Pacific Health Disparities
Institutional racism
& Data

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Outline Pacific Health Disparities, institutional racism & Data

1. **Rheumatic fever**: *systematic collection of data important for programme evaluation and improvement*
2. **Access to Lead Maternity Carer**: *analysis and presentation of data important to improve health care*

1. Rheumatic fever and data collection

HOME nzherald.co.nz

2012

Record on rheumatic fever 'shameful'

9 Nov, 2012 05:30 AM

4 minutes to read

Trent Boswell-Wakefield and Johan Schoonbee from the Hawke's Bay Magpies rugby team get involved in a rheumatic fever promotion. Photo / Glenn Taylor

"Third World disease associated with child poverty and overcrowding"

"Shameful and intolerable"

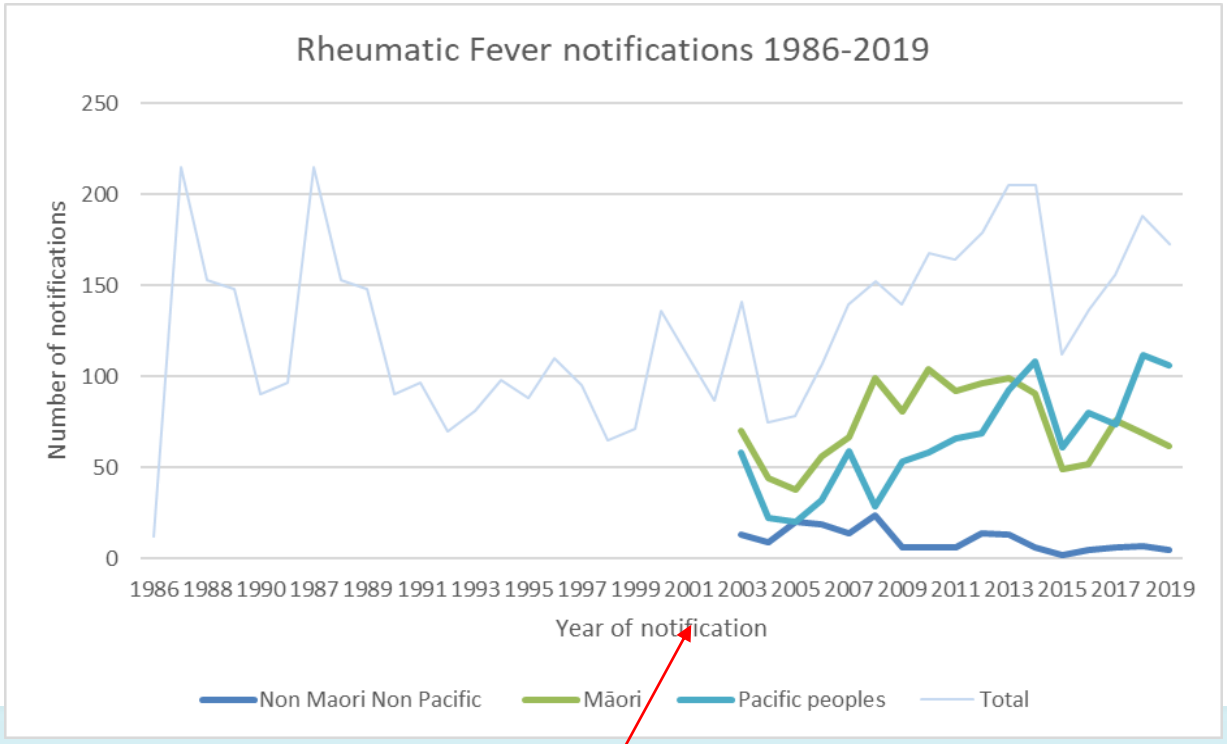
"Big increase ……disproportionally in Māori, Pacific and poor people"

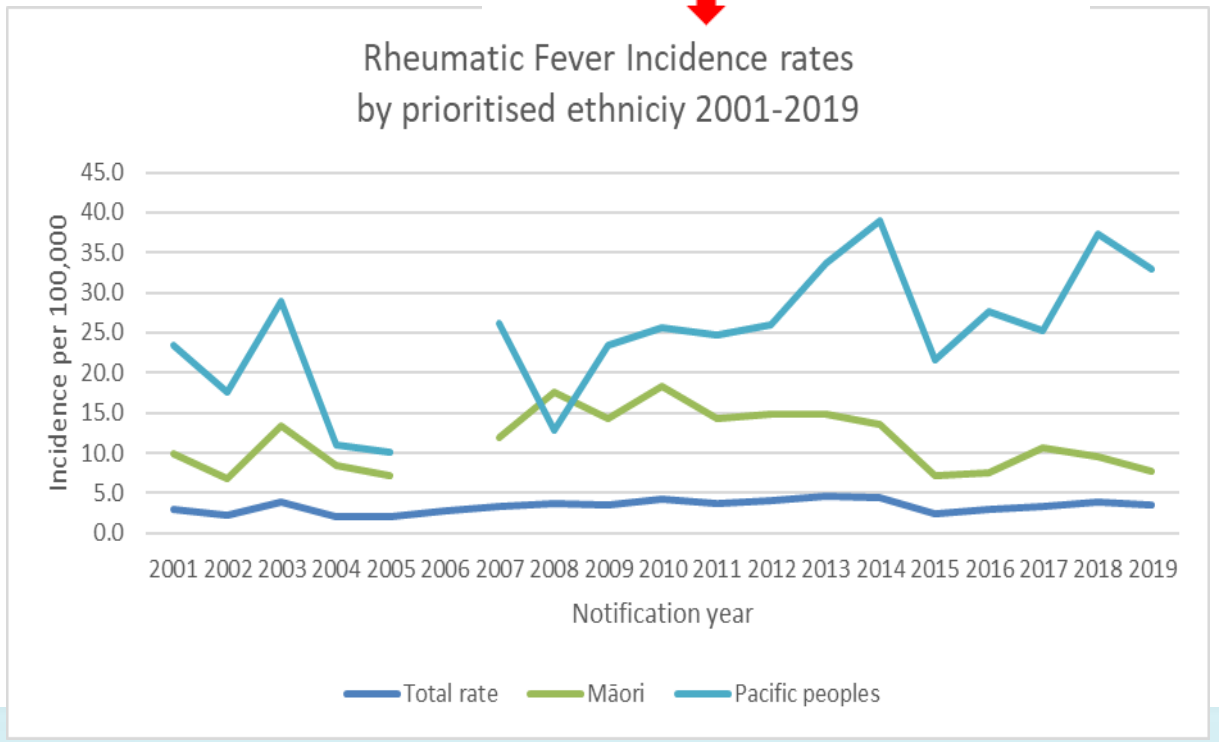
"Occurred while the income gap widened"

"Throat swabbing important, but a "band-aid': real problem is poverty, overcrowding and poor housing quality"

