

# Data Access Policy for

Youth19

Nov 2019

## PURPOSE OF THE DOCUMENT

This document provides background and identifies the process of applying to use Youth19 data. This is based on the AHRG Data Access and Policies document from previous Youth2000 surveys.

The AHRG Data Access and Policies document for access to previous Youth2000 survey data is available from [Youthresearch@auckland.ac.nz](mailto:Youthresearch@auckland.ac.nz). The processes are very similar and where you propose to use both sets of data we can ensure this is co-ordinated.

## BACKGROUND

**The Adolescent Health Research Group (AHRG)** is a multidisciplinary collaboration of youth & wellbeing health researchers who come together to carry out high quality research to support youth health and development in Aotearoa / New Zealand and beyond. Our main activity has been the Youth2000 survey series, a series of comprehensive, scientifically rigorous adolescent health and wellbeing surveys, involving over 36,000 adolescents over two decades as shown:

1998/9	Adolescent Health Research Group (AHRG) formed
2000	Alternative Education (AE) survey, Northern region, 268 adolescents
2001	High school student survey 'Youth2000', National survey of 9699 adolescents
2006	Teen parent survey, Northern region, 220 adolescents
2007	High school student survey 'Youth07', National survey of 9107 adolescents
2007	School Climate survey (staff and school environments)
2009	AE survey, Northern region, 335 adolescents
2012	High school student survey, 'Youth12', National survey of 8,500 adolescents
2012	Kura kaupapa Maori survey
2012	School Climate survey (staff and school environments)
2019	Youth19 Rangatahi Smart Survey, (in progress as of 2019) adolescents (7750 high school and kura students with further AE students and adolescents not in Education Training or Employment being surveyed at the time of writing).
2019	School Climate survey (staff and school environments)

**Youth19** is our most recent survey. Youth19 samples adolescents from Auckland, Northland and Waikato regions (the "Northern region" of New Zealand), this large area includes approximately half of the Aotearoa/ NZ youth

population and is the most culturally diverse section of the country. Youth19 is a key activity from two HRC funded research projects ([www.youth19.ac.nz](http://www.youth19.ac.nz)):

- Harnessing the Spark of Life. PI, Terryann Clark; investigators Sonia Lewycka; Jade La Grice; Matt Shepherd; Shiloh Groot
- Smart Survey. PI, Terry Fleming; investigators Roshini Peiris-John, Sue Crengle, Dave Parry

It also includes a school environment survey led by Dr's John Fenaughty and Roshini Peiris-John.

**The AHRG members and Youth19 investigators** are listed in Appendix One. Youth19 investigators have responsibility with the funders (HRC) for the Youth19 data, while the AHRG has guardianship or kaitiakitanga for all other Youth2000 data. The AHRG and the Youth19 investigators work closely together.

## **ACCESSING YOUTH19 DATA**

To request to use Youth19 data contact [Dr Terry Fleming directly](mailto:Dr.Terry.Fleming@vuw.ac.nz) ([terry.fleming@vuw.ac.nz](mailto:terry.fleming@vuw.ac.nz)) or via [Kylie Sutcliffe](mailto:kylie.sutcliffe@vuw.ac.nz) ([kylie.sutcliffe@vuw.ac.nz](mailto:kylie.sutcliffe@vuw.ac.nz))

and:

- 1) Express your interest and arrange to discuss the fit with the group priorities and available data.
- 2) Develop a Data Access Proposal (DAP) describing the aims, methods, significance and publications planned and the data that is requested (as shown in Appendix Four, with two example DAPs in Appendix Five). Where this includes prior Youth2000 series data it goes to the full AHRG for review. Where this includes Youth19 data only, it is approved, adjusted or declined by the Youth19 investigators and then the AHRG are invited to contribute.
- 3) If your DAP is approved, you will be provided with a letter of agreement and a named contact person. On your agreement to the letter, data will be provided within conditions including those below.

### **Conditions of data use:**

#### **a. Progress reports and discussion of findings:**

- i. Those granted access to data will provide regular progress reports/email to the agreed contact person (usually these are 3 monthly)
- ii. A copy of all statistical coding used in the analysis must be available to the research group.
- iii. Draft analyses and key discussion points must be reviewed with all co-authors and the agreed contact person prior to submission
- iv. Please notify the agreed contact person of all presentations and publications so we can track these outputs

- v. We request that you present your final findings to the AHRG. (e.g. presentation to a meeting and a brief email summary and link to full text)

**b. 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. 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 researcher must advise the Principal Investigator or named contact person when the datasets and subsets of data have been deleted.

