



# Auckland Women's Health Council

## Submission of the Auckland Women's Health Council on the Women's Health Strategy

### Executive Summary

1. **Many women<sup>1</sup> in this country do not have accessible, affordable, available, and culturally appropriate and acceptable health care.** Beyond this, an unacceptable number of women are harmed in some way – often extremely seriously – by their experiences of health care, and many more have their basic health care rights breached. The women's health strategy must address the inequities and disparities, and harm/injury experienced by women in health care.
2. **The Aotearoa New Zealand women's health strategy MUST focus on more than sexual and reproductive health.** It MUST focus on the leading causes of loss of quality of life, disability and death for women. The strategy must:
  - take a life course approach that addresses health needs in different stages in a woman's life;
  - focus on achieving and maintaining health not just treating ill-health;
  - acknowledge the factors that influence women's lives and health such as ethnicity, disability, sexual identity and background;
  - address the social determinants of health: gender is a social determinant of health, interacting with other factors such as income and poverty, education, occupation, housing, and domestic violence;
  - include a national health needs assessment for women and provide for gender analysis in any assessment of population health needs; a gendered approach to the collection and utilisation of health data;
  - examine the pathways and quality of care for women within the health system; identify evidence-based strategies that could be implemented to ensure women receive the best available care;
  - consistently recognise, promote and allocate resources to address a broader, integrated women's health agenda;
  - address the barriers to women seeking early care (which include time, responsibilities, care of other family members, childcare, jobs and transport, as well as financial considerations), and develop and implement strategies to improve timely access to care;
  - require that all medical and health research in Aotearoa New Zealand is appropriately designed to facilitate the inclusion of gendered analyses, and that appropriate and representative numbers of women are included in clinical trials;
  - involve consumers in monitoring and reviewing the progress of the women's health strategy, and assessing how the health system has performed against the strategy.

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1 In this submission, use of the nouns women, woman and wāhine are inclusive of all New Zealanders who were born with female anatomy and physiology whether they identify as cis- or transgender, or gender diverse. We also acknowledge transgender women who may face the same health issues and social determinants of health as those assigned female at birth.

## Critical Issues in Women's Health

3. **Cancer:** the strategy must address increasing cancer incidence, and delays in diagnosis and treatment; cervical screening must be free; HPV self-testing in the home must be adopted as the preferred means of cervical screening; there must be better education for practitioners and consumers on gynaecological cancers; and better and earlier diagnosis of ovarian and uterine cancer; there must be compulsory further education for all GPs regarding bowel cancer particularly regarding the fact that bowel cancer can occur at any age.
4. **Periods and menstrual health:** There must be better education and training for practitioners about endometriosis and earlier diagnosis and an improved understanding that crippling period pain is not normal. The provision of period products free to those who need it should be considered, or at the very least GST should be removed and/or period products should be re-evaluated by Pharmac for subsidy as an essential health product.
5. **Maternity and postnatal issues:** staffing/midwifery shortages and the closure of primary birthing units must be addressed; women must get the postnatal in-hospital care that they are entitled to and not be forced or encouraged to leave before they are ready; there must be an improved focus on antenatal and postnatal mental health, especially for wāhine Māori.
6. **Patient Safety:** The disproportionate impact of medical injury and harm caused by treatment must be addressed in the women's health strategy. It is critical that the women's health strategy includes mechanisms to address past harm in those still suffering the impacts of dangerous or harmful medical treatment, and ensure robust harm minimisation responses when it occurs in the future.
7. **Menopause:** there is a vital need for both health practitioners and women to be better educated about perimenopause and menopause, along with better support and treatment.
8. **Attitudes to Women and Women's Health Conditions:** The gender bias and appalling attitudes of some health care providers towards women must stop! The medical training curriculum in our medical schools must include compulsory women's health (not just obstetrics and gynaecology) to the highest level. This must include education in gender bias, and healthcare professionals acknowledging and addressing bias and discrimination in their practice. The clearly deep-seated and entrenched bias and discrimination against women on multiple levels must be eradicated and this should be a clear, non-negotiable expectation within the women's health strategy.
9. **Better Health Education for Women:** The women's health strategy must advocate for better health education for girls and women, so that they have a better understanding of their own bodies and how to achieve and maintain health. Women cannot be expected to know when something is not normal/ something is wrong, and advocate for themselves in a health care setting if they don't have sufficient knowledge of their bodies and how they work.
10. **Pandemics and climate change:** The women's health strategy must address the disproportionate impact of pandemics and climate change on women's health. Despite obvious disparities between genders, there is a lack of gender-disaggregated health data as a variable when assessing the health effects of climate change in research in Aotearoa New Zealand, and in strategic planning of mitigation and adaptation policies. This disregard for gender differences is particularly concerning as climate change is predicted to worsen existing social and economic inequalities.