Notified cases NZ since 1986-2019

Based on census population

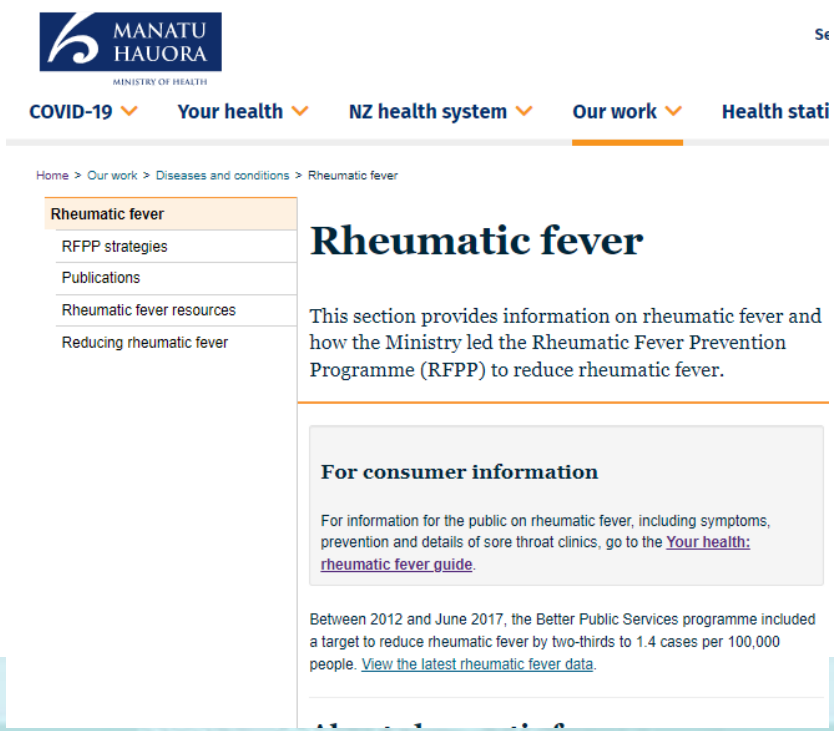




Health and Disability Act 2000

Source: ESR annual reports supplemented with data from EpiSurv 11 July 2022. First and recurrent attacks.

Rheumatic Fever Prevention Plan 2011



-Target: Reduce incidence to 1.4/100,000

-2012-June 2017: Better Public Service Programme: $65m to identify and trial new initiatives

RFPP strategies

The Rheumatic Fever Prevention Programme (RFPP) had three main strategies to reduce rheumatic fever rates throughout New Zealand:

- increase awareness of rheumatic fever, what causes it and how to prevent it
- reduce household crowding and therefore reduce household transmission of strep throat bacteria within households
- improve access to timely and effective treatment for strep throat infections in priority communities.

https://www.tewhatuora.govt.nz/for-the-health-sector/health-sector-guidance/rheumatic-fever-guidance/new-content-page-2

Interventions RPFF 2011

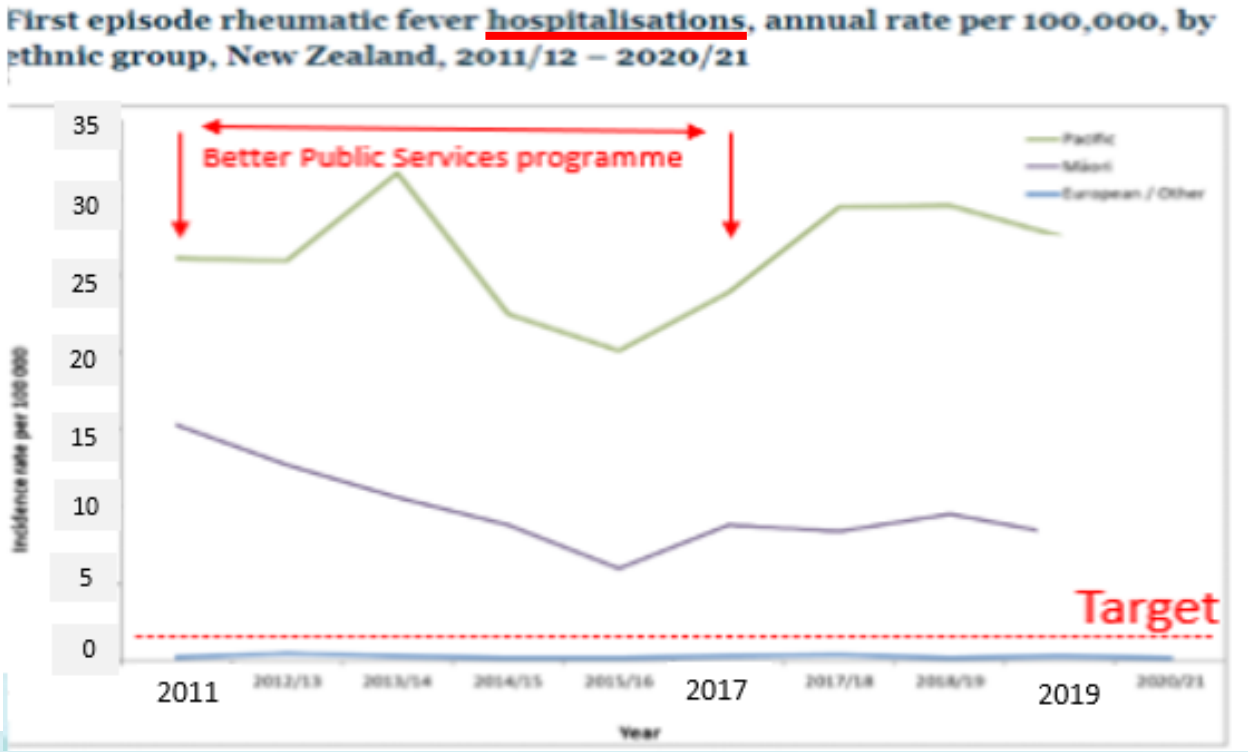
Healthy Homes Initiatives: low income families with children at risk* of RF who live in crowded houses 9 different providers in different areas

Early treatment 'strep throat': School throat swabbing programmes for high risk children* 8 different providers in CMDHB

** Māori and Pacific children who live in crowded circumstances of high deprivation areas*

https://www.tewhatuora.govt.nz/keeping-well/new-content-page-13/healthy-homes-initiative/

Rheumatic Fever Prevention Plan 2012-2017



- Better Public Service Programme: $65m to identify and trial new initiatives

-Target: Reduce incidence to 1.4/100,000

Since 2017 programme has continued with extra funding

https://www.health.govt.nz/our-work/diseases-and-conditions/rheumatic-fever/reducing-rheumatic-fever

Rheumatic Fever data collections

1. National Surveillance (notifiable Public Health Act 1956). standard questionnaires, to inform preventive strategies for causative factors and risk population, which includes *family history RF*, *crowding*, *housing* etc. (MoH, ESR)
2. *Hospitalisations* (ICD codes). National Minimal Data Set NMDS (DHB, MoH).
3. *Registers* (local) to monitor compliance prophylaxis (DHB)
4. *Other routinely collected data* (PHOs, GPs, Pharmac, lab)

"Surveillance", "notifying" under Public Health Act
"monitoring", "reporting" "registration", "data collection" Not set up for surveillance

Is a rheumatic fever register the best surveillance tool to evaluate rheumatic fever control in the Auckland region?

Diana Lennon, Te Aro Moxon, Philippa Anderson, Alison Leversha, Timothy Jelleyman, Peter Reed, Catherine Jackson

ABSTRACT

AIM: To determine the most accurate data source for acute rheumatic fever (ARF) epidemiology in the Auckland region.

