

DATA ACCESS POLICY: National Youth Health Surveys

POLICIES AND PROCEEDURES FOR

APPLYING TO BE AN ASSOCIATE INVESTIGATOR WITH THE ADOLESCENT HEALTH RESEARCH GROUP

# April 2011

Note: This document will be valid for 12 months at which time it will be reviewed by the Adolescent Health Research GroupTABLE OF CONTENTS

 ***Page***

1. INTRODUCTION 3

2. ROLES AND RESPONSIBILITIES 3

3. DOCUMENTATION AND SECURITY OF DATA 5

4. RESPONSIBILITIES FOR ETHNIC SPECIFIC DATA ANALYSIS 5

5. PUBLIC ACCESS TO DATA 5

6. USE OF THE SURVEY QUESTIONS AND M-CASI INSTRUMENT 6

7. THE PROJECT’S GENERAL POLICY RELATING TO PUBLICATION 6

8. AUTHORSHIP 6

9. ACKNOWLEDGEMENTS 7

10. FINAL APPROVAL OF PUBLICATIONS AND CONFERENCE ABSTRACTS 7

11. DISPUTES 8

1. INTRODUCTION

1.1 The Adolescent Health Research Group (AHRG) is a multidisciplinary team of youth health researchers based at The University of Auckland who have/will undertaken three nationally representative secondary school surveys in 2001, 2007 and 2012. These are also known as the Youth2000 National health and wellbeing survey series – Youth’01, Youth’07 and Youth’12. The AHRG aims to promote the healthy development and wellbeing of all New Zealand youth though the undertaking of scientific research that delivers high quality useable data to all stakeholders. The AHRG shared values include: consensus decision making; members commitment to whole project in addition to contributing to specialist area; an explicit focus on a strengths-based ecological approach that is holistic and encourages work that crosses different domains.

1.2 This document is the project policy document that identifies the process of applying to be an associate investigator in order to conduct analyses or undertake a project utilising data from the national youth health surveys. This document also describes the conduct, roles and responsibilities of associate investigators, the safe-keeping of the data, use of the data in analyses and issues concerning publication and authorship. All AHRG members and associate investigators are expected to abide by this policy.

1. ROLES AND RESPONSIBILITIES

The AHRG provides guardianship or kaitiakitanga for these data and has sole responsibility for its safe use. The AHRG chair and a project’s Principal Investigator(s) have responsibility on behalf of a project for the safe guardianship and use of the data (see website [www.youth.2000.a.c.nz](http://www.youth.2000.a.c.nz) for the names of the current chair and principal investigators). These data provide rich opportunities for other researchers to undertake a wide range of analyses, which the research group encourages and supports.

* 1. Who is an Associate Investigator?

These are researchers or groups who may wish to analyse and report on some of the national youth health datasets. An associate investigator may be a researcher, colleague or a student of an established study investigator.

* 1. How do I become an Associate Investigator?

 The AHRG may approve access to any data by other suitably qualified researchers who apply to use it. A person wishing to become an associate investigator should apply directly to the AHRG through the project’s Principal Investigator(s). An application to become an associate investigator to use the data, should include Data Access Proposal (DAP) describing the aims, methods, significance and publications planned and the data that is requested (Appendix 4. And 5.). A flow chart (Appendix 1.) provides guidance on this process.

* 1. What are the reporting responsibilities of the Associate Investigator to the AHRG?

The associate investigator will provide regular 3 monthly progress reports/email to the project Principal Investigator(s). A copy of all statistical coding used in the analysis must be available to the AHRG on completion of the work/project.

1. DOCUMENTATION AND SECURITY OF DATA

All electronic and paper copies and sub-sets of data must be kept secure and used only for authorised purposes. Only data that have been authorized for particular purposes should be used. Once data have been utilised for the particular purpose, all corresponding data files should be deleted by the associate investigator(s). No person with approved access to study data shall at any time provide access to the study data to any other person or party who does not have approval for access to the same data. The associate investigator must advise the Principal Investigator when the datasets and subsets of data have been deleted.

1. RESPONSIBILITIES FOR ETHNIC SPECIFIC DATA ANALYSIS

There are additional responsibilities to consider with ethnic specific data analysis and/or comparisons between ethnic groups. Ethnic specific co-investigators/co-authors should be involved in the development, analysis, interpretation and dissemination of results/information (Appendix 6.). When you need to assign a single ethnicity to a participant in analyses, the ethnic prioritisation method should be used. Maori specific data are the joint responsibility of Principal Investigator(s) and Maori co-investigators with support from the Maori advisory group. Pacific data are the joint responsibility of Principal Investigator(s), Pacific co-investigators and the Pacific advisory group. Asian data are the joint responsibility of Principal Investigator(s), Asian co-investigators and the Asian advisory group.