There must be a change in our culture to ensure that women must not suffer a greater loss in health as the result of pandemics and weather events, and the women's health strategy must incorporate a blueprint for bringing about that change.

## Other Considerations for the Women's Health Strategy

11. **The Code of Rights must underpin all aspects of the strategy**, in particular it must address breaches of consumer rights, particularly informed consent in the delivery of women's health services.
12. **There must be a separate LGBTQI+ health strategy**. The LGBTQI+ community has specific unmet health needs that cannot be adequately addressed in the women's, Māori, Pāsifika or disabled health strategies despite the natural overlap and intersectional nature of all health strategies.

While it is vital that the women's health strategy intersectional and must consider needs of wāhine Māori, Pasifika, gay women, women with disability, trans, intersex and gender diverse people who have health needs that are in common with those whose assigned birth gender is female, that is not enough to ensure that members of the LGBTQI+ community have their health needs adequately met.

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# Background to the Auckland Women's Health Council

The AWHC was founded almost 35 years ago (July 1988) just before the release of *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters* (the Cartwright Report).<sup>2</sup> AWHC has a special interest in women's health, patient rights, informed consent and decision-making in health care, health consumer advocacy, the Code of Health and Disability Services Consumers' Rights ('Code of Rights'), consumer voice and representation, and medical ethics.

Subsequent to the Cartwright Inquiry, the AWHC played a significant role in assisting with the establishment of the National Cervical Screening Programme and in monitoring the implementation of many of the other recommendations contained in the Cartwright Report. Several of our members were involved in a variety of the working groups set up following the release of the Cartwright Report and one was appointed as the first patient advocate at National Women's Hospital, fulfilling one of the key recommendations from the inquiry. Subsequently, AWHC made submissions on the Health and Disability Commissioner Act 1994, then once the legislation was passed and the first Health and Disability Commissioner appointed, we made submissions and participated in consultation meetings that occurred during the development of the 'Code of Rights'.

The AWHC has had a long and sustained interest in patient rights, advocacy and consumer representation; our goal is to provide an independent feminist voice focused on women's and family/whānau health and health services. Over the last three and a half decades we have been active in advocating for upholding patient/ consumer rights, including making formal submissions on a wide range of health topics, such as the legislation and regulations governing various health and disability services, and in consumer representation roles relating to health and disability services.

Our priorities include: that women have the right to make informed decisions regarding their own health care and treatment; that women participate in all decision-making processes for health care services; and that women have accessible, affordable, available, and accountable health care services.

*'Historically, it has been assumed that there wasn't anything fundamentally different between male and female bodies other than size and reproductive function, and so, for years, medical education has been focussed on the male "norm", with everything that falls outside that designated as "atypical" or even "abnormal".'*

— Caroline Criado Perez, from *Invisible Women*<sup>3</sup>

In our submission on the Pae Ora (Healthy Futures) Bill, Auckland Women's Health Council argued strongly for the inclusion of a women's health strategy under the Pae Ora (Healthy Futures) Act. It is important to understand why we are such strong supporters of the women's health strategy; that the women of Aotearoa New Zealand suffer chronically unmet health needs. In this submission we outline the underlying issues in women's health, because therein lies much of the rationale for what we submit must be included in the women's health strategy.

## The Need for a National Women's Health Strategy

We are far from a situation in which all women in this country have accessible, affordable, available, and culturally appropriate and acceptable healthcare. Beyond this, an unacceptable number of women are

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2 Cartwright SR, 1988: [The Report of the Committee of Inquiry into Allegations of the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters](#), Government Printing Office, accessed at

3 Criado Perez C, 2020: *Invisible Women – exposing data bias in a world designed for men*, Vintage Publishing.

harmed in some way — often extremely seriously — by their interactions with and experiences of health care, and many more have their basic health care rights breached. For women who are Māori, Pāsifika, living with a disability or members of the LGBTQI+ community, the barriers and discrimination they face are multiplied.

For centuries women’s health has been misunderstood, misdiagnosed, ignored or invisible. All too often symptoms of physical disease or ill-health have been attributed to our gender, sexuality, hormones and reproductive organs, absolving medical practitioners through the ages of any obligation to investigate or understand us, much less treat us appropriately and with intelligence and dignity.<sup>4, 5, 6, 7</sup>

Gabrielle Jackson wrote in her book *Pain and Prejudice: a call to arms for women and their bodies*:

“From the earliest days of medicine, women have been considered inferior versions of men. In *On the Generation of Animals*, the Greek philosopher Aristotle characterised female as a mutilated male and this belief has persisted in medical culture.”<sup>8</sup>

Dr Patricia Niland and Professor Antonia Lyons write about “bias in medical textbooks used between 2004 and 2006, with gender-specific information scarce or absent for cardiovascular disease, alcohol abuse and pharmacology, and a general inference that women’s health problems were aberrations of the male norm.”<sup>9</sup>

In the third decade of the 21<sup>st</sup> century, it is clear that for the women/wāhine of Aotearoa New Zealand little has changed. Our health system is failing half the population. The overwhelming evidence is that it is a health system designed by men for men.