METHOD: To assess coverage of the Auckland Regional Rheumatic Fever Register (ARRFR), (1998–2010) for children <15 years and resident in Auckland at the time of illness, register, hospitalisation and notification data were compared. A consistent definition was applied to determine definite and probable cases of ARF using clinical records. (www.heartfoundation.org.nz)

RESULTS: Of 559 confirmed (definite and probable) RF cases <15 years (median age 10 years), seven were recurrences. Of 552 first episodes, the ARRFR identified 548 (99%), hospitalisations identified 501 (91%) including four not on the register, and public health notifications identified 384 (70%). Of hospitalisation cases, 33% (245/746), and of notifications 20% (94/478) did not meet the case definition and were therefore excluded. Between 1998–2010, eight cases, initially entered as ARF on the ARRFR, were later removed once further clinical detail was available.

CONCLUSION: The ARRFR produced the most accurate information surrounding new cases of ARF (for children <15 years) for the years 1998–2010 in Auckland. This was significantly more accurate than medical officer of health notification and hospitalisation data.

Rheumatic heart disease (RHD), the long-term sequela of acute rheumatic fever (ARF), can persist for life.[1] Despite ARF being preventable, the associated morbidity and mortality continue to be a significant global burden falling largely on low-income countries.[2] However, it remains a significant issue in some indigenous and low-income communities in the industrialised world. The diagnosis of rheumatic fever is an estimate of probability using clinical and laboratory parameters, as there is no single diagnostic test. Internationally, the Jones criteria have been used with modifications made over time to improve specificity at the expense of sensitivity. New Zealand has led the way with the use of echocardiography to support the diagnosis.[3,4] A case definition with precise cut-offs for each criteria have been in place since the 1980's with ongoing modifications[5] (Heart Foundation of New Zealand guidelines www.heartfoundation.org.nz).

In New Zealand by the 197, ARF hospitalisation rates in children and young people had declined.[6] However, the disease persisted and over the last 25 years, until the end of the study period 2010, national ARF hospitalisation rates had not improved.[7] Most (80%) cases occur between 5–14 years of age, predominately in Māori and Pasifika and in lower socioeconomic areas.[4] Rheumatic fever has been a disease legally notifiable to medical officers of health since 1986.[8]

Comparing data quality AKL 1998-2010:

Hospitalisation: 501/552 (91%) first episode cases identified by ICD codes

Local register: 548/552 (99%) in ARRFR register

National surveillance: 384/552 (70%) notified

Case definition:

-Of hospitalisations, 245/746 (33%) did not meet case definition

-Of notifications, 94/478 (20%) did not meet case definition

Conclusions

There was under-notification (30%) and overreporting (33%)

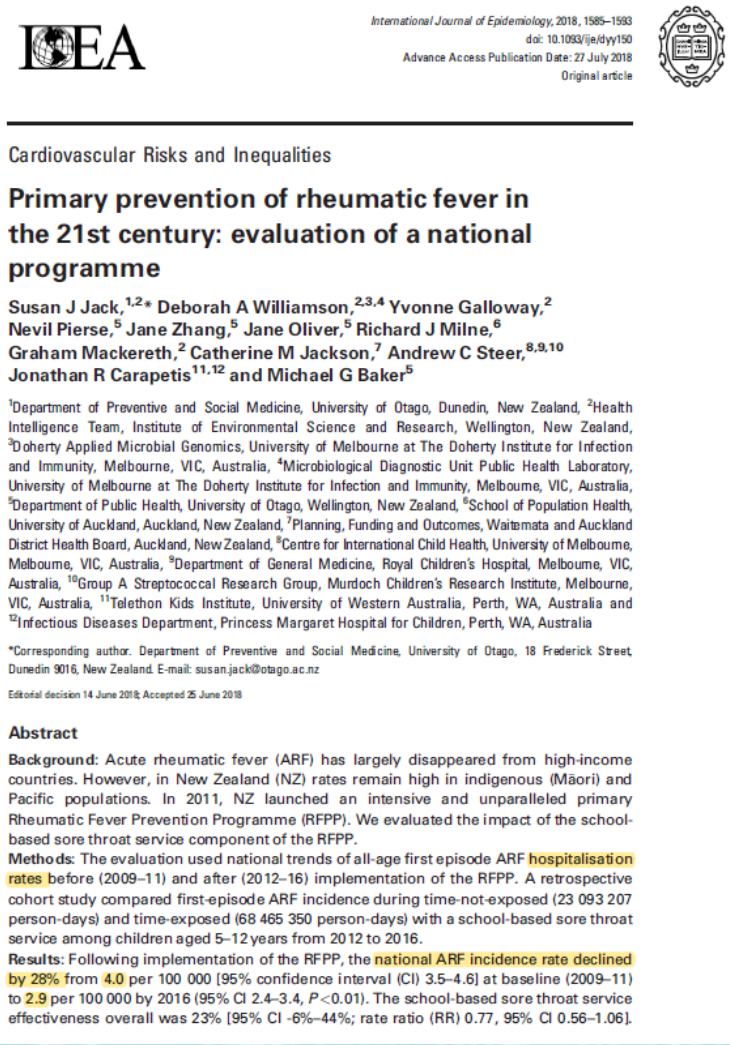
Local register produced most complete case information

BUT

-a register is NOT a surveillance tool

Register may be more complete, but it only reports ARF case incidence in AKL, it doesn't collect any other surveillance data

Evaluation: No ‘official’ MoH evaluation RFPP



International Journal of Epidemiology, 2018, 1585–1593
doi: 10.1093/ije/dyy150
Advance Access Publication Date: 27 July 2018
Original article

Cardiovascular Risks and Inequalities

Primary prevention of rheumatic fever in the 21st century: evaluation of a national programme

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Editorial decision 14 June 2018; Accepted 25 June 2018

Abstract

Background: Acute rheumatic fever (ARF) has largely disappeared from high-income countries. However, in New Zealand (NZ) rates remain high in indigenous (Māori) and Pacific populations. In 2011, NZ launched an intensive and unparalleled primary Rheumatic Fever Prevention Programme (RFPP). We evaluated the impact of the school-based sore throat service component of the RFPP.

Methods: The evaluation used national trends of all-age first episode ARF hospitalisation rates before (2009–11) and after (2012–16) implementation of the RFPP. A retrospective cohort study compared first-episode ARF incidence during time-not-exposed (23 093 207 person-days) and time-exposed (68 465 350 person-days) with a school-based sore throat service among children aged 5–12 years from 2012 to 2016.

Results: Following implementation of the RFPP, the national ARF incidence rate declined by 28% from 4.0 per 100 000 [95% confidence interval (CI) 3.5–4.6] at baseline (2009–11) to 2.9 per 100 000 by 2016 (95% CI 2.4–3.4, $P<0.01$). The school-based sore throat service effectiveness overall was 23% [95% CI -6%–44%; rate ratio (RR) 0.77, 95% CI 0.56–1.06].