**c. Responsibilities for ethnic specific data analysis**

There are additional responsibilities to consider with ethnic specific data analyses 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 Two). When you prepare your DAP you will need to specify how you will do this and the processes to be used.

**d. Responsibilities for other minority group analyses**

There are additional responsibilities to consider in relation to research specifically reporting on groups that have previously been pathologized in research, including gender, sexuality, and sex diverse young people, and young people with disabilities. People with expertise in these areas should be involved in the development, analysis, interpretation and dissemination of results/information where such identities are an analytic focus. When you prepare your DAP you will need to specify how you will do this and any additional support you will require.

**e. Publication**

Research carried out as part of this project is expected to result in publications in academic and/or policy and community friendly formats. Publication timelines will be agreed 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.

All publications must discuss participants and their communities with respect

Publications are expected to contribute directly or indirectly to improving health outcomes. We request you provide a plain language commentary, a friendly brief outline or similar to ensure outputs can easily be shared with multiple stakeholders. This may be as simple as a plain language summary that can introduce your paper on our website or a blog, or as complex as a video, infographic or report. Please discuss this with your contact person.

**f. Authorship**

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 standard criteria for co-authorship. It is the responsibility of the first author and the contact person to discuss authorship with co-authors, both in the initial stages of a paper's preparation and as outputs are completed and author lists are finalised. We recommend keeping a simple list of author contributions and then finalising the author list based on this in agreement with your contact person.

**g. Acknowledgements**

When submitting an article for publication or a paper for presentation it is essential that authors acknowledge groups, agencies, funding bodies and individuals that supported the research. Youth19 is funded by the Health Research Council of New Zealand. Example wording will be provided via your contact person.

**h. Final approval of publications including conference abstracts**

In addition to all the co-authors, a project's Principal Investigator(s) or their nominee must approve any paper, report or conference abstract before it is submitted. This will be arranged via your contact person. This is to ensure consistency of descriptions of methodology, consistency with past papers, appropriate authorship, etc.

**DISPUTES**

The Youth19 Principal Investigators (Terryann Clark and Terry Fleming) are responsible for ensuring the overall conduct Youth19. In the first instance, any project disputes should be referred to either one or both of them. In the event of an unresolved dispute they will consult with the research group. The Principal Investigators retain responsibility for the final decision and will document in detail the different perspectives in the dispute and the reasons for all related decisions.

## **APPENDIX ONE. AHRG members and Youth19 Investigators**

**The AHRG** is a multidisciplinary team of youth health researchers. As of 2019, the AHRG includes:

1. AP Terryann Clark (Co-Principal Investigator (PI) Youth19, PI Youth12; UOA)
2. Dr Terry Fleming (Co-PI Youth19; VUW)
3. AP Simon Denny (PI Youth07, PI school environment surveys Youth07 and Youth12)
4. Dr Roshini Peiris-John (Co-PI school environment survey Youth19)
5. AP Sue Crengle (Otago)
6. AP Melody Oliver (UOA)
7. Dr John Fenaughty (UOA, Co-PI school climate survey Youth19)
8. Dr Jemaima Tiatia-Seath (UOA)
9. Dr Jennifer Utter
10. Dr Pat Bullen (UOA)
11. Dr Mathijs Lucassen (Open University, United Kingdom)
12. Dr Kelsey Deane (UOA)
13. Dr Sonia Lewycka
14. Dr Jude Ball (Otago)
15. Dr Lara Graves (UOA)
16. Kylie Sutcliffe (VUW)
17. Lovely Dizon (UOA)
18. Kristy Kang (UOA)
19. Dr Bridget Farrant (UOA)

The Youth19 investigators

Terry Fleming (Co-PI), Terryann Clark (Co-PI), Roshini Peiris-John, Sue Crengle, Lara Graves, Sonia Lewycka, John Fenaughty in collaboration with the AHRG.

**The Youth19 survey is funded by the Health Research Council of New Zealand**

## APPENDIX TWO

This document is based on current best practice for ethnic specific analysis using guidelines by the Adolescent Health Research Group and others.