In their 2021 petition, the Gender Justice Collective said:

“Currently, the quality of health care that many women, wāhine, intersex, trans women and non-binary people can access depends on where they live, how much money they have and what colour they are. Racism, poverty, prejudice, discrimination, ignorance, lack of appropriate training, and a failure to listen and engage with the community are just some of the reasons for this. So, too is a lack of political will.”<sup>10</sup>

The issues that women are faced with every day in their interaction with the health system run far deeper than just inherent bias and discrimination in Aotearoa New Zealand health policy and service provision. Women have traditionally been left out of medical research altogether. Dr Janine Austin Clayton, associate director for women’s health research at the US National Institutes of Health, says “We literally know less about every aspect of female biology compared to male biology.”<sup>11</sup>

For example, almost everything we know about heart disease is based on studies of men, despite the fact that heart disease and heart attacks present differently in women. Heart disease is the leading cause of death in women, and although we have fewer heart attacks than men, we are more likely to die. A *Lancet* editorial in 2019 said: “The structural gender bias in cardiology stems from a historical failure to ensure gender

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4 McVean A, 2017: [The History of Hysteria](#), Office for Science and Society, Separating Sense from Nonsense, 31 July 2017.

5 Pagan CN, 2018: [When Doctors Downplay Women’s Health Concerns](#), *New York Times*, 3 May 2018.

6 Volck W, et al. 2013: Gynecologic knowledge is low in college men and women, *Journal of Paediatric and Adolescent Gynecology*, 2013 Jun;26(3):161-6.

7 Liu KA and Dipietro Mager NA, 2016: Women’s involvement in clinical trials: historical perspective and future implications. *Pharm Pract (Granada)*; Jan-Mar;14(1):708.

8 Jackson G, 2019: *Pain and Prejudice: a call to arms for women and their bodies*, Allen and Unwin: NSW, Australia.

9 Niland P and Lyons AC, 2011: Uncertainty in medicine: meanings of menopause and hormone replacement therapy in medical textbooks, *Soc Sci Med*; 2011 Oct;73(8):1238-45.

10 [https://www.genderjustice.nz/nwhs\\_petition](https://www.genderjustice.nz/nwhs_petition)

11 Rabin RC, 2014: [Health Researchers Will Get \\$10.1 Million to Counter Gender Bias in Studies](#), *New York Times*, 23 September 2014.

balance in cardiology research.” Women die because doctors assume that women experience heart attacks the way men do, and “women get consistently worse care... women with heart attack symptoms were less likely to receive aspirin, be resuscitated, or be transported to the hospital in ambulances using lights and sirens than were men.”<sup>12</sup>

A paper in *Nature* in 2010 concluded that “gender inequalities in biomedical research are undermining patient care.” The authors called “on journals, funding agencies and researchers to give women parity with men, in studies and in the clinic.”<sup>13</sup>

In Aotearoa New Zealand women suffer under an inadequately resourced and under-regulated health system. For example:

- Women are disproportionately affected by the harms caused by surgical mesh; 76% of ACC claims for mesh injury between 2005/06 and 2017/18 were from women.<sup>14</sup>
- Aotearoa New Zealand has a tragically high rate of maternal suicide, with 30 maternal deaths by suicide reported by the PMMRC between 2006 and 2018. “Wāhine Māori have statistically significant higher rates of maternal mortality than New Zealand European women... [suicide] remains the single largest cause of maternal death in Aotearoa/New Zealand, with suicide accounting for 44 percent of direct causes of maternal death since 2006.”<sup>15</sup>
- Access to contraceptive advice and contraception is “often guided by morality rather than evidence and informed consent.”<sup>16</sup>
- A number of small provincial birthing units have closed forcing women to have to travel long distances — sometimes for two hours or more — to have their babies. According to the Ministry of Health 2017 report on maternity, 11 primary birthing facilities have closed around the country.<sup>17</sup> Since this report was written a further unit, Lumsden, has been downgraded to a “hub” forcing local women to travel to Southland or Dunedin hospitals.<sup>18</sup>
- In a review of severe maternal morbidity (SMM) in New Zealand in 2018, researchers found that “severe maternal morbidity was 6.2 per 1000 deliveries with higher rates for Pacific, Indian and other Asian racial groups.”<sup>19</sup> The research found that “that over a third of cases were potentially preventable, being due to substandard provider care with increased preventability rates for racial/ethnic minority women.” Provider factors such as inappropriate diagnosis, delay or failure to recognise high risk were the most common factors associated with potential preventability of SMM. Pāsifika women had over twice the rate of preventable morbidity.
- Prof Jackie Cumming (Professor of Health Policy and Management, Victoria University of Wellington) has said that there are “alarmingly high rates of unmet need due to cost, particularly for Māori and Pacific women and women in the areas of lower socio-economic status.”<sup>20</sup>

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12 No authors listed, 2019: Cardiology’s Problem Women, *The Lancet*, Editorial Vol. 393, Iss. 10175, P959, March 09, 2019.