1. PUBLIC ACCESS TO DATA

The data are not accessible to the public except through the mechanisms set out in the AHRG Data Access Policy.

1. USE OF THE SURVEY QUESTIONS AND M-CASI INSTRUMENT

The AHRG has agreed that the questions and the methodology used by AHRG survey projects will be freely shared (although some questionnaire items may belong to other researchers and have limitations or copyrights restricting their use e.g. The Reynolds Adolescent Depression Scale).

The M-CASI technology used by the AHRG is owned by the developing company, Stream Interactive and any queries about purchasing the technology will be directed to them (see website <http://www.streaminteractive.co.nz/> ).

1. THE PROJECT’S GENERAL POLICY RELATING TO PUBLICATION

All research carried out as part of this project is expected to result in publications in scholarly journals, monographs, theses, dissertations, books or other appropriate report formats. Publication timelines will be determined for all proposed analyses. Failure to submit work for publication by agreed dates will result in review of the agreed access to data and authorship of the work. Advice of any publication date, conference abstracts or presentations must be given to the AHRG well in advance of the publication date and a copy of the final publication, abstract or presentation should be forwarded to the principal investigator/s.

1. AUTHORSHIP

In order to ensure appropriate analyses are undertaken and the safety of study participants all proposed analyses must be submitted to a project’s Principal Investigator(s) for approval by the AHRG. All papers and reports prepared for publication must also be submitted to the projects’ principal investigator for approval by the AHRG. This process will also ensure that all AHRG members have the opportunity to contribute and be authors on project publications.

Reports and scientific papers submitted for publication will generally have authors listed by name. In these cases the researcher who leads the work resulting in the submission of the work for publication will usually write the first draft of the manuscript and be the first author. All authors must meet the criteria for co-authorship (see Appendix 3.). It is the responsibility of the first author and a project’s Principal Investigator(s) to discuss authorship with all co-authors in the initial stages of a papers’ preparation. Any disputes will be referred to the AHRG chair for facilitation of resolution.

1. ACKNOWLEDGEMENTS

When submitting an article for publication or a paper for presentation it is essential that authors acknowledge advisory groups, agencies, funding bodies and individuals that supported the research.

For example: This research was supported by The Ministries of Youth Development, Health, Education, Justice, Pacific Island Affairs, Department of Labour and ALAC. We thank the participating students and schools, the project workers, and the project advisory groups for their contributions to this study. The authors also wish to thank (xxxxxxx as appropriate) for their thoughtful comments and suggestions on earlier drafts of this paper.

1. FINAL APPROVAL OF PUBLICATIONS AND CONFERENCE ABSTRACTS

In addition to all the co-authors, a project’s Principal Investigator(s) must approve any paper, report or conference abstract prepared for publication from an AHRG project before it is submitted for consideration for publication. This will ensure consistency of descriptions of methodology, consistency with past papers, appropriate authorship, etc.

1. DISPUTES

A project’s Principal Investigator(s) is responsible for ensuring the overall conduct of a project. In the first instance any project disputes should be referred to the Principal Investigator(s) for clarification. In the event of an unresolved dispute the Principal Investigator(s) will consult with the AHRG chair. The AHRG chair will facilitate resolution of the dispute and will involve other members of the AHRG and appropriate advisory groups in this process. The AHRG chair will aim to achieve a consensus outcome to the disputed issue. If this is not possible the chair will take responsibility for the final decision and will document in detail the different perspectives in the dispute and the reasons for all related decisions.

12.1 With regard to any dispute involving Maori specific issues the Maori co-investigators will inform and seek the advice of the Maori advisory group. This advice shall be forwarded to the Principal Investigator(s) and AHRG chair who shall work conjointly with the Maori co-investigators to resolve the dispute.

12.2 With regard to any dispute involving Pacific specific issues the Pacific co-investigators will inform and seek the advice of the Pacific advisory group. This advice shall be forwarded to the Principal Investigator(s) and AHRG chair who shall work conjointly with the Pacific co-investigators to resolve the dispute.

12.3 With regard to any dispute involving Asian specific issues the Asian co-investigators will inform and seek the advice of the Asian advisory group. This advice shall be forwarded to the Principal Investigator(s) and AHRG chair who shall work conjointly with the Asian co-investigators to resolve the dispute.

 **APPENDIX 1.** – DATA ACCESS PROPOSAL FLOW CHART

Develop a proposal in accordance with the DAP (Data Access Policy)

**NOT ACCEPTED**: The proposal is not accepted.

Feedback is given to the applicant about alterations/amendments to their proposal or reasons for application decline.

Every effort will be made to ensure that feedback is supportive and encourages an appropriate re-submission. A meeting may be called to facilitate re-submission and discussion.

**ACCEPTED**: The proposal is accepted and a liaison co-investigator will be assigned to the Associate Investigator.

Any other issues raised and co-investigators who are interested in participating in the project will be discussed.