-Hospitalisation rates evaluated, not surveillance data

-”Evaluation plan was not built into the design of RFPP”

-”No national SOPs: some schools included active case finding”

-”Overall decline likely due to ‘multiple approaches working in concert’ but can’t unravel”

-”Cost-effectiveness of RFPP should be evaluated but hasn’t”

-No evaluation of official national surveillance data, which systematically collects information risk factors and interventions such as referral to Pacific engagement strategy worker

-No evaluation of the impact of Healthy Homes Initiative on Rheumatic Fever

Jack SJ, Williamson DA, Galloway Y, Pierse N, Zhang J, Oliver J, Milne RJ, Mackereth G, Jackson CM, Steer AC, Carapetis JR, Baker MG. Primary prevention of rheumatic fever in the 21st century: evaluation of a national programme. Int J Epidemiol. 2018 Oct 1;47(5):1585-1593

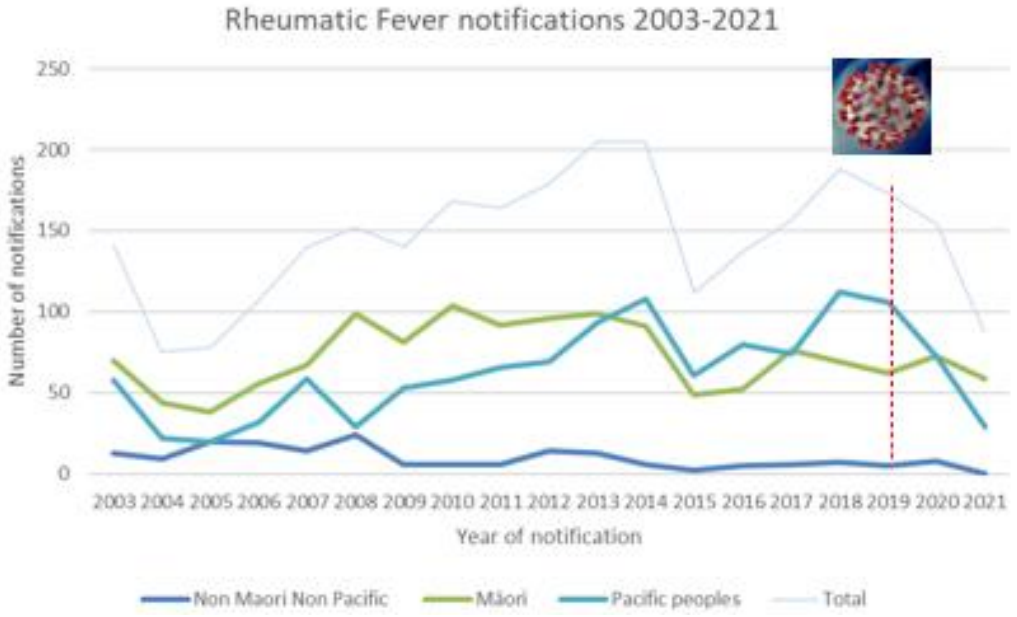
Recent developments

nzherald.co.nz

The rheumatic fever question: Is New Zealand finally tackling the disease or did Covid restrictions cause a brief lull?

17 May, 2022 05:00 AM

5 minutes to read



May 2022

https://www.nzherald.co.nz/nz/the-rheumatic-fever-question-is-new-zealand-finally-tackling-the-disease-or-did-covid-restrictions-cause-a-brief-lull/WT5QXK4KBFGXY624WCCVL367LQ/

Conclusions rheumatic fever data collection

- Intervention and control programmes do prevent cases, but are *not coordinated* nor *systematically registered*. Interventions influence incidence, but without documentation we don't know how
- Only the *effect of throat swabbing* ('band-aid') has been evaluated. The effect of Healthy Homes has not even though it was part of the programme
- Many different 'databases' are used for evaluation (mostly hospitalisations), except our official national surveillance that is designed for this purpose (Public Health Act 1956).
- Implementation and evaluation are both unplanned and not standardised. *Therefore we don't learn…*

2. Access to Lead Maternity Carer (LMC)

2015

Growing Up in New Zealand

ABOUT ▾ STUDY PARTICIPANTS ▾ USING GROWING UP DATA ▾ NEWS ▾

Lead maternity carer system working for most New Zealand mothers

04 August 2015

Two decades after New Zealand introduced a choice-based model of primary maternity care, almost all mothers-to-be enrol with a carer early in their pregnancy and most are happy with the choice of carers available.

NZ has a choice based model of maternity care introduced in early 1990s

98% women are enrolled

Māori 95%, Pacific 95% and European NZ 99%

HOME nzherald.co.nz

Dr Cameron Grant: ***"worrying ……groups taking longer to hire a midwife …..most at risk of poor birth outcomes."***

MANATU HAUORA
MINISTRY OF HEALTH

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  - Birth and afterwards
  - The first year
  - Under fives
  - Services and support during pregnancy
    - Finding out if you're pregnant
    - Maternity care
    - Choosing a midwife or specialist doctor

Maternity care

Your lead maternity carer is a midwife or specialist doctor who provides maternity care for you. You choose who provides your maternity care.

Healthline Freephone 24/7 0800 611 116

Call Healthline on 0800 611 116 for health advice.

Screening diabetes, hepatitis B and syphilis + interventions
Vaccinations whooping cough, influenza and COVID-19

Lead Maternity Carer:

- Support from first visit till 6 weeks after birth, 24/7
- Develop plan for your care, labour and birth
- Health advice
- Refer if necessary
- Visit you (at home or in hospital) at least 7 times after baby is born
- Refer you to Well Child Tamariki Ora after birth
- Help enrol your baby at GP

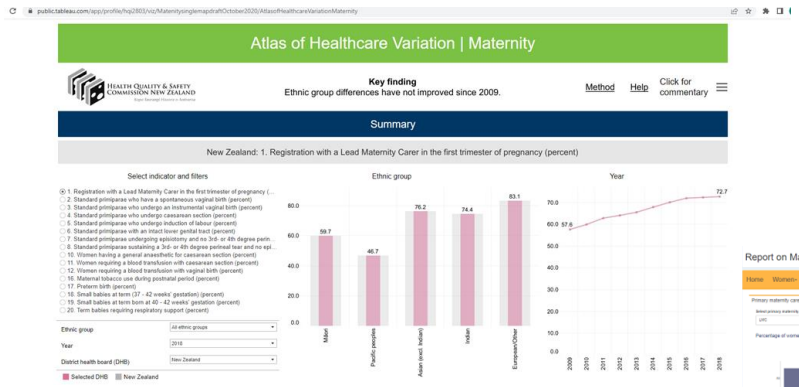
New Zealand Maternity Clinical Indicators: background document

Released 2022

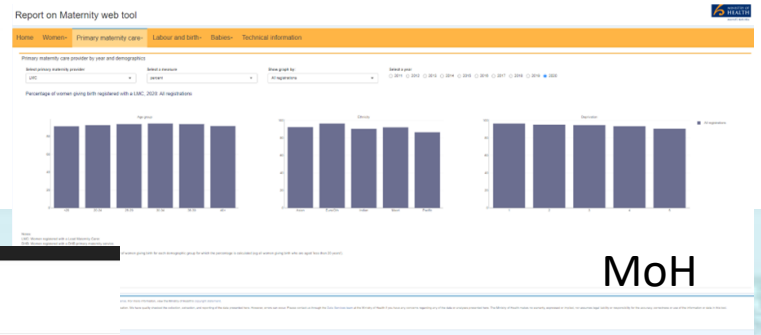
health.govt.nz

- Lists 20 indicators around pregnancy and birth
- First indicator is *'Access to a LMC in the first trimester of pregnancy'*

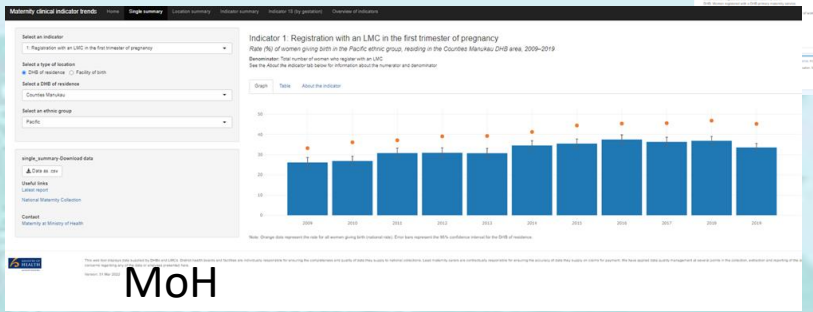
- THREE different dashboard presenting the same information in different ways