13 Kim A, 2010: Sex bias in trials and treatment must end, *Nature*, vol. 465, pp 688–689.

14 ACC, 2018: [ACC Treatment Injury Claims: Surgical Mesh-Related Claim Data From 1 July 2005 to 30 June 2018](#), ACC.

15 PMMRC, 2021: [Fourteenth Annual Report of the Perinatal and Maternal Mortality Review Committee | Te Pūrongo ā-Tau Tekau mā Whā o te Komiti Arotake Mate Pēpi, Mate Whaea Hoki: Reporting mortality and morbidity 2018](#), Health Quality & Safety Commission.

16 WHA: [A Case for a National Women’s Health Strategy in Aotearoa New Zealand](#), Women’s Health Action.

17 MoH, 2019: [Report on Maternity 2017](#), Wellington: Ministry of Health.

18 Johnston, M, 2019: [Mothers-to-be fear roadside births in frosty Southland after maternity service downgrade](#), *New Zealand Herald*, 9 June 2019.

19 Lawton BA *et al.* 2018: Preventability review of severe maternal morbidity. *Acta Obstet Gynecol Scand.*, 2018 Dec 26.

20 Cumming, J., 2017: [New Zealand’s health service performs well, but inequities remain high](#), *The Conversation*, Sept 20 2017.

- Inequity of access to quality pelvic floor health care, rehabilitation services and education on prevention (pre and post birth).<sup>21</sup>

It simply is not good enough for women in Aotearoa New Zealand to be receiving such grossly inadequate care, or for the quality of care to be so clearly tied to their ethnicity. According to Stats NZ, at 31 March 2020, females made up 51% of our population, and that 51% of the population experiences significant barriers and unmet need, including for many a lack of accessible, affordable, available, and culturally appropriate and best practice health care.

## The Aotearoa New Zealand Women’s Health Strategy

### What Our Women’s Health Strategy MUST Be

The Aotearoa New Zealand women’s health strategy MUST focus on more than sexual and reproductive health. It MUST focus on the leading causes of loss of quality of life, death and disability for women and the factors that influence women’s health.

Bonita and Beaglehole write that the global discourse on health largely views women in terms of their reproductive capacity, a persisting myth reflecting gender bias that shifts the focus away from non-communicable diseases, violence, and other injuries.<sup>22</sup> For example, gender bias results in women being asked fewer questions, and receiving fewer examinations and fewer diagnostic tests for coronary heart disease and other non-communicable diseases compared with men with similar symptoms.<sup>22</sup>

Frustratingly this is an all too familiar issue in women’s health; women are ignored or invisible, misunderstood and misdiagnosed. As a priority, the Expert Advisory Committee on Public Health (Pae Ora (Healthy Futures) Act Section 93) must include gender experts, advisors in women’s health and well-being, and lived experience consumers to ensure that this will no longer be the case in Aotearoa New Zealand.

### A Life Course Approach

***The strategy must take a life course approach that addresses health needs in different stages in a woman’s life.*** The health needs of adolescent women are vastly different from the health needs of postmenopausal women. While we tend to separate women into groups based on their sexual and reproductive stages and health, women’s health needs change significantly over the course of their lives in ways that are not necessarily dominated by their hormones and childbearing.

The life course approach focuses on understanding the changing health care needs of women and girls throughout their lives. The World Health Organisation describes the life course approach as one that “takes a temporal and societal perspective on the health and well-being of individuals and generations, recognising that all stages of a person’s life are intricately intertwined with each other, with the lives of others born in the same period, and with the lives of past and future generations. Adopting a life-course approach involves taking action early in the life-course, appropriately during life’s transitions, and together as a whole society.”<sup>23</sup>

Rather than focus on a woman’s reproductive system, a life course approach considers the many influences on a woman’s health: her biology and anatomy; behaviour, background and culture; and social determinants of health.

It is an holistic approach and considers the “whole” woman and is a “cornerstone of policy frameworks focused on improving health and health equity.”<sup>23</sup> It also offers a greater opportunities for health promotion,

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21 Wilson D and Watt K, 2021: [Perinatal pelvic floor health for all women of Aotearoa/New Zealand](#), written submission in support of the Petition of Don Wilson and Kirsty Watt: To improve pelvic floor health care for New Zealand women pre and post birth to the New Zealand Parliament.

