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Foetal alcohol spectrum disorder in Aotearoa, New Zealand: Estimates of prevalence and indications of inequity

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Abstract

Introduction: Foetal alcohol spectrum disorder (FASD) is 100% caused by alcohol. The lifelong disability caused by prenatal alcohol exposure cannot be reversed. Lack of reliable national prevalence estimates of FASD is common internationally and true of Aotearoa, New Zealand. This study modelled the national prevalence of FASD and differences by ethnicity.

Methods: FASD prevalence was estimated from self-reported data on any alcohol use during pregnancy for 2012/2013 and 2018/2019, combined with risk estimates for FASD from a meta-analysis of case-ascertainment or clinic-based studies in seven other countries. A sensitivity analysis using four more recent active case ascertainment studies was performed to account for the possibility of underestimation.

Results: We estimated FASD prevalence in the general population to be 1.7% (95% confidence interval [CI] 1.0%; 2.7%) in the 2012/2013 year. For Māori, the prevalence was significantly higher than for Pasifika and Asian populations. In the 2018/2019 year, FASD prevalence was 1.3% (95% CI 0.9%; 1.9%). For Māori, the prevalence was significantly higher than for Pasifika and Asian populations. The sensitivity analysis estimated the prevalence of FASD in the 2018/2019 year to range between 1.1% and 3.9% and for Māori, from 1.7% to 6.3%.

Discussion and Conclusions: This study used methodology from comparative risk assessments, using the best available national data. These findings are probably underestimates but indicate a disproportionate experience of FASD by Māori compared with some ethnicities. The findings support the need for policy and prevention initiatives to support alcohol-free pregnancies to reduce lifelong disability caused by prenatal alcohol exposure.

KEYWORDS
alcohol consumption during pregnancy, foetal alcohol spectrum disorder (FASD), inequity Aotearoa/New Zealand, prevalence

1 | INTRODUCTION

Alcohol is a major contributor to ill health. It is responsible for 3 million deaths worldwide every year and 5% of the global burden of disease [1, 2], placing it alongside tobacco use as one of the leading preventable causes of death and disability and a focus of considerable policy attention [3]. Alcohol causes harm not only to the drinker but also has 'second-hand' effects and there is increasing attention paid to measuring the harm that alcohol causes to others. The impact of alcohol consumption on the foetus, resulting in lifelong disability, is a striking example of harm to others from alcohol products.

Foetal alcohol spectrum disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges [4]. FASD is 100% caused by alcohol and is a leading cause of preventable intellectual and neurodevelopmental disability worldwide [5]. Alcohol is teratogenic and impacts from drinking during pregnancy can be severe, irreversible and associated with considerable disability for exposed children throughout their life [6–8].

The lack of a reliable national prevalence estimate for FASD is relatively common internationally as diagnosis of FASD requires observational, behavioural, dysmorphology and neurodevelopmental testing [9]. In Aotearoa, New Zealand there are no national studies determining the prevalence of FASD using clinical diagnosis. Given the lack of active case-ascertainment studies of the prevalence of FASD internationally, the World Health Organization Global Burden of Disease Study has developed an alternative methodology [10], which has been used in meta-analyses to estimate the worldwide prevalence of FASD [11] among children and youth in the general population.