HSQC



MoH



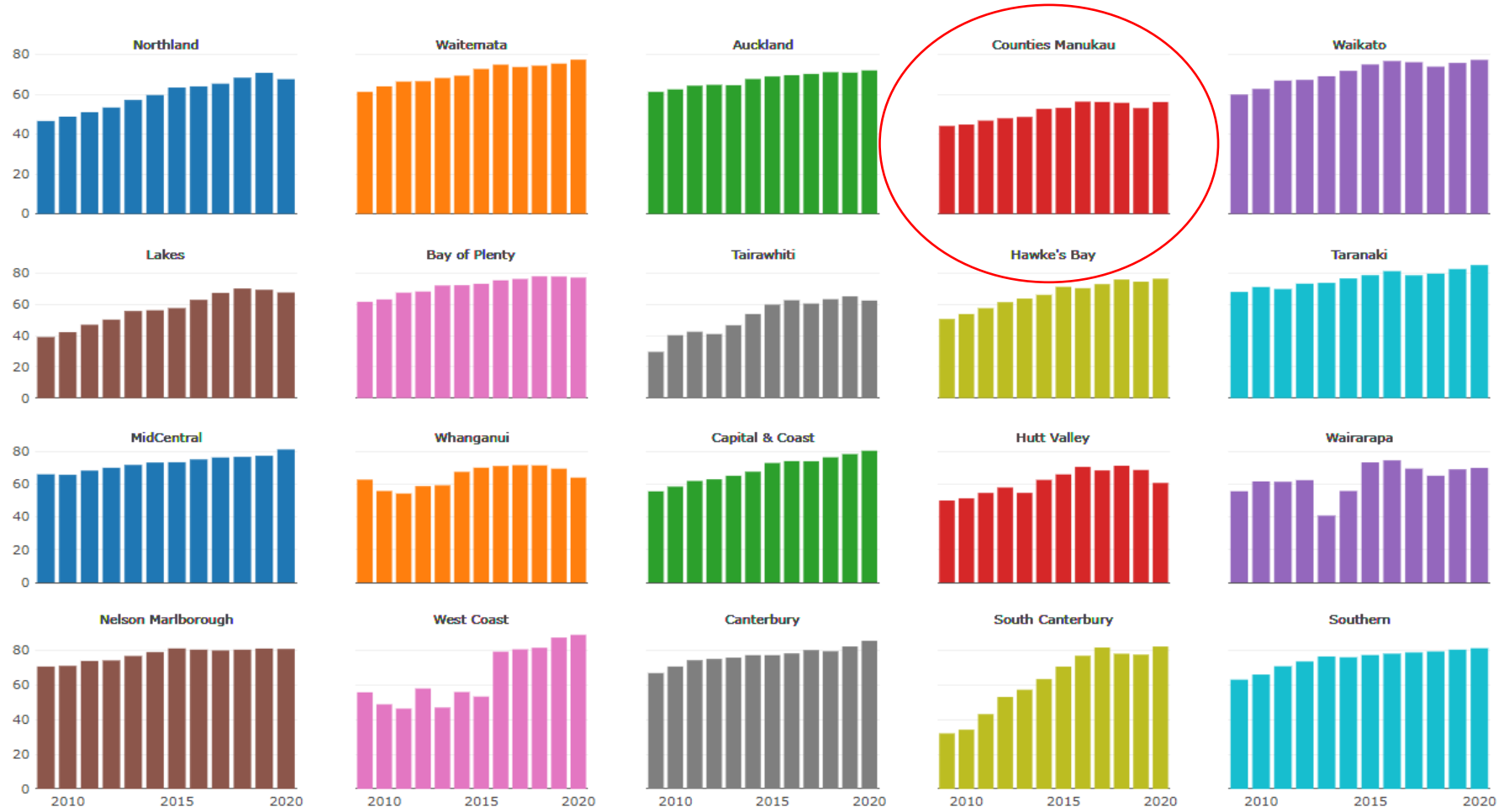
MoH

2009-2020

Indicator 1: Registration with an LMC in the first trimester of pregnancy

Denominator: Total number of women who register with an LMC
See the *About the indicator* tab below for information about the numerator and denominator

Graph - annual | Graph - time series | Table | About the indicator



https://minhealthnz.shinyapps.io/maternity-clinical-indicator-trends/

Counties Manukau

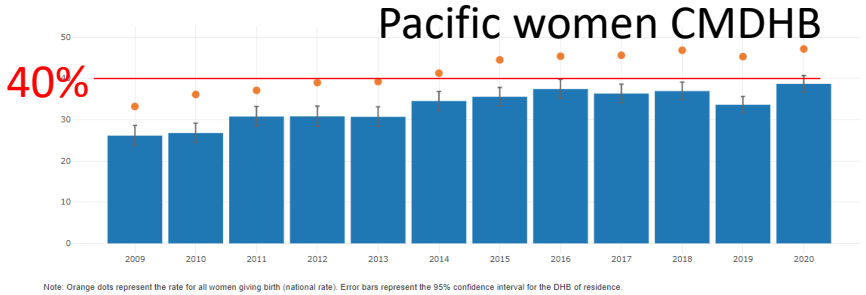
Indicator 1: Registration with an LMC in the first trimester of pregnancy

Rate (%) of women giving birth in the Pacific ethnic group, residing in the Counties Manukau DHB area, 2009–2020

Denominator: Total number of women who register with an LMC
See the *About the indicator* tab below for information about the numerator and denominator

Graph | Table | About the indicator

Pacific women CMDHB



Note: Orange dots represent the rate for all women giving birth (national rate). Error bars represent the 95% confidence interval for the DHB of residence.

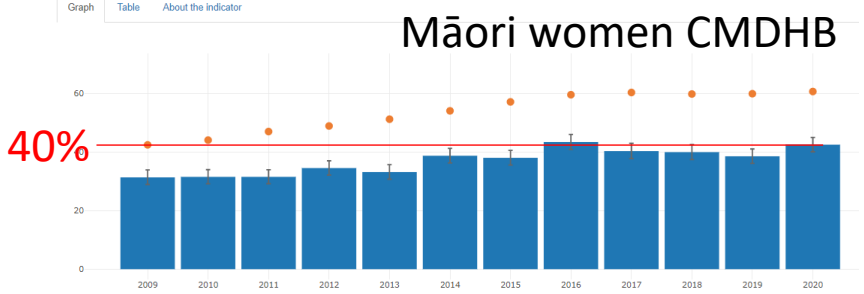
Indicator 1: Registration with an LMC in the first trimester of pregnancy

Rate (%) of women giving birth in the Maori ethnic group, residing in the Counties Manukau DHB area, 2009–2020

Denominator: Total number of women who register with an LMC
See the *About the indicator* tab below for information about the numerator and denominator

Graph | Table | About the indicator

Māori women CMDHB



Note: Orange dots represent the rate for all women giving birth (national rate). Error bars represent the 95% confidence interval for the DHB of residence.