It is the responsibility of the Associate Investigator to organise a meeting of all interested parties and keep them involved during this process.

Principal Investigator will contact the applicant to discuss the outcome of the review.

Principal Investigator(s) will distribute the proposal to the biostatistician for consultation and then to the Adolescent Health Research Group for review.

Submit proposal to Principal Investigator(s)

**APPENDIX 2.** Guidelines for using national youth health data for manuscripts, reports and conference presentations/abstracts (2001, 2007, 2012)

Proposal submission in accordance with DAP guidelines and flowchart (Appendix 1.)

All successful/ accepted manuscripts should be forwarded to the Principal investigator(s) and project team with a copy of final proof.

\*Any rebuttals for peer reviewed journals should be discussed with project team.

After final sign-off by AHRG, submit manuscript, report or conference presentation/abstract as per authorship guidelines (Appendix 3.).

Finalised version of manuscript, report or conference presentation/abstract to project team for feedback and final approval.

If project has ethnic specific analysis, then appropriate co-investigators will participate in the analysis and interpretation.

Ethnic specific co-investigators (Māori: Sue Crengle and Terryann Clark, Pacific: Tasileta Teevale, Asian: Shanthi Ameratunga).

Liaison co-investigator will be assigned to assist in project.

Project team meet to discuss project and responsibilities. (Associate investigator, liaison co-investigator, AHRG co-investigators +- ethnic specific investigators).

This may occur several times where appropriate.

Data analysis and interpretation in consultation with consultant biostatistician (Elizabeth Robinson).

**APPENDIX 3. Authorship**

Authorship

Consistent with academic journals the research group adopts the following authorship policy:

Each author should have participated sufficiently in the work to take public responsibility for the content. Authorship credit should be based on substantial contributions to: (a) conception and design or analysis and interpretation of data; and to (b) drafting the article or revising it critically for important intellectual content; and on (c) final approval of the version to be published. Conditions (a), (b) and (c) must all be met. Participation solely 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 Acknowledgements.

**APPENDIX 4. Youth2000 Data Access Proposal (DAP)**

**Adolescent Health Research Group**

Lead Author(s)

Data of submission to PI

Proposed Title

Research questions to be addressed or study objectives

Background (brief overview of the literature, gaps in the literature that this proposed manuscript will fill importance of topic etc)

Proposed co-authors

Proposed analyst(s)

Type of publication (full publication, abstract, presentation at conference, thesis, other)

Will this work result in a manuscript for a peer reviewed journal? YES/NO

Proposed outlet (Journal [first and second choices] or conference name)

Proposed timeline (analysis, first draft, second draft, review by others, submission)

Variables to be used in paper (from data dictionary)

Analytic methods proposed

**APPENDIX 5. Example of a DAP**

Family Meals and Wellbeing among NZ young people

**Lead Author(s):** Jennifer Utter

**Data of submission to AHRG:** 29 June 2010

\*This DAP is submitted to fulfil the requirements of a Families Commission research project. Investigators of the original grant application were myself, Simon, Elizabeth, Terry, Shanthi and Sue Grant.

**Research questions to be addressed or study objectives:**

1. To describe the prevalence of young people who ate meals with their family in the previous week.

2. To describe the demographic characteristics (age, sex, ethnicity, nzdep) and household characteristics (who young people live with, family size, number of homes, parental figures) of young people who share meals with their families.

3. To describe the relationship between family meals and family connection and parental monitoring.

4. To describe the relationship between family meals and dietary indicators, health and wellbeing indicators, and risk taking behaviours among young people, and to determine if these associations are significant while controlling for demographics and family connection/ monitoring variables.

*Family connection (scale)*

Fun with family (home11)

Get along (home12)

Relationship with family (home13)

Relationships with mum and dad (home14 and 16)

*Parental monitoring (scale)*

Family wants to know where you are (home19)

Parents knowledge of student (home18)

Friends come to students house (home23)

Dietary indicators Fast food consumption (food5)

Food availability at home (food9)

Fruit and vegetable consumption (food10)

Parental support for healthy eating (food13,15)

*Health and wellbeing indicators*

Overweight/ obesity

Unhealthy weight loss behaviours (food26, 29)

WHO wellbeing index

Depression (RADS)

Risk‐taking behaviours

Current cigarette use

Binge drinking

Current marijuana use

Inconsistent contraception use

Suicidal thoughts

**Background:**

Family meals provide a forum for all family members to regularly spend time together, discuss family issues, and role modelling and monitoring of family member behaviours. Furthermore, family meals also provide a forum for the provision and sharing of healthy foods. A growing body of international research suggests that the health and social outcomes for children and young people are better among those who regularly eat meals with their families. Yet, data from Youth’07 suggests that fewer than 60% of young people in

New Zealand eat a meal with their family most nights of the week. A growing body of research is emerging to suggest that regular family meals provide an

important, protective benefit for children and young people with regard to a number of health and social outcomes. Reports of studies conducted in the US have documented that adolescents who eat meals with their families are less likely to use alcohol, tobacco or marijuana, less likely to be depressed or experience problems at school, less likely to adopt unhealthy weight control behaviours, and more likely to have better nutrition and eating patterns. A Japanese study has found that sharing family meals was associated with lower rates of obesity and adequate sleep for children and adolescents. Furthermore, many of these studies have been longitudinal studies which have demonstrated some of these benefits over a five year period.