When applied in Aotearoa, New Zealand this method resulted in a pooled estimate of the prevalence of drinking during pregnancy of 26.7% (95% confidence interval [CI] 19.2%; 34.9%) and estimated the prevalence of FASD in Aotearoa, New Zealand as 2.1% (95% CI 1.2%; 3.3%) [11]. This has been the most rigorous estimate available for New Zealand (previous estimates of prevalence have ranged between 1% and 5%) [12]. However, the study used a pooled estimate of drinking during pregnancy [11] which was based on studies conducted mainly prior to 2006 and several of which had limitations such as covering only one or two regions [13–15]. Others underrepresented regions where Māori and Pasifika live [16], or had small numbers [17]. Since these studies were conducted, self-reported data on the prevalence of any drinking during pregnancy have become available from the large nationally representative samples of the New Zealand Health Survey in Aotearoa, New Zealand allowing this current study to complement previous estimates by using large national samples. This survey is currently our most robust health survey with a relatively high response rate (80%). The survey is conducted face to face, but sensitive questions including drinking during pregnancy are self-completed away from the interviewer. While this may reduce social desirability bias, known to reduce reported alcohol use in pregnancy [18], it is unlikely to eliminate it due to the sensitivity of the subject. The New Zealand Health Survey includes a large sample of Māori women, allowing for estimation of inequities in FASD for Māori compared to non-Māori in accordance with our Te Tiriti o Waitangi (founding document of Aotearoa New Zealand) partnership in Aotearoa, New Zealand.

This study aimed to estimate the prevalence of FASD in Aotearoa, New Zealand, by ethnicity, using the World Health Organization Global Burden of Disease Study methodology and prevalence estimates of drinking during pregnancy based on nationally representative survey data.

2 | METHODS

2.1 | Design

The estimate of FASD prevalence was based on the method proposed by Lange et al. [11] using standard methodology from comparative risk assessments used in the World Health Organization Global Status Reports on Alcohol and Health [19]. The estimate for FASD includes FASD with sentinel facial features, previously diagnosed as foetal alcohol syndrome, as well as FASD without sentinel facial features, previously diagnosed as alcohol-related neurodevelopmental disorder [20].

The prevalence of FASD in Aotearoa, New Zealand, was predicted by combining data on the prevalence of alcohol use during pregnancy in Aotearoa, New Zealand, and estimations of the average number of pregnant women who consumed alcohol per one case of FASD based on countries with data from case-ascertainment studies or clinic-based methods. The prevalence of FASD was calculated by applying this average to the prevalence of alcohol use during pregnancy in Aotearoa, New Zealand.

Countries with FASD prevalence estimates available from Lange et al. [11] are Australia, Canada, Croatia, France, Italy, South Africa, Norway and USA. As in Lange et al. [11] we excluded South Africa as their drinking pattern was considerably riskier than Aotearoa, New Zealand and it would have led to an unrealistic outcome. Estimates from Australia were low because the studies included in Lange et al. [11] reported foetal alcohol syndrome only.

2.2 | Data

2.2.1 | Prevalence of drinking during pregnancy

Data on the prevalence of any alcohol use during pregnancy were obtained from the Ministry of Health's New Zealand Health Survey for the years 2012/2013 ($n = 13{,}000$) and 2018/2019 ($n = 13{,}752$). The target population for the survey was Aotearoa, New Zealand's usually resident population of all ages (including those living in non-private accommodation). The New Zealand Health Survey has a multi-stage, stratified, probability-proportional-to-size sampling design using a dual-frame approach (area-based sample and electoral roll sample). Area-based sample: a sample of Statistics New Zealand's primary sampling units (PSU) are selected (probability-proportional-to-size). Households are selected from a random start point within each PSU and then one adult aged 15 years or over is randomly selected from each selected household. To increase the sample size of Māori an electoral roll sample is also used, and similar processes except the sample of PSUs is selected with probability proportional to the number of addresses on the electoral roll containing at least one person who has self-identified as having Māori ancestry [21].

The survey questionnaire was administered through face-to-face interviews, using computer-assisted personal interviewing software. Participants were adults aged 15 years and older. Response rates in 2012/2013 and 2018/2019 were 80% for each survey [21]. The calibrated weighting method was used to reduce bias due to non-response [21].

2.2.2 | Foetal alcohol spectrum disorder

Prevalence data were available for seven countries for FASD [11].

2.3 | Analysis

The prevalence of FASD was predicted by applying the quotient derived from other countries with available data, to the country-specific prevalence of alcohol use during pregnancy. The Monte Carlo method was applied to derive the CIs for the point estimates by generating 1,000,000 samples and using the 2.5th and 97.5th percentiles of the resulting distribution as the CI (for details on the methods, see Lange et al. [11]).