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, Pākehā/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 as per Ministry of Health data ethnicity protocols (MoH, 2017).
4. Ethnic comparisons will typically be between the ethnic group of interest and Pākehā/ 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:

Ministry of Health. (2017). HISO 10001:2017 Ethnicity Data Protocols. Wellington: Ministry of Health. <https://www.health.govt.nz/publication/hiso-100012017-ethnicity-data-protocols>

Didham, R., & Callister, P. (2012). The effect of ethnic prioritisation on ethnic health analysis: a research note. *The New Zealand Medical Journal (Online)*, 125(1359), 58. <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2012/vol-125-no-1359/view-didham>

Cormack, D. & Robson, C. (2010). Classification and output of multiple ethnicities: issues for monitoring Māori health. Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare. <https://www.fmhs.auckland.ac.nz/assets/fmhs/Te%20Kupenga%20Hauora%20Māori/docs/classification.pdf>

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

### **APPENDIX THREE: 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 FOUR. Youth19 Data Access Proposal (DAP)**

Lead Author(s)

Data of submission

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 FIVE. Example DAPs**

### **EXAMPLE DAP 1**

Lead Author(s): Aravinda Guntupalli with Mathijs Lucassen

Co-authors include TC, Brigit Farrant, RPJ and JF

Data of submission to PI: 24 October 2019

Proposed Title: The wellbeing of sexual and gender minority youth with long term health conditions in Northern New Zealand

Research questions to be addressed or study objectives:

- To establish the overall general health status and prevalence of long-term health conditions of sexual and gender minority youth compared to cisgender heterosexual youth (cis-heterosexual for brevity);
- To explore the impact these long-term health conditions have on the functioning of sexual and gender minority youth, compared to cis-heterosexual youth;
- For sexual and gender minority youth as well as cis-heterosexual youth with long-term health conditions explore their access to and utilisation of healthcare and their service user experience.

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

Long-term health conditions are challenging for the young people that have them and require regular clinical monitoring and adequate health care provision. These conditions are known to make young people feel different physically and socially to their peers, and those with these conditions grapple "...constantly with balancing the dilemma of feeling and acting normal or feeling, being and revealing difference" (p. 63) [1]. Like young people with long-term conditions, sexual and gender minority youth must also cope with the challenges linked to being different to the majority, as well as whether they should disclose their sexuality and/or gender identity to others. Despite these similar tensions, little is known about the prevalence and experiences of the sexual and gender minority youth that also have a long-term health condition (such as depression, asthma, diabetes and epilepsy). To date Meyer's minority stress model has been widely cited to explain the elevated rates of issues for sexual and gender minority people [2]. According to this model, the mistreatment and resulting distress that sexual and gender minority people experience is what increases their risk for a range of negative health outcomes, including being at an increased risk of having a long-term health condition.

It is important to note that despite challenging environments, most sexual minority youth in New Zealand (including those questioning their sexuality) report good general health, liking school and having caring friends, additionally many contribute to their communities through volunteering [3]. However difficulties persist, with earlier Youth'2000 results from Youth'01, Youth'07 and Youth'12 highlighting that sexual minority youth were less likely to rate their general health as good (OR 0.46, 95% CI 0.39–0.53) compared to their exclusively opposite-sex attracted peers [3]. Sexual minority youth (specifically young people attracted to the same sex or both sexes) also appear to be more likely to have a long-term health problem or condition, such that in Youth'12 34.0% (95% CI 27.8–40.2) of sexual minority youth reported this compared to 19.9% (95% CI 18.9–20.9) of exclusively opposite-sex attracted youth [4]. To date, population-based results in terms of the general health of gender minority youth in New Zealand has not been explored. Moreover, it is still unknown from population-based studies whether gender minority youth are more likely to have a long-term health problem or condition when compared to their cisgender (i.e. not transgender) peers. But health care access issues have been raised. For example, 39.2% of transgender students in Youth'12 indicating that they had not been able to access this when they needed it, and they were more likely to experience these access issues than their cisgender peers (OR 2.7, 95% CI 1.8–4.1) [5].

