s Principal Investigator and others as appropriate;
9. On completion of the work (and no later than 12 months after the LiLACS NZ data are provided), to provide documented copies of the analysis code and a summary of the results to LiLACS NZ, and to return the data to LiLACS NZ investigators as directed.

I have read the LiLACS NZ Policy Statement and Code of Practice for Investigators, and the terms and conditions described above, and agree to abide by them.
### Applicant

<table>
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<tr>
<th>Name of Applicant</th>
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- [ ] Summer student
- [ ] Master’s candidate
- [ ] Doctoral candidate
- [ ] Co-investigator
- [ ] Associate investigator
- [ ] International collaborator
- [ ] Research associate
- [ ] Other, Comment

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### Approved by authorised person on behalf of LiLAC Study NZ:

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