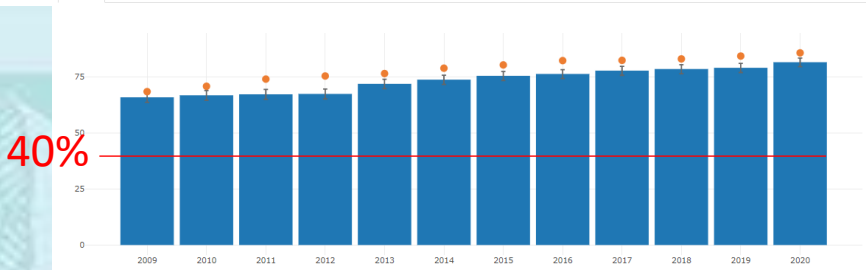
Indicator 1: Registration with an LMC in the first trimester of pregnancy

Rate (%) of women giving birth in the European or Other ethnic group, residing in the Counties Manukau DHB area, 2009–2020

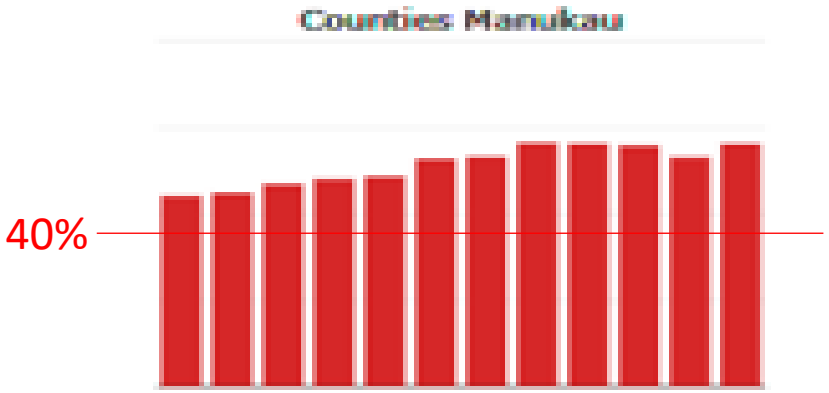
Denominator: Total number of women who register with an LMC
See the *About the indicator* tab below for information about the numerator and denominator

Graph | Table | About the indicator

European women CMDHB



Note: Orange dots represent the rate for all women giving birth (national rate). Error bars represent the 95% confidence interval for the DHB of residence.



https://minhealthnz.shinyapps.io/maternity-clinical-indicator-trends/

Access to LMC

Report on Maternity web tool

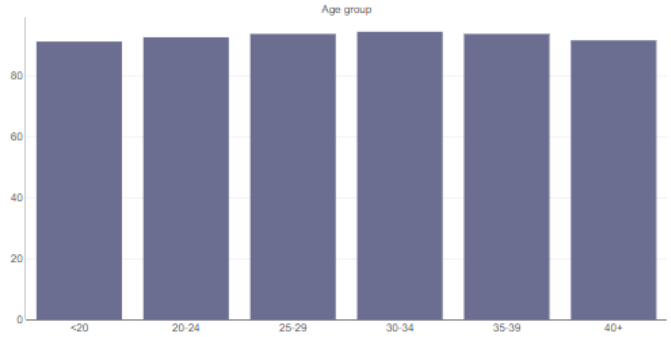
Home | Women- | Primary maternity care- | Labour and birth- | Babies- | Technical information

Primary maternity care provider by year and demographics

Select primary maternity provider | Select a measure | Show graph by: | Select a year

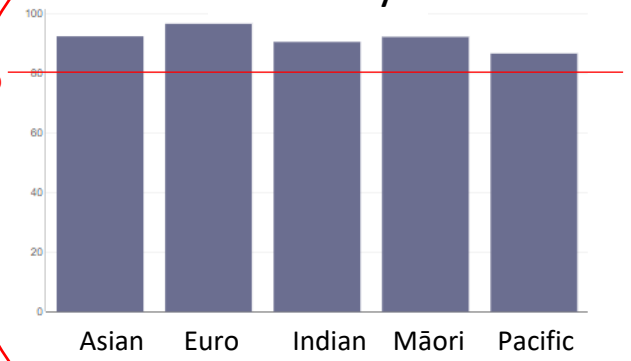
2011 2012 2013 2014 2015 2016 2017 2018 2019 2020

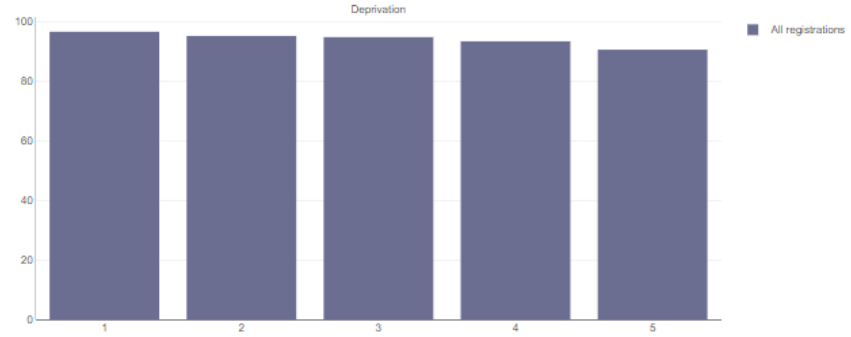
Percentage of women giving birth registered with a LMC 2020, all registrations



ethnicity

80%





Notes:
LMC: Women registered with a Lead Maternity Carer.
DHB: Women registered with a DHB primary maternity service.
Trimester is the trimester at first maternity care registration.
The denominator used to calculate percentages is the total number of women giving birth for each demographic group for which the percentage is calculated (eg all women giving birth who are aged 'less than 20 years').
Asian ethnic group excludes Indian ethnic group.
Source: National Maternity Collection

Show the data table

Version published: 2022-08-14

https://minhealthnz.shinyapps.io/report-on-maternity-web-tool/

Timely access to LMC

Report on Maternity web tool

Home | Women- | Primary maternity care- | Labour and birth- | Babies- | Technical information