In addition to differences when sexual and gender minority individuals are compared to cisgender heterosexual individuals, there are also likely to be 'within group differences' for sexual and gender minority people. There is sparse population-based data in the field in relation to physical health and gender minority individuals, but results from the Canadian Community Health Survey of adults aged 18 to 59 who indicated their sexual identity (n=159,824) suggest such within group differences exist in terms of sexuality [6]. In particular gay men (42.1% having no conditions) and bisexual women (31.3% having no conditions) in their study were the only sexual minority groups to be significantly more likely to report chronic conditions in comparison to the heterosexual reference group [6]. Within-group differences for sexual minority adults have also been reported upon in the Netherlands, based on a survey of a random sample of patients (i.e. regular health care users) from general practices (n=9684) [7]. In this Dutch study the proportion of people with one or more chronic conditions was significantly higher among gay men (OR 1.86, 95% CI 1.06–3.28) and lesbian women (OR 1.88, 95% CI 1.05–3.37) than among heterosexual respondents [7]. Differences for bisexual women (OR 1.21, 95% CI 0.65–2.27) were non-significant when compared to heterosexual women. Whilst the prevalence of chronic diseases was significantly lower among bisexual men (OR 0.23, 95% CI 0.09–0.56) compared to heterosexual men.

The current proposed study seeks to explore the overall wellbeing of sexual and gender minority youth with long term health conditions in Northern New Zealand using Youth'19 data. The study

will be unique in that it will include both sexual and gender minority youth, and (numbers permitting) explore within-group differences amongst sexual and gender minority participants.

Proposed co-authors: Mathijs Lucassen, Terry Fleming, Terryann Clark, John Fenaughty and others from the AHRG.

Proposed analyst(s): Aravinda Guntupalli (and Mathijs Lucassen)

Type of publication (full publication, abstract, presentation at conference, thesis, other): Full publication (and conference presentation funding permitting).

Will this work result in a manuscript for a peer reviewed journal? Yes

Proposed outlet (Journal [first and second choices] or conference name: LGBT Health (impact factor 3.31)

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

Data provided by Dec 2019

First draft complete by March/April 2020

Second draft/review complete by June/July 2020

Submit by Aug/Sept 2020

Variables to be used in paper (from data dictionary):

Intro1 (*How old are you?*); Intro2 (*How do you describe yourself? I am a boy or man etc*);  
Ethn1 (*Which ethnic group do you belong to?*) [or prioritized ethnicity variable – if available];  
Gender1 (*Which of the following best describes you? Trans boy or man etc*); Gender2 (*What sex were you at birth, even if it is different today?*); Gender3 (*Have you...not gone to the doctor or other health care provider because you were worried what they might think of your gender or sex? etc*); Sex 3 (*Have you... Not gone to the doctor because you were worried they might tell others about your sexuality? etc*); Sex26 (*Who are you attracted to? I am attracted to males and females etc*); Sex40 (*Have you ever had sex? (by this we mean sexual intercourse). Only include sex that you wanted, or consented to - this does not include sexual abuse or rape*);  
Sex44 (*Are you (or might you be) transgender or gender-diverse? By this, we mean that your current gender is different from your gender at birth...*); Sex29 (*About how old were you when you first 'came out', or told people about your sexuality?*); Sex45 (*At about what age did you start to identify as transgender or gender-diverse (even if you did not know the word for it)?*);  
Sex46 (*Who have you 'come out' to, or told about being transgender or gender-diverse? (You may choose as many as you need)*); Sex47 (*Which of the following best describes your sexual orientation?*); Sex70 (*Have you ever had sex with: (Only include sex that you wanted or consented to - this does not include sexual abuse or rape.)*); NZDep [if available – otherwise

SES variable/s as applicable]; Hlth1 (In general how would you say your health is?); Hlth2 (*Do you have any long-term health problems or conditions (lasting 6 months or more) (e.g. asthma, diabetes, depression)?*); Hlth3 (*Does this health problem or condition cause you difficulty with, or stop you doing etc*); Hlth6 (*Where do you usually go for health care?*); Hlth7 (*When was the last time you went for health care (excluding looking online)?*); Hlth8 (*Which of the following places have you used for health care in the last 12 months?*); Hlth9 (*In the last 12 months, did you get a chance to talk to a doctor or other health provider privately...*); Hlth10 (*In the last 12 months, did a doctor or other health provider tell you that what you talked about with them was confidential...*); Hlth12 (*In the last 12 months, has there been any time when you wanted or needed to see a doctor or nurse (or other health care worker) about your health, but you weren't able to?*); Hlth13 (*Here are some reasons people don't get health care even though they need to. Have any of these ever applied to you?*).