22 Bonita R and Beaglehole R, 2014: Women and NCDs: overcoming the neglect, *Glob Health Action*; May 5;7:23742.

23 Müller A (ed), 2021: *The life-course approach: from theory to practice*. World Health Organisation: Europe.

disease prevention and management, in particular for non-communicable diseases, which are the top causes of disability-adjusted life years and death in New Zealand women.

However, the life course approach should not just take into account a woman's changing health needs over the different stages of her life, but the barriers to accessing health care, such as:

- poverty, low or fixed income, or significant commitments that reduce disposable income.
- childcare or elder care commitments, difficulty attending appointments that are only available during working hours, lack of transport options, or the need to bring children to appointments.
- reduced mobility or disability with age and/or the impacts of degenerative conditions, loss of independent transport options due to age.
- reduced cognitive abilities as the result of dementia.
- social isolation due to health conditions or loss of family members and friends in old age.

### Achieving and Maintaining Health

**The strategy must focus on achieving and maintaining health not just treating ill-health.** While women in Aotearoa New Zealand live longer on average than men, they live more of their life with disability or poor health. In 2013, wāhine/women had a life expectancy of 83.2 years, yet their health expectancy was only 65.2 years, meaning that on average they spend 18 years in poor health!<sup>24</sup>

Addressing health and well-being – or lack of – in women/wāhine is not just about having a well-resourced, highly functional health system that delivers best practice, evidence-based medicine. To attain health, well-being and healthy longevity necessitates addressing social and commercial determinants of health and focusing on prevention of disease, particularly non-communicable and degenerative diseases, which significantly take away from productive healthy lives and contribute to disability-adjusted life years (DALYs).

In 2019, nine of the top ten causes of DALYs for New Zealand women were non-communicable diseases<sup>25</sup>:

- Ischaemic heart disease
- Alzheimer's and other dementias
- Falls
- Chronic obstructive pulmonary disease
- Anxiety disorders
- Stroke
- Breast cancer
- Gynaecological diseases
- Back and neck pain
- Depressive disorders

In New Zealand in 2019, the top ten causes of death in women were:<sup>25</sup>

- Ischaemic heart disease
- Alzheimer's and other dementias
- Stroke
- Chronic obstructive pulmonary disease
- Trachea, bronchus and lung cancer
- Colorectal cancer
- Breast cancer
- Lower respiratory tract infection
- Diabetes mellitus
- Falls

The *Health and Disability System Review – Final Report – Pūrongo Whakamutunga* concluded that “The health and disability system is not the main factor in determining health outcomes. If New Zealand does not

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24 MSD, 2016: *The Social Report 2016 | Te pūrongo oranga tangata*, Ministry of Social Development, June 2016, Wellington: NZ.

25 [WHO: Global health estimates: Leading causes of DALYs: Disease burden, 2000–2019](#) (Top 10 causes of DALY and death in New Zealand for females aged all ages 2019).

significantly reduce intergenerational poverty and act on the social determinants of health, little that happens in the health and disability system would have a lasting impact.”<sup>26</sup>

It is imperative that the social and commercial determinants of health are given a high priority in the women’s health strategy. Health education and prevention of disease must be a high priority in order to ensure that our wāhine/women spend more of their lives in good health. Health education for girls must start in primary school and continue into high school, so that knowledge of what good health looks like and how it is achieved is embedded early in life.

## Factors That Influence Women’s Lives and Health

***The strategy must acknowledge the factors that influence women’s lives and health, such as ethnicity, disability, sexual identity and background.***

Many of the factors that influence a woman’s health are entirely beyond her control. Disability and ethnicity or cultural identity are two factors that significantly impact on the health and well-being of women/wāhine of Aotearoa New Zealand.

We acknowledge that there are separate health strategies for Māori, Pāsifika and those living with disabilities. However, the women’s health strategy must also consider, analyse and address the unmet health needs of these women who face a multiplicity of barriers and discrimination.

International studies, particularly in the USA, have shown that, for example, disabled women with breast cancer may experience higher rates of morbidity and mortality than non-disabled.<sup>27</sup> Studies, including those in Aotearoa New Zealand, have also shown that disabled women experience multiple barriers when accessing health services (such as cervical and breast cancer screening), such as structural, physical, economic, attitudinal and knowledge barriers.<sup>28, 29, 30</sup>

The *Health and Disability System Review – Final Report* stated that “Evidence shows that disabled people have more frequent contact with the health and disability system but do not achieve equity of health outcomes when compared with the rest of the population. They report poorer health than their non-disabled peers and may experience multiple barriers in accessing health services.”<sup>26</sup>

“Physically disabled adults experience a higher prevalence of chronic diseases including arthritis, asthma, cardiovascular disease, diabetes, high blood pressure, high cholesterol and stroke,” and “people who have an intellectual disability have high levels of unmet health need.”<sup>31</sup>

It is important that the definitions of disability used comply with the UN Convention on the Rights of Persons with Disabilities. It is apparent that not all health entities and health related Government agencies use an adequate or complete definition of disability, and the women’s health strategy must ensure it is inclusive of all women living with a disability.