The overall aim of the proposed study is to determine how participation in family meals is associated with a range of important health and social benefits for children and young people.

**Proposed co‐authors:**

Simon, Elizabeth, Shanthi, Terry and Sue Grant were all co‐investigators on the Families Commission grant application.

Other members in the Adolescent Health Research Group may be interested

**Proposed analyst(s):**

Jennifer Utter, in consultation with Elizabeth

**Type of publication:**

Full publication(s) in peer‐reviewed journal(s)

Report for Families Commission

**Proposed outlet:**

Journal of Adolescent Health

Public Health Nutrition

**Proposed timeline:**

July – initial analyses

August/ September – prepare manuscript revisions and feedback on manuscript

October – submission of article for peer‐review

November/ December – preparation and submission of final report to FC

**Variables to be used in paper:**

Family meals (food8)

As noted above:

Demographics

Household characteristics

Family connection

Parental monitoring

Dietary indicators

Health and wellbeing indicators

Risk taking behaviours

**Analytic methods proposed:**

The prevalence of young people who share meals with their families will be presented as weighted frequencies with 95% confidence intervals. Chi‐square tests will be used to determine statistically significant differences (p<0.05) between demographic and household characteristics and frequency of family meals. The independent association between family meals and family connection/ monitoring will be estimated while adjusting for age, sex, and ethnicity of the students. Multiple regression models will be used to determine the associations between family meals and student dietary indicators, health and wellbeing indicators, and risk‐taking behaviours while controlling for age, sex, NZDep, ethnicity, and parental connectedness/ monitoring.

**APPENDIX 6.** Adolescent Health Research Group (AHRG) guidelines for using ethnicity data

On the 9th June 2009, Elizabeth Robinson, Shanthi Ameratunga, Sue Crengle and Terryann Clark met as a sub-group of the Adolescent Health Research Group to discuss principles of ethnic specific analysis utilising the youth health data (Youth2000 & Youth’07).

This document is based on current best practice for ethnic specific analysis within the Adolescent Health Research Group.

1. All ethnic specific analyses must be conducted under the guidance and support of the ethnic specific co-investigators within the AHRG. The AHRG co-investigators will give recommendations for amendment where necessary and have the ability to recommend that the research does not proceed should there be any serious concerns about the analysis and its interpretation.
2. Analyses that present/and or compare ethnic specific data for the 5 major level-one ethnic groups (Māori, Pakeha/NZ European, Pacific Island, Asian, Other) will use the Statistics New Zealand Prioritisation Methods (Statistics New Zealand, 2005).
3. When reporting exclusively on an ethnic specific area (e.g. Asian or Pacific students), total ethnic reporting is appropriate.
4. Ethnic comparisons will typically be between the ethnic group of interest and Pakeha/ NZ European (the NZ European group defined by the prioritisation method).
5. All ethnic specific analyses should consider socio-economic factors in the analyses.

For further reading and information:

<http://www2.stats.govt.nz/domino/external/web/carsweb.nsf/55d63ae38ba3a25e4c2567e6007f6686/35d9b7e17a1d6151cc25701100031353?OpenDocument>

<http://www.stats.govt.nz/NR/rdonlyres/F9967810-E15B-4D28-A8E3-DBAD6B80954C/0/UnderstandingWorkingEthnicityData.pdf>

Lang, K (2001). [*Review of the Measurement of Ethnicity – Policy Perspectives Paper*](http://www.stats.govt.nz/NR/rdonlyres/35EE9E8F-0098-437D-B345-4290AC274A2B/0/policymain.pdf), Statistics New Zealand, Wellington.

Statistics New Zealand (2004). [*Report of the Review of the Measurement of Ethnicity*](http://www.stats.govt.nz/NR/rdonlyres/330AC1F7-72DB-4CDA-A8ED-C29E7BB03DDD/0/RME2004.pdf), Statistics New Zealand, Wellington.

Statistics New Zealand (2005). The Statistical Standard for Ethnicity 2005, Statistics New Zealand, Wellington.

Statistics New Zealand (2005). The Standard Classification for Ethnicity 2005, Statistics New Zealand, Wellington.