Youth'19 questions will allow for a more comprehensive assessment of gender identity and sexual orientation. Depending on the number of sexual and gender minority students up to 8 categories could be used in this paper (see Table 1), categories that would include a gender diverse group and would not combine bisexual participants with monosexuals (i.e. exclusively homosexual participants), specifically:

1. Transgender & gender diverse [including those who are non-binary and not sure of their gender identity – depending on numbers this group could be further divided into trans males, trans females and non-binary – although numbers will probably not allow for this];
2. Exclusively heterosexual cisgender males [the proposed reference group for comparing all male groups];
3. Exclusively heterosexual cisgender females [the proposed reference group for comparing all female groups];
4. Bisexual cisgender males;
5. Bisexual cisgender females;
6. Exclusively homosexual cisgender males;
7. Exclusively homosexual cisgender females; and,
8. Other cisgender sexual minority individuals.

Because of the commonly cited sex differences for male and female adolescents in terms of health and wellbeing outcomes, it will be important to have male and female categories for the cisgender youth. Hence at a minimum the categories should at least be:

- Transgender & gender diverse;
- Exclusively heterosexual cisgender males;
- Exclusively heterosexual cisgender females;

- Sexual minority cisgender males [inclusive of 4 and 6 above and males from 8]; and,
- Sexual minority cisgender females [inclusive of 5 and 7 above and females from 8].

Table 1. Categories for gender identity and sexual orientation

Gender identity	Question/item	Responses	Proposed categories
A.	“How would you describe yourself” (Intro2)	<ol style="list-style-type: none"> <li>1. <i>I am a boy or man</i></li> <li>2. <i>I am a girl or woman</i></li> <li>3. <i>I identify in another way</i></li> </ol>	<ul style="list-style-type: none"> <li>• Cisgender males = A1 &amp; B2 (not asked C)</li> <li>• Cisgender females = A2 &amp; B2 (not asked C)</li> <li>• <b>Transgender &amp; gender diverse</b> = A3; or A1 &amp; B1; or A1 &amp; B3; or A2 &amp; B1; or A2 &amp; B3; or A3 &amp; B1; or A3 &amp; B3.</li> </ul>
B.	“Are you (or might you be) transgender or gender-diverse...” (Sex44)	<ol style="list-style-type: none"> <li>1. <i>Yes</i></li> <li>2. <i>No</i></li> <li>3. <i>I’m not sure</i></li> <li>4. <i>I don’t understand the question</i></li> </ol>	[excluded = B4 & C responses]
C.	[if gender diverse asked] “Which of the following best describes you?” (Gender1)	[participant can provide multiple responses and participant can’t clearly be categorised as trans boy or trans girl based on the responses provided]	
Sexual orientation	Question/item	Responses	Proposed categories
D. [sexual attractions]	“Who are you attracted to?” (Sex26)	<ol style="list-style-type: none"> <li>1. <i>The opposite sex or a different sex...</i></li> <li>2. <i>The same sex...</i></li> <li>3. <i>I am attracted to males and females</i></li> <li>4. <i>I’m not sure</i></li> <li>5. <i>Neither</i></li> <li>6. <i>I don’t understand this question</i></li> </ol>	<ul style="list-style-type: none"> <li>• <b>Exclusively heterosexual cisgender males</b> = Cisgender male [as above] &amp; D1 &amp; E1 &amp; F1 [or answered ‘no’ sex in Sex40]</li> <li>• <b>Exclusively heterosexual cisgender females</b> = Cisgender female [as above] &amp; D1 &amp; E1 &amp; F2 [or answered ‘no’ sex in Sex40]</li> <li>• <b>Bisexual cisgender males</b> = Cisgender male [as above] &amp; D3 &amp; E2 &amp; E3 &amp; E4 &amp; F1 or F2 or F3 [or answered ‘no’ sex in Sex40]</li> </ul>
E. [sexual identity]	“Which of the following best describes your sexual orientation?” (Sex47)	<ol style="list-style-type: none"> <li>1. <i>Straight</i></li> <li>2. <i>Mostly straight</i></li> <li>3. <i>Bisexual</i></li> <li>4. <i>Pansexual</i></li> <li>5. <i>Takatāpui</i></li> <li>6. <i>Gay or lesbian</i></li> <li>7. <i>I’m not sure yet</i></li> <li>8. <i>Something else, please state:</i></li> <li>9. <i>I don’t understand this question</i></li> </ol>	<ul style="list-style-type: none"> <li>• <b>Bisexual cisgender females</b> = Cisgender female [as above] &amp; D3 &amp; E2 &amp; E3 &amp; E4 &amp; F1 or F2 or F3 [or answered ‘no’ sex in Sex40]</li> <li>• <b>Exclusively homosexual cisgender males</b> = Cisgender male [as above] &amp; D2 &amp; E6 &amp; F2 [or answered ‘no’ sex in Sex40]</li> <li>• <b>Exclusively homosexual cisgender females</b> = Cisgender female [as above] &amp; D2 &amp; E6 &amp; F1 [or answered ‘no’ sex in Sex40]</li> </ul>