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26 Health and Disability System Review, 2020: *Health and Disability System Review – Final Report – Pūrongo Whakamutunga*. Wellington: HDSR, accessed at <https://www.systemreview.health.govt.nz/final-report>

27 McCarthy EP, et al., 2006: Disparities in breast cancer treatment and survival for women with disabilities, *Annals of Internal Medicine*, 2006 Nov 7;145(9):637-45.

28 Hanlon E and Payne D, 2017: Cervical screening for women with physical disabilities, *Kai Tiaki Nursing New Zealand*, December 2017/January 2018; vol. 23 no. 11: pp22-25.

29 Krahn GL, et al., 2015: Persons with disabilities as an unrecognized health disparity population, *American Journal of Public Health*, 2015 Apr;105 Suppl 2(Suppl 2):S198-206.

30 Pearson, J et al., 2022: Access to and engagement with cervical and breast screening services for women with disabilities in Aotearoa New Zealand, *Disabil Rehabil*; May;44(10):1984-1995.

31 Mirfin-Veitch B and Paris A, 2013: [Primary health and disability: A review of the literature](#), Te Pou o Te Whakaaro Nui.

Māori have been at the sharp end of inequities and disparities in our health system for decades. There have been myriad reports, medical papers and media articles that set out the issues — from overt racism to widespread deprivation — that plague Māori health. Between 1992 and 2016 alone, there were 107 Ministry of Health reports on Māori health outcomes and disparity in outcomes between Māori and non-Māori.<sup>32</sup> It is hard to see where there has been any improvement in health outcomes for Māori in the last thirty years, despite these 107 (and more since 2016) reports.

Manatū Hauora data shows that wāhine Māori have a life expectancy at birth nearly seven years shorter than non-Māori,<sup>33</sup> and are more likely to report being unable to access GP and after-hours services because of a lack of transport or the cost.<sup>34</sup>

Dr Sarah-Jane Paine told Māori current affairs show *The Hui* in 2021 that wāhine Māori have trouble accessing treatment, and when they do, it's often of a lower standard; for example, research shows Māori women are less likely to be offered C-sections and epidurals when in labour.<sup>35</sup>

A 2020 study published in the *New Zealand Medical Journal* confirms that racial discrimination is associated with a range of poorer health outcomes and reduced access to and quality of healthcare.<sup>36</sup> It is clear that racism compounds experiences and outcomes for women.<sup>37</sup> Unfortunately, racism operates at the highest levels of the health system in Aotearoa New Zealand. Research published in *Kotutui: New Zealand Journal of Social Sciences Online* in 2019, found that inequalities in the health system are reproduced in advisory committees.

Māori and Pasifika leaders “noted their knowledge and interests were devalued and they experienced racism and tokenistic engagement. Some indicated it took considerable effort to establish credibility, be heard, have impact, and navigate advisory meetings, but even then their inputs were marginalised.”<sup>38</sup>

The women's health strategy must be a catalyst for change in the health of wāhine Māori and Pāsifika women. Māori and Pāsifika health leaders must be embraced and their expertise endorsed and recognised. And it is vital that culturally appropriate healthcare is prioritised in the strategy.

***The strategy must address the social determinants of health.*** Gender is a social determinant of health, and there is a complex interplay between gender and other factors, such as income and poverty; education; occupation; housing; tobacco, alcohol and drug use; and domestic violence.

While many of the social determinants of health lie outside of the health system – income and poverty; education; occupation; housing and homelessness; tobacco, alcohol and drug use; and domestic violence – health policy, including the women's health strategy, must take account of these and the myriad other factors that influence a woman's health.

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32 MoH, 2017: Ministry of Health reports on Māori health outcomes and disparity in outcomes between Māori and non-Māori from 1992 to 2016, Ministry of Health, July 2017.

33 MoH, 2018: [Life Expectancy](#), Manatū Hauora | Ministry of Health: New Zealand.

34 MoH, 2018: [Primary health care](#), Manatū Hauora | Ministry of Health: New Zealand.

35 Slatherly D, 2021: [Why Māori women aren't accessing the healthcare they need, and how the new Māori Health Authority could fix that](#), *The Hui*, NewsHub, 4 May 2021.

36 Talamaivao N, *et al.*, 2020: Racism and health in Aotearoa New Zealand: a systematic review of quantitative studies, *NZ Med J*; Sep 4;133(1521):55-68.