Primary maternity care provider by year and demographics

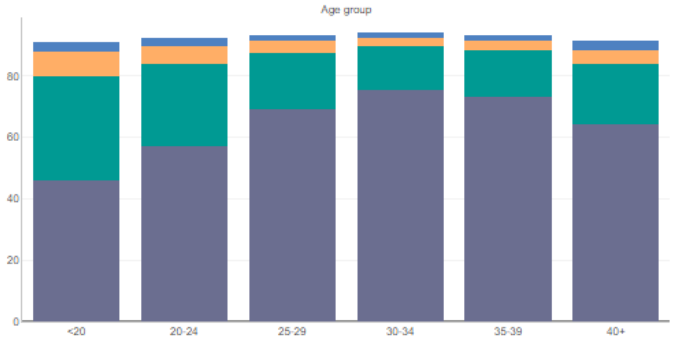
Select primary maternity provider: LMC

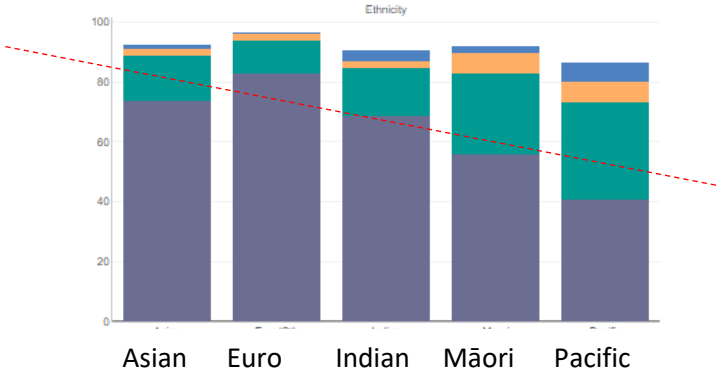
Select a measure: percent

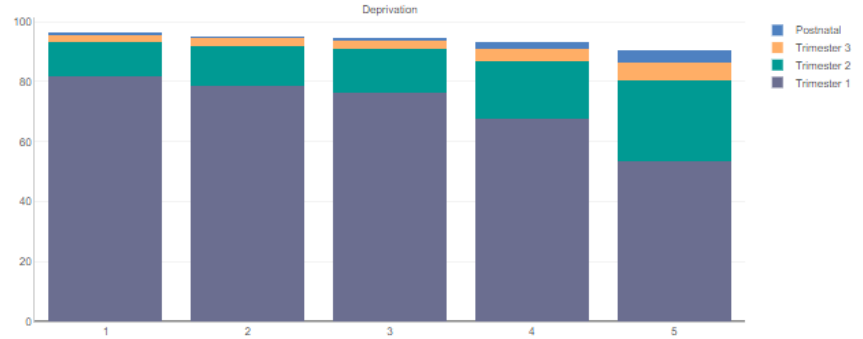
Show graph by: Registrations by trimester

Select a year: 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020

Percentage of women giving birth registered with a LMC, 2020: Registrations by trimester







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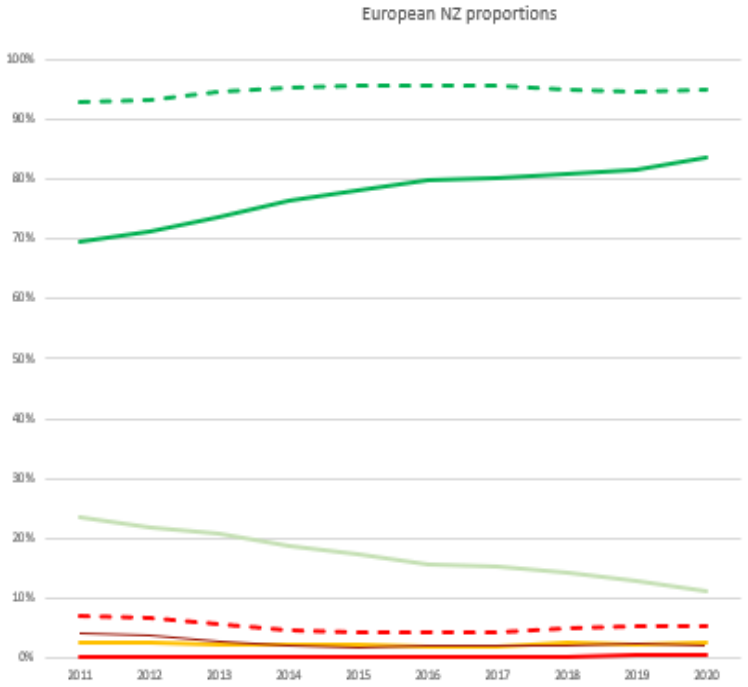
The denominator used to calculate percentages is the total number of women giving birth for each demographic group for which the percentage is calculated (eg all women giving birth who are aged 'less than 20 years').
Asian ethnic group excludes Indian ethnic group.
Source: National Maternity Collection

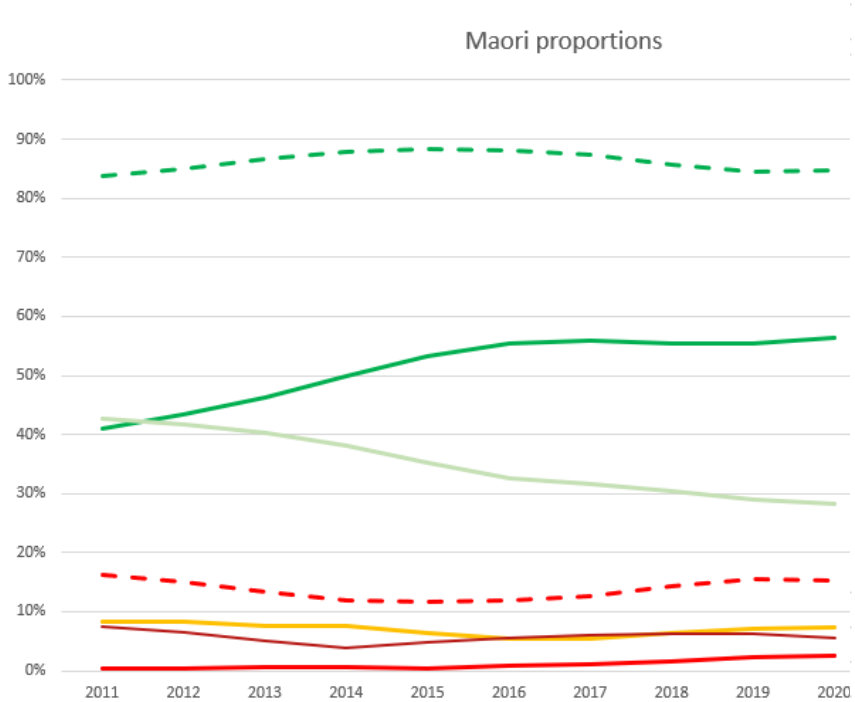
Show the data table

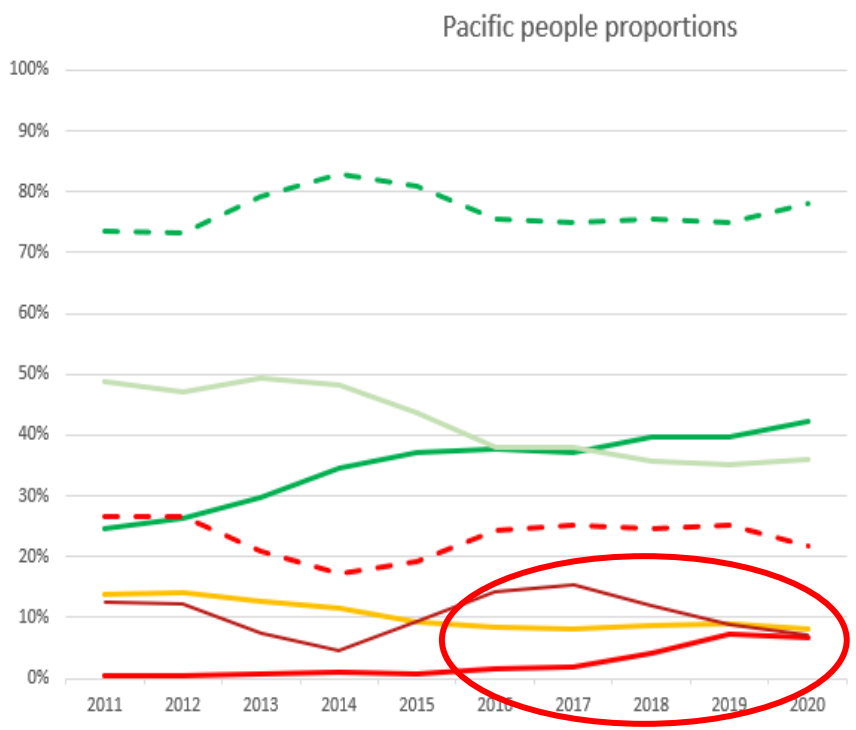
Postnatal
Trimester 3
Trimester 2
Trimester 1