F. [sexual behaviour]	“Have you ever had sex with...” (Sex70) [ <u>of those who have ever had sex Sex40</u> ]	[participants can provide multiple responses]  1. <i>Females</i>  2. <i>Males</i>  3. <i>People who identify as transgender or non-binary</i>	<ul style="list-style-type: none"> <li>• <b>Other cisgender sexual minority individuals</b> = Cisgender male or cisgender female [as above] &amp; D4 &amp; E5 &amp; E7 &amp; E8 [<u>to check E8 open responses</u>] &amp; F1 or F2 or F3 [or answered ‘no’ sex in Sex40] [excluded = D5 &amp; D6 &amp; E9 responses]</li> </ul>
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Analytic methods proposed: Descriptive statistics (including numbers and percentages), bivariate analyses and multiple regression analyses.

## References

1. Lambert, V. and D. Keogh, *Striving to live a normal life: a review of children and young people's experience of feeling different when living with a long term condition*. Journal of Pediatric Nursing, 2015. 30(1): p. 63-77.
2. Meyer, I.H., *Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence*. Psychological Bulletin, 2003. 129(5): p. 674-697.
3. Lucassen, M.F.G., et al., *What has changed from 2001 to 2012 for sexual minority youth in New Zealand?* Journal of Paediatrics and Child Health, 2015. 51(4): p. 410-418.
4. Lucassen, M.F.G., et al., *Youth'12 the health and wellbeing of secondary school students in New Zealand: Results for young people attracted to the same sex or both sexes*. 2014, Auckland: The University of Auckland.
5. Clark, T.C., et al., *The health and well-being of transgender high school students: Results from the New Zealand Adolescent Health Survey (Youth'12)*. Journal of Adolescent Health, 2014. 55(1): p. 93-99.
6. Tjepkema, M., *Health care use among gay, lesbian and bisexual Canadians*. Health Reports, 2008. 19(1): p. 53-64.
7. Bakker, F.C., et al., *Do homosexual persons use health care services more frequently than heterosexual persons: Findings from a Dutch population survey*. Social Science & Medicine, 2006. 63(8): p. 2022-2030.

## EXAMPLE DAP 2

### Does vaping precede or follow cigarette smoking among New Zealand secondary school students?

**Lead Author(s):** Jude Ball & Terry Fleming with TC SC RPJ SL KS & perhaps other members of the AHRG

**Proposed Title:** Does vaping precede or follow cigarette smoking among New Zealand secondary school students?

#### Research questions to be addressed or study objectives

- What is the prevalence of smoking (frequent/regular/ever) and vaping (frequent/regular/ever) in the Youth19 sample?
- What is the prevalence of dual use (regular smoking AND regular vaping)? How is smoking, vaping and dual use patterned by sex, ethnicity, SES and rural/urban? (NOTES: Need to decide how to do this in discussion with TC & SC. Best to use adjusted ORs to look at relative differences (after adjusting for other demog factors) Note: If patterning is different for smoking & vaping, that provides an argument that vaping is appealing to a different group from smoking. O'seas studies suggest that vaping has wider appeal, including groups not at high risk of smoking)
- Among vapers:
  - o What proportion of regular/ever vapers sometimes or always use e-cigs that contain nicotine?
  - o What proportion of regular vapers have worries about vaping, want to cut down/give up, or have tried to cut down/give up?
  - o **What proportion of (regular?) vapers were NOT tobacco smokers at the time that they tried vaping for the first time?**
  - o **What proportion of ever vapers are never smokers?**
  - o **What proportion of (regular?) vapers began smoking *after* trying vaping for the first time (i.e. they were not smokers when they initiated vaping but were current smokers at the time of the survey)?**
  - o How many quit smoking after beginning vaping (i.e. they were smokers when they initiated vaping, but were not current smokers at the time of the survey)? How many had quit both smoking and vaping (i.e. they were smokers when they initiated vaping, but were not current vapers OR current smokers at the time of the survey)?
- Among smokers:
  - o What proportion of dual users have worries about smoking, want to cut down/give up, or have tried to cut down/give up?
  - o What proportion of exclusive smokers (i.e. smoke but do not vape) have worries about smoking, want to cut down/give up, or have tried to cut down/give up?