The prevalence of FASD was predicted by linking an estimation of the average number of pregnant women who consumed alcohol per one case of FASD based on countries with available data, to the prevalence of alcohol use during pregnancy in Aotearoa, New Zealand.

Following Lange et al. [19], the best estimator for the number of women drinking during pregnancy that led to one case of FASD ($N_{\text{drink\_woman\_F}}$) in n countries is:

$$N_{\text{drink\_woman\_F}} = \frac{\sum_{i=1}^{n} P_{\text{drink}_i} \cdot N_{\text{births}_i}}{\sum_{i=1}^{n} P_{\text{F}_i} \cdot N_{\text{births}_i}}, \quad (1)$$

where P_{drink_i} is the prevalence of mothers consuming alcohol during their pregnancy for country i, N_{births_i}, the number of births in country i, and P_{F_i} the prevalence of FASD in country i, with $i = 1,\ldots,n$. FASD prevalence point estimates for Aotearoa, New Zealand, ($P_{\text{F\_NZ}}$) were then obtained by linking the prevalence of mothers consuming alcohol during pregnancy in Aotearoa, New Zealand, ($P_{\text{drink\_NZ}}$) and the estimator $N_{\text{drink\_woman\_F}}$ as follows:

$$P_{\text{F\_NZ}} = \frac{P_{\text{drink\_NZ}}}{N_{\text{drink\_woman\_F}}}. \quad (2)$$

TABLE 1 FASD prevalence from case ascertainment population studies published 2015–2022.

Country	Canada	Poland	UK	USA
FASD prevalence	1.8%	1.9%	1.8%	1.1%
FASD prevalence less conservative	2.9%	–	3.6%	5.0%

Abbreviation: FASD, foetal alcohol spectrum disorder.

The Monte Carlo method was applied to derive the CIs for the point estimates by generating 1,000,000 samples and using the 2.5th and 97.5th percentiles of the resulting distribution as the CI. For that, P_{F_i} was assumed following a binomial distribution, and P_{drink_i} was assumed to follow a normal distribution. Monte Carlo samples simulated from these distributions, which are applied in Equation (1) and then in Equation (2), provide a full distribution for P_{F_NZ} from where CI can be obtained. For details, see supplementary appendix of Lange et al. [11].

Prevalence of alcohol use during pregnancy was estimated using SAS 9.4, and the Monte Carlo simulations were done using SAS 9.4 and Python 3.8.

2.4 | Sensitivity analysis

A sensitivity analysis was performed to account for the possibility of underestimation given that the standard methodology [11] for predicting FASD did not include more recent case ascertainment studies. We found four articles published using case ascertainment population studies [22–25] for estimating FASD prevalence from 2015 to 2022, which represents the period after the Lange et al. 2017 study. Three of them also provided less conservative estimates reflecting, for example, possible cases and communities with highest numbers. In this sensitivity analysis, we estimated FASD prevalence for Aotearoa/New Zealand in 2018/2019 by using the prevalence estimates in Table 1. Results are given in Table 3.

Cumulative estimates of FASD were calculated by averaging the two-point estimates for 2012/2013 and 2018/2019 and then multiplying by the time length, in years, between the two surveys (8 years), respectively.

3 | RESULTS

3.1 | Prevalence of FASD

3.1.1 | Findings for the total population

Our analysis showed that at the time of their interviews in 2012/2013, $n = 565$ women reported being pregnant within the past 12 months and of those women, 18.9% (95% CI 15.6%; 22.8%) reported having consumed alcohol during their pregnancy. In the 2018/2019 survey, $n = 537$ women reported pregnancy and 15.3% (95% CI 15.1%; 15.4%) reported having consumed alcohol during their pregnancy (Table 2). The decrease in prevalence of drinking during pregnancy between 2012/2013 and 2018/2019 was statistically significant.