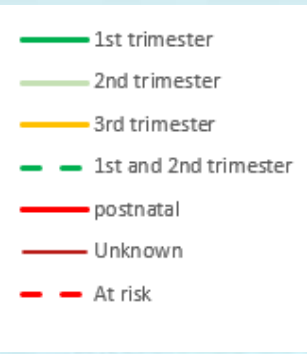
https://minhealthnz.shinyapps.io/report-on-maternity-web-tool/

Timely access LMC by ethnicity past decade



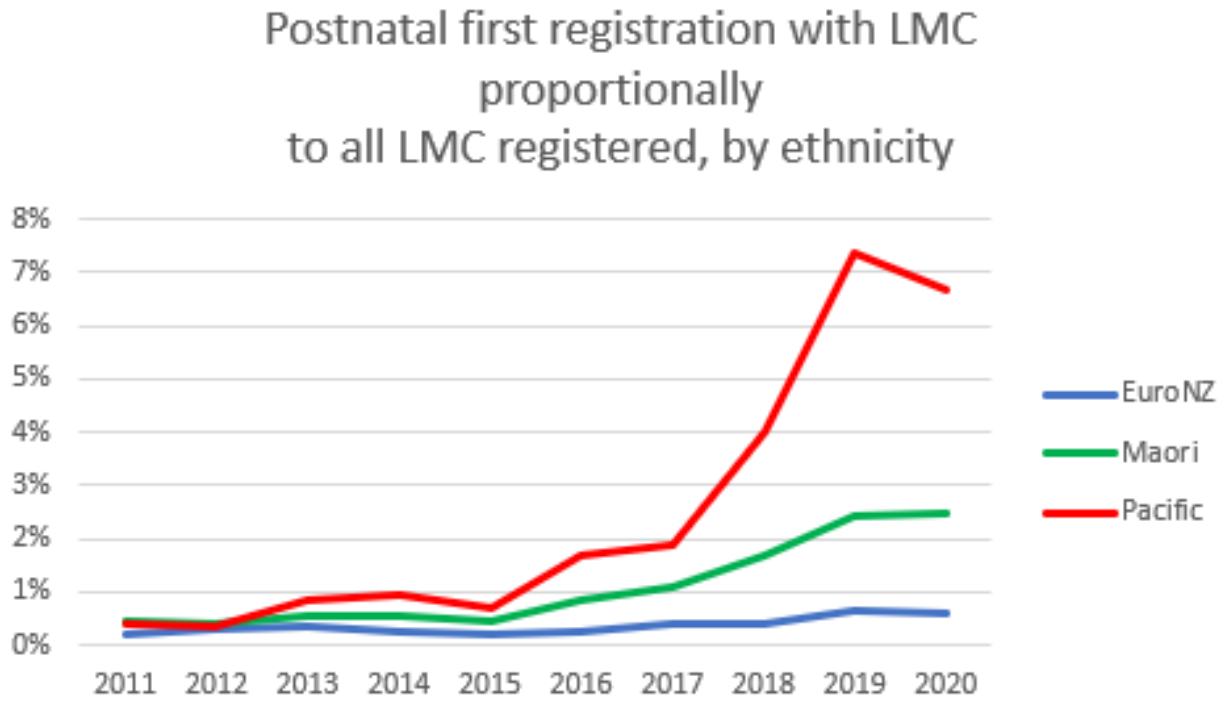






Data extracted from https://minhealthnz.shinyapps.io/report-on-maternity-web-tool/

Postnatal first LMC registration by ethnicity



No:

Screening for diabetes, hepatitis B, syphilis

No:

Maternal vaccinations whooping cough, influenza, COVID-19

Data extracted from https://minhealthnz.shinyapps.io/report-on-maternity-web-tool/

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Report on Maternity web tool

Key findings about births in 2020:

1. 58,670 women gave birth and 58,995 babies were live-born, a slight decrease from 2019.
2. The birth rate in 2020 was 57.8 per 1,000 females of reproductive age; also a slight decrease from 2019 (60.1 per 1000 females of reproductive age).
3. Most women giving birth (93.5%) received care from a community-based Lead Maternity Carer.
4. Just over two-thirds (69.3%) of women giving birth registered with a Lead Maternity Carer in their first trimester of pregnancy; up from just over half (53.8%) in 2011.
5. Most women gave birth at a secondary (40.3%) or tertiary maternity facility (45.4%), 9.7% of women gave birth in a primary facility or birthing unit. These rates have been stable over the last 10 years. 4.6% of women had home births, which is an increase from the past 9 years, where 3.1-3.5% of women had home births each year.
6. Induction of labour, epidural analgesia, and episiotomy rates have continued an upward trend over the last 10 years. Rates of augmentation of established labour has continued a downward trend over this same period.
7. Caesarean section rates have increased over the last eleven years to 29.8% of all births in 2020, the highest ever recorded. Emergency Caesarean section rates have generally increased over the same period, whereas Elective Caesarean rates have remained roughly the same. There has been a corresponding decrease in spontaneous vaginal birth (58.3%) and no significant change to rates of instrumental vaginal birth (9.6%).
8. There have been no changes to average birthweight or distribution of gestational age at birth in 2020 compared to 2019. In 2020, 7.9% of babies were born preterm (before 37 weeks gestation).
9. As in previous years, babies of small birthweight were more common among women under 20 years and aged 40 years and over, Indian women, and women residing in areas of high neighbourhood deprivation.
10. Preterm births were more common among women under 20 years and aged 40 years and over, Māori women, Indian women, and women residing in areas of high neighbourhood deprivation.

1. In 2020, only 42% of Pacific women have access to LMC in the first trimester (Māori 69%; European 85%)

2. Postnatal access for Pacific women increased from 0% in 2013 to 7% in 2020. (Māori 1% to 2%; European 0% to 1%) Women who use private health care are not included. Including these would make this inequity even bigger

3. Women who do not access LMC at all are not included.

5. "Unknown" trimester of access for Pacific women is on average 9.3% in past decade (Māori 5.7%; European 2.6%)

→ The only mention of ethnicity

https://www.health.govt.nz/publication/report-maternity-web-tool

Conclusions dashboard(s)

- Pre-defined format, not flexible. Prone to miss detail and unexpected trends.
- Don’t allow for breakdowns by multiple variables.
- The databases *are* downloadable, but this requires specific skills and is time consuming.
- Dashboards imply to show ‘real-time’ data, but publications are > 1 year delayed.
- Conclusions on MoH website are general and biased towards the majority ethnic group. The worrisome trend for Pacific women is not included in the “Key Finding in 2020” while this needs urgent action.
- It is not clear for whom the dashboards are published: who is responsible to undertake action and respond to changes in trends?

Discussion Pacific Health Disparities, Institutional racism & Data

1. Reliable population data is important for equitable health outcomes

    R*esponse rate census 2023*

2. Public health programmes need coordinated implementation, and evaluation plans to be effective. *'Random' data-collection ≠ surveillance.*

    Improve and use our official national surveillance

3. Dashboards have many limitations. 'Pre-formatted', no flexibility, conceals unanticipated trends

    Choose the most appropriate way of presenting data for its purpose.

Te Whatu Ora
Health New Zealand

Te Aka Whai Ora
Māori Health Authority

Te Pae Tata
Interim New Zealand Health Plan

2022

"Implement a nationally consistent system of data capture, analytics and intelligence that supports the use of health intelligence and insights to ensure equity of access and outcomes from all health services across Aotearoa."