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

From a public health perspective, the advent of e-cigarettes has brought both opportunities and risks (Farsalinos, 2018). E-cigs offer an alternative nicotine delivery system with much lower health risks than combustible tobacco, so for nicotine-dependent smokers they are a potentially life-saving technology (Abrams et al., 2018). However, e-cigarettes are not risk free, and for adolescents they represent a new addition to the array of harmful substances available (US Department of Health and Human Services, 2016). Research shows that, in adolescents, e-cig use clusters with tobacco use, binge drinking, cannabis use and other risk behaviours (White et al, 2015). Longitudinal studies consistently show that adolescent vaping is associated with increased risk of subsequent combustible tobacco use (Soneji et al., 2017). However, whether this is a *causal* relationship, or due to common liability (i.e. factors that make young people vulnerable to both vaping and smoking) continues to be debated. Since e-cigarettes have only been widely available for approximately 10 years, the impacts of long term use

are still unknown. Therefore, vaping in the adolescent population (particularly among non-smokers) is of public health concern.

Although there has been ongoing surveillance of vaping prevalence in Year 10 students in NZ since 2012 (via ASH year 10 and YIS surveys) this will be the first New Zealand study to examine prevalence of e-cig use in the secondary school population as a whole. NZ research to date suggests that, in 14-15 year olds, occasional vaping is very common with a third of Year 10 students reporting having tried vaping in 2018 (ASH New Zealand, 2018). However, in this age group the majority of vaping (irrespective of smoking status) is motivated by curiosity (White, Li, Newcombe, & Walton, 2015) and regular vaping is uncommon, e.g. in 2018 only 4% reported vaping weekly or more often, and less than 2% reported daily vaping (ASH New Zealand, 2018). ASH's factsheet about Year 10 vaping tends to minimise risks to non-smokers, emphasising that: 'Fewer than 1% of Year 10 students who never smoked reported using e-cigarettes daily' and 'Students who smoke were over 4 times more likely to have tried an e-cigarette (even a single puff or vape) than students who never smoked'. ASH concludes 'Youth smoking rates continue to decline, daily use of e-cigarettes is rare and is largely confined to those who have smoked' (ASH New Zealand, 2018).

However, closer analysis puts into question the statement that vaping is 'largely confined to those who have smoked.' Although regular (weekly or more often) vaping is uncommon in never smokers (at 1.1%), never smokers are a very large group compared to smokers and actually make up over a third of regular vapers (1.1% of 23,078 in the 2018 ASH sample = 254 students). Among regular (at least monthly) smokers, regular vaping is common with 31% report vaping weekly or more often. Smokers represent approximately two-thirds of regular vapers (31% of 1,400 in the 2018 ASH sample = 430 students). Our analysis, which will report the proportion of vapers by smoking status, will provide a more transparent analysis of the extent to which vaping is an issue in non-smokers.

Importantly, it will also be the first (as far as we are aware) to investigate the proportion of adolescents who initiate e-cig use *before* tobacco use in the NZ setting. Although the sequencing of substance use does not prove causality, it would be cause for public health concern if a significant proportion of adolescents were trying vaping and then subsequently taking up combustible tobacco smoking. Longitudinal studies from overseas show that this is the case, but evidence from NZ is lacking. Conversely, if there is evidence that use of e-cigs precedes quitting of smoking in a significant proportion of adolescents, this would be good news from a public health perspective and would help to balance risks at the population level. (TC note: Think we could also highlight how this is an important information to inform strategy for Maori programming and policy since the greatest burden of smoking is Maori)

It MAY be the first NZ study to make a distinction between vaping of nicotine-containing substances, and other substances. As Merry & Bullen (2018) note 'there is no evidence about the use of nicotine e-cigarettes in adolescents' in NZ, and '[t]his will become increasingly relevant as these devices become more readily available' (p42).

Findings about whether young people have worries about their own vaping may have important public health and policy implications:

- Lack of concern among those vaping nicotine may suggest that young people have little awareness about the risk of addiction
- Significant levels of concern may indicate ambivalence/regret and suggest that greater protections are needed to prevent use and support young people to stop vaping.

**Proposed analyst(s):** Dan and or Jude With oversight from Sonia

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

Original research article

**Will this work result in a manuscript for a peer reviewed journal?** YES

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

Drug and Alcohol Review?

ANZJPH?

Journal of Adolescent Health?

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

**Variables to be used in paper (from data dictionary)**

(NB Adolescent smoking measures are typically: never/ever smoking, current ('occasional' or more often), regular (= at least monthly), and daily. However the most frequent common measure we have for both smoking and vaping is 'Once or twice a week' so JB suggests) creating 'frequent smoker/vaper' variables for reporting.

Variable name for our study	Youth19 Vars from data dictionary	Answer cats
Ever_smoked	Cig1: Have you ever smoked a whole cigarette?	Y/N
Reg_smoker	Cig4: How often do you smoke now?	<b>N = Not regular smoker:</b> Never – I don't smoke now Occasionally <b>Y = Regular smoker:</b> Once or twice a month Once or twice a week Most days Daily
Cur_smoker	Cig4: How often do you smoke now?	<b>N = Not current smoker:</b> Never – I don't smoke now  <b>Y = Current smoker:</b> Occasionally Once or twice a month Once or twice a week Most days Daily
Freq_smoker	Cig4: How often do you smoke now?	<b>N = Not frequent smoker:</b> Never – I don't smoke now Occasionally Once or twice a month  <b>Y = Frequent smoker:</b> Once or twice a week Most days Daily
Ever_vaped	ECig1: Have you ever vaped or used an e-cigarette?	Y/N
Reg_vaper	ECig2: How often do you vape or use e-cigs now?	<b>N = Not regular vaper:</b> Never Occasionally <b>Y = Regular vaper:</b> Once or twice a month Once or twice a week More than twice a week
Cur_vaper	ECig2: How often do you vape or use e-cigs now?	<b>N = Not current vaper:</b> Never <b>Y = Current vaper:</b> Occasionally Once or twice a month

		Once or twice a week More than twice a week
Freq_vaper	ECig2: How often do you vape or use e-cigs now?	<b>N = Not frequent vaper:</b> Never Occasionally Once or twice a month <b>Y = Frequent vaper:</b> Once or twice a week More than twice a week
Dual_use	Reg_smoker Reg_vaper	Y= Y to Reg_smoker AND Y to Reg_vaper
Nicotine	ECig4: When you vape or use e-cigs do they contain nicotine?	Yes, always Yes, sometimes No Don't know
Vape_worries	Drugs5: Do you worry about doing any of these things: Vaping (esp among regu users)	A lot Some A little Not at all Does not apply to me
Smoked_first	Ecig3: When you first began vaping or using e-cigs did you smoke ordinary cigarettes (tobacco)?  NB this is more important of regular vapers (not esp important for those who have tried once or twice)	Y/N
Smoked_after	Ecig3 Cur_smoker	Y = N to Ecig3 AND Y to Cur_smoker Else N
Quit_smoke	Ecig3 Cur_smoker	Y = Y to Ecig3 AND N to Current smoker
Quit_both	Ecig3 Cur_smoker	Y = Y to Ecig3 AND N to Current smoker AND N to Current vaper
Smoke_worries	Drugs5: Do you worry about doing any of these things: Smoking	A lot Some A little Not at all Does not apply to me
Excl_smoker	Cur_smoker Cur_vaper	Y= Cur_smoker = Y AND Cur_vaper = N
Demographic variables:	Age: Intro1 Sex: Intro2 Ethnicity: (Ethnic_P?) School decile NZ Dep	

	Rural/urban	
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### Analytic methods proposed

Descriptive statistics and logistic regression. Detail TBC.

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