Based on these prevalence estimates, the prevalence of FASD was estimated at 1.7% (95% CI 1.0%; 2.7%) or 170 children with FASD per 10,000 live births in 2012/2013. For 2018/2019 it was estimated at 1.3% (95% CI 0.9%; 1.9%) or 130 children with FASD per 10,000 live births. The decline in the prevalence of FASD between 2012/2013 and 2018/2019 was not statistically significant. These prevalence levels translate into 1066 (95% CI 599; 1663) and 776 (95% CI 492; 1112) children born with FASD in those years, respectively (Table 2).

3.1.2 | Findings by ethnicity

Māori women had the highest prevalence of alcohol use during pregnancy, and consequently the highest estimated FASD prevalence. This was not statistically significant when compared to European/others but was statistically significant relative to Pasifika and Asian populations (Table 2).

3.1.3 | Sensitivity analysis

The sensitivity analysis showed that the more recent case ascertainment studies, that is, 2015–2022, gave similar prevalence estimates to the ones based on the methodology of Lange et al. It also showed that when the less conservative FASD estimates from the more recent case ascertainment studies were applied, the prevalence of FASD was estimated to be higher in the population and in the ethnic groups (Table 3).

3.1.4 | Cumulative numbers of children born with FASD 2012 to 2019

For the period 2012 to 2019, we estimated there were 7368 (95% CI 4363; 11,098) children born with FASD in Aotearoa, New Zealand. For the same period but by using the less conservative approach from the sensitivity analysis, we estimated there were 12,978 (95% CI 9411; 17,369) children born with FASD.

TABLE 2 Prevalence of alcohol use during pregnancy, prevalence of FASD in the general population and estimated number of live births with FASD in Aotearoa, New Zealand by ethnicity.

2012/2013	Māori	European/others	Asian	Pasifika	All population
Drinking during pregnancy	34.0% (25.1%, 44.2%)	19.8% (15.3%, 25.2%)	4.3% (0.5%, 15.5%)	10.1% (4.0%, 23.4%)	18.9% (15.6%, 22.8%)
FASD	2.9% (1.7%, 4.4%)	1.7% (1.0%, 2.5%)	0.4% (0.0%, 0.8%)	0.9% (0.3%, 1.6%)	1.7% (1.0%, 2.7%)
Number of live births	17,657	28,245	8507	6794	61,203
Children born with FASD	506 (294, 779)	471 (280, 713)	31 (3, 65)	58 (21, 106)	1066 (599, 1663)
2018/2019	**Māori**	**European/others**	**Asian**	**Pasifika**	**All population**
Drinking during pregnancy	24.4% (23.9%, 25.0%)	18.0% (17.7%, 18.3%)	2.4% (2.2%, 2.6%)	6.8% (6.4%, 7.2%)	15.3% (15.1%, 15.4%)
FASD	2.1% (1.3%, 2.9%)	1.5% (1.0%, 2.2%)	0.2% (0.1%, 0.3%)	0.6% (0.4%, 0.8%)	1.3% (0.9%, 1.9%)
Number of live births	16,644	25,065	10,618	5693	58,020
Children born with FASD	342 (217, 490)	379 (241, 544)	21 (13, 31)	33 (21, 47)	776 (492, 1112)

Abbreviation: FASD, foetal alcohol spectrum disorder.

TABLE 3 FASD prevalence estimates for Aotearoa/New Zealand 2018/2019 by ethnicity based on case ascertainment population studies (2015 onwards).

NZ 2018/2019	Māori	European/others	Asian	Pasifika	All population
FASD prevalence	1.7% (1.3%, 2.3%)	1.3% (0.9%, 1.7%)	0.2% (0.1%, 0.2%)	0.5% (0.4%, 0.6%)	1.1% (0.8%, 1.4%)
FASD prevalence less conservative	6.3% (4.8%, 8.0%)	4.6% (3.6%, 5.9%)	0.6% (0.5%, 0.8%)	1.7% (1.3%, 2.2%)	3.9% (3.0%, 5.0%)

Abbreviation: FASD, foetal alcohol spectrum disorder.