37 Matheson A, *et al.*, 2021: Women, Patriarchy and Health Inequalities: The Urgent Need to Reorient Our Systems, *Int J Environ Res Public Health*; 2021 Apr 23;18(9):4472.

38 Came H, *et al.*, 2019: Māori and Pasifika leaders' experiences of government health advisory groups in New Zealand, *Kotutui: New Zealand Journal of Social Sciences Online*.

There is no lack of research and analysis in Aotearoa New Zealand on the social determinants of health; recognition of the need to address them is not new:

In 1998 a report from the National Advisory Committee on Health and Disability<sup>39</sup> found that:

- social, cultural and economic factors are the main determinants of health;
- there are persisting health inequalities as a result of socioeconomic factors in New Zealand and some evidence that these may be worsening;
- current trends in many socioeconomic factors in New Zealand are likely to widen health inequalities further;
- there are good reasons for intervening to reduce socioeconomic inequalities in health;
- there are evidence-based interventions for reducing these inequalities.

Twenty-five years on from this report and these issues remain, and progress has been inadequate. What is required is an all of Government, cross-party commitment to addressing and resolving the social determinants of health that currently ensure that many New Zealanders go without many of the things they need for health and wellbeing. All the health strategies under the Pae Ora (Healthy Futures) Act must address the social determinants of health.

In this submission, we wish to focus on one factor: poverty... specifically poverty in childhood. Poverty and material hardship has been a major policy focus of the current Labour Government. However, the Covid pandemic, recent weather events and the cost of living crisis have only served to place more pressure on families living with the highest levels of deprivation in Aotearoa New Zealand.

Despite Government commitments to reducing the number of children living in poverty in this country, not only has there been no improvement, but it has gotten worse.

In 2019, 235,400 children (21.0%) lived in a low-income household.<sup>40</sup> In addition, in 2018/2019:<sup>41</sup>

- children living in the most disadvantaged communities were more than twice as likely to end up in hospital as those from the most advantaged communities;
- one in five children lived in households without access to enough food or healthy food; severe-to-moderate food insecurity was experienced in 42.8% of households with children with income at or below \$50,000 per annum.
- 282,228 children lived in damp housing and 237,543 in housing with mould;
- 77,976 under-18 year olds lived in homes without access to one or more basic household amenities such as safe tap water, cooking and washing up facilities, a bath or shower, a toilet, a refrigerator or a supply of electricity.

A 2021 report found that none of the Government-convened Welfare Expert Advisory Group's (WEAG) 42 key recommendations on a programme of 'overhaul' for the welfare system had been fully implemented.<sup>42</sup> The report's authors say that "The number of children living in benefit-receiving households has risen by over

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39 National Health Committee, 1998: [The Social, Cultural and Economic Determinants of Health in New Zealand: Action to Improve Health](#), A Report from the National Advisory Committee on Health and Disability, June 1998.

40 A low income household is defined as one with equivalised disposable income below 50% median income after housing costs. Housing costs are regarded as non-discretionary, as households cannot simply decide not to incur them. See footnote 41.

41 Duncanson M, et al., 2020: *Child Poverty Monitor 2020 Technical Report*, NZ Child and Youth Epidemiology Service, University of Otago, Dunedin.

42 Neuwelt-Kearns C, et al. 2021: [Children can't live on promises: A 2021 stocktake of implementation of the Welfare Expert Advisory Group's 2019 recommendations](#), Child Poverty Action Group, December 2021.

15% in the last two years to 208,000 children, roughly one in every five in Aotearoa. Yet the social security system still provides inadequate income and other support for these families, who are among the most likely to live in entrenched poverty.”<sup>42</sup>

The report goes on to express concern that “it could take decades to implement welfare reform as envisioned by WEAG”<sup>42</sup>, thus ensuring that the children who currently live in poverty may be consigned to lifetime of health inequity and poor health outcomes. As this submission is being written, it has been revealed that scant progress has been made in reducing child poverty in the four years since this country began measuring and reporting on material hardship. After a 2.3 per cent decline in material hardship between 2018-21, no further gains were made in 2022. The newly released figures only go to June 2022, before the advent of the current cost of living crisis; next year’s figures may tell a more devastating story.<sup>43</sup>

One out of every five girls in Aotearoa New Zealand live their lives in poverty, and the impact that this will have on the health of those girls later in life cannot be underestimated. A recent study of 10,784 adults in the US found that “severe indicators of childhood poverty are associated with general and chronic health problems as well as adult depression.”<sup>44</sup>

Data from the Dunedin Multidisciplinary Health and Development Study found that, compared with those from high socioeconomic status backgrounds, children who grew up in low socioeconomic status families had poorer health at the age of 26 across all health measures (except systolic blood pressure), irrespective of health in infancy or adult socioeconomic status.<sup>45</sup> The study concluded that subsequent higher socioeconomic status “did not mitigate or reverse the adverse effects of low childhood socioeconomic status on adult health.”

A subsequent analysis of data from the Dunedin Study, that followed the cohort to the age 32, confirmed that “low childhood [socioeconomic status] was associated with an increased risk of substance dependence and poor physical health in adulthood.” The authors found that adults who had “experienced childhood disadvantage were especially likely to experience multiple health problems by the time they reached adulthood” compared with those from high childhood socioeconomic status group.<sup>46</sup>

This study also found that there was an intergenerational impact on health: low socioeconomic status children were more likely than high socioeconomic status children to carry a familial liability to poor health.<sup>46</sup>

For the health of our wāhine/women, we must address poverty in Aoteroa New Zealand, and the financial barriers to health, not just the barriers to accessing health care, must be addressed in the women’s health strategy.

#### A National Health Needs Assessment and Gender Analysis

***The strategy must include a national health needs assessment for women and provide for gender analysis in any assessment of population health needs; a gendered approach to the collection and utilisation of health data.***

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43 Grant M and Prickett K, 2023: [Child poverty in NZ: The plateau is a signal for change](#), *New Zealand Herald*, 23 March 2023.

44 Lee H, *et al.*, 2021: Childhood Poverty, Adverse Childhood Experiences, and Adult Health Outcomes, *Health Soc Work*; Aug 5;46(3):159-170.

45 Poulton R, *et al.*, 2002: Association between children's experience of socioeconomic disadvantage and adult health: a life-course study, *Lancet*; Nov 23;360(9346):1640-5.

46 Melchior M, *et al.*, 2007: Why do children from socioeconomically disadvantaged families suffer from poor health when they reach adulthood? A life-course study, *Am J Epidemiol*; Oct 15;166(8):966-74.

We cannot possibly improve the health of our wāhine/women if we do not first undertake a gendered health needs assessment. Gender-based analysis by must be an integral part of the women's health strategy and there must be equitable allocation of health research resources to the health concerns of women.

The argument for a gendered health needs assessment is effectively set out in [The Need for a National Women's Health Strategy](#) on page 5. Just three of hundreds of examples in the medical literature and in the media illustrate the attitude to women's health:

- for patients with irritable bowel syndrome, doctors were more likely to suggest that male patients receive X-rays and more likely to offer female patients tranquilisers and lifestyle advice;<sup>47</sup>
- women report more severe levels of pain, more frequent incidences of pain, and pain of longer duration than men, but are nonetheless treated for pain less aggressively;<sup>48</sup>
- women repeatedly told by multiple doctors that their issues were stress-related or all in their heads, only to finally be diagnosed with serious neurological problems, like multiple sclerosis and Parkinson's disease.<sup>49</sup>

Women's bodies, with their complex hormones and reproductive organs, are left out of medical research, even research on conditions that predominantly affect women, such as pain syndromes and autoimmune diseases. Within the provision of health services in Aotearoa New Zealand – and elsewhere – women's health is at the bottom of the pile in terms of resourcing, in terms of informed consent, and in terms of being managed and treated appropriately and in a timely manner.

It is all too apparent that many women's health issues are simply put in the too hard basket; it is easier to ascribe the symptoms women present with to either mental health and psychological issues, or to our sex, than to fully investigate a physical cause for what we experience... and it has been this way for centuries.

Here, in the third decade of the 21<sup>st</sup> century it needs to stop, and we must have a thorough gendered analysis of the health needs of ALL our wāhine/women.

#### Examination of the Pathways and Quality of Care for Women

***The strategy must facilitate the examination of the pathways and quality of care for women within the health system, and identify evidence-based strategies that could be implemented to ensure women receive the best available care.***

Pathways set out a process of best practice to be followed in health care for women. Such pathways may be very different from the pathways for men, even for the same condition or disease. They guide evidence-based healthcare and appropriate pathways should lead to improved quality of care for women. They should also contribute to ensuring that women can access quality healthcare no matter where in Aotearoa New Zealand they live.

#### The Need for Resources to Address a Broader, Integrated Women's Health Agenda

***The strategy must consistently recognise, promote and allocate resources to address a broader, integrated women's health agenda.***

We recognise that adequate resourcing of our health system is a tight-rope act. There are always more and more demands for better financial, staffing, medicines and capital resourcing. However, the long term

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47 Hamberg K *et al.*, 2004: Male and female physicians show different patterns of gender bias: a paper-case study of management of irritable bowel syndrome, *Scandinavian Journal of Public Health*, 2004;32(2):144-52.

48 Hoffmann DE and Tarzian AJ, 2001: The girl who cried pain: a bias against women in the treatment of pain, *Journal of