4 | DISCUSSION

The previous global burden of disease study on which this analysis is based determined that prevalence levels that exceed 1% are elevated [11]. According to this the current study found the prevalence level for the total population of FASD in Aotearoa, New Zealand was elevated in both 2012/2013 and 2018/2019. Our study also indicates there may be inequities in the prevalence of FASD in Aotearoa, New Zealand with Māori having the highest prevalence of drinking in pregnancy and therefore estimated FASD, significantly higher than Pasifika and Asian populations. The sensitivity analysis using more recent case ascertainment studies with improved methods supported these results. Taking the findings from the main and sensitivity analysis together prevalence of FASD in Aotearoa, New Zealand ranged from 1.7% to 6.3% among Māori to 1.3% to 4.6% among European/others and was lower among Pasifika and Asian ethnicities in 2018/2019.

The differences by ethnicity are not unexpected. Previous research has found some populations—including some indigenous populations—have considerably higher rates of FASD than the general population [11, 26] and in our study Māori women report a significantly higher rate of drinking during pregnancy as compared to other ethnicity groups as has been found previously [27]. Higher alcohol consumption among Māori is partly attributable to ongoing processes of colonisation [28] and similar effects are found in other colonised indigenous peoples (e.g., [29]). The prevalence of FASD among Pasifika and Asian groups was lower, and this was related to the lower prevalence of drinking during pregnancy among these groups. The decline in the prevalence of alcohol use during pregnancy, and thus the estimated FASD, observed between 2012 and 2019 is in line with a decrease in per capita alcohol consumption in Aotearoa, New Zealand [30].

4.1 | Implications and need for support

The estimates of people born in Aotearoa, New Zealand with FASD during the years 2012/2013 to 2018/2019 range from almost 7000 to 13,000 and have considerable implications for those individuals and their whānau (family) and for the community more broadly. People

born with FASD are at increased risk of poor educational outcomes, developing mental health and substance abuse issues, encountering the justice system, being incarcerated, benefit dependence and premature mortality—including through suicide [31]. FASD has not been recognised as a fundable disability by the Ministry of Health in New Zealand, precluding access to Government disability and support services for around 80% of the FASD community [32, 33]. This failure, along with other systemic failings have been highlighted in a 2021 report to the Prime Minister by the Disability Rights Commissioner and the Children's Commissioner, which suggest the New Zealand government may be in breach of international conventions and Te Tiriti o Waitangi [34].

FASD is a serious public health problem associated with considerable economic burden. Although the data on the economic burden of FASD are scarce and are probably conservative, a systematic review estimates the mean annual cost for children with FASD at U.S. $22,810 for children and U.S. $24,308 for adults [35]. Separately, the overall annual cost to Aotearoa, New Zealand, including the use of services and support, has been conservatively estimated at approximately NZ$15,000 for every individual with FASD or NZ$690 million annually in 2016 [36]. This excludes the cost of incarcerating individuals with FASD due to their inappropriate behaviours related to their disability and unmet disability needs. Many are being repeatedly incarcerated due to being unable to follow court-imposed conditions of a community-based sentence [37].

4.2 | How to reduce the human burden of FASD?

As with other forms of alcohol harm, changing the environment to protect the population is likely to be a highly effective approach. [38]. High levels of alcohol consumption among New Zealand women of child-bearing age are relatively common and drinking patterns prior to pregnancy have been found to predict drinking patterns during pregnancy in Aotearoa, New Zealand [16]. Among drinkers in the past 12 months, 31% of women aged 18–24 years consumed 6+ drinks at least monthly in 2018/2019, as did around 23% of 25–34 and 35–44-year-old women [39].

Prenatal brain injury cannot be reversed so, for FASD the key is prevention along with meeting the disability needs of those with FASD in our communities [40]. Policy initiatives aimed at reducing alcohol use during and before pregnancy [41] include taxation, where the effect applies to all groups of drinkers including women, and pricing policies. In Scotland women reduced their level of drinking following the introduction of minimum unit pricing [42]. Restrictions on alcohol advertising/promotion and limited numbers and opening hours of liquor outlets are also highly effective to support alcohol-free pregnancies [40]. Consumption in a small but extremely heavy drinking cluster of women of child bearing age, was predicted by strong liking for alcohol marketing, purchasing from off-premises after 11 PM and from on-premises after 3 AM. The results suggest that changes to the alcohol environment, such as restrictions to marketing and availability, are important strategies in the prevention of FASD [43]. Further, other ways of addressing the issue such as warning labels have generally been shown to be ineffective. Independently of other FASD prevention efforts, warning labels are often ineffective in changing alcohol use [44, 45] and do not support alcohol-free pregnancies [46]. Currently in Aotearoa, there are calls for alcohol policy reform, and this is under consideration by the government [47].

Māori health advocates have called for support led by mātauranga Māori (Māori knowledge) service providers and models of practice that affirm the place of wairuatanga (spirituality and identity) in holistic care [48].

4.3 | Limitations

This secondary analysis is subject to a number of limitations. The prevalence of drinking in pregnancy in Aotearoa, New Zealand is likely to be underestimated, even in a well conducted and large national survey. The response fraction of 80%, while considered high, means selection bias could favour less heavy drinking participants [49]. In addition, some measurement bias is likely. The survey question about any drinking in pregnancy will be associated with a degree of social desirability bias in reporting. Participants may have been reluctant to report their true alcohol use or have minimised their alcohol use in their own memory, particularly during pregnancy [50]. Alcohol use during pregnancy was self-reported and may be subject to other reporting biases [10].

The method itself has some shortcomings. Consideration of the effect of timing, dose and frequency of prenatal alcohol exposure on the risk of FASD was not possible [11], although related to risk of FASD. This means the exposure measure of any drinking in pregnancy can only be weakly associated with risk, and that association will vary between populations. In some cases, the international studies from which the risk estimate was derived

had lower prevalence of drinking (and heavy episodic drinking) in the population compared with Aotearoa, New Zealand so the estimate of risk from the meta-analysis maybe be biased downwards. Also, the published studies we used to estimate the prevalence of FASD did not rely on the same diagnostic guidelines or case definitions [10]. This may have affected the estimated pooled prevalence of FASD in these studies and the direction of this effect depends on the sensitivity and specificity of the diagnostic system [11, 51]. Applying the prevalence levels of FASD from other countries to Aotearoa, New Zealand will introduce a level of uncertainty and this may be especially the case when estimating FASD among populations with high prevalence of drinking during pregnancy, for example, Māori. Some of these limitations highlights the need for an active case ascertainment study in Aotearoa, New Zealand to further/better identify the prevalence and needs of individuals with FASD.

5 | CONCLUSION

This study estimated FASD using standard methodology from comparative risk assessments using the best available national data on consumption and the estimates were supported by sensitivity analysis using more recent case ascertainment studies. The limitations in the data available predispose to under estimation but show disparities between Māori and some ethnicities. The estimates of up to 13,000 babies born with FASD 2012–2019 support the urgent need for policy and prevention initiatives to reduce alcohol use during and before pregnancy to reduce the lifelong disability caused by prenatal alcohol exposure.

AUTHOR CONTRIBUTIONS

Romeo: Conceptualisation, analysis, figures, writing. **Huckle:** Conceptualisation, writing, funding acquisition. **Casswell:** Conceptualisation, writing, funding acquisition. **Connor:** Conceptualisation, writing, funding acquisition. **Rehm:** Funding acquisition and review. **McGinn:** Conceptualisation, writing

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CONFLICT OF INTEREST STATEMENT

None to declare.

ETHICS STATEMENT

Low risk ethics approval was received from Massey University. Approved application number 4000020372. A low risk ethics application was appropriate as defined by a Massey University ethics check list and as all participants/data are anonymous to researchers and de-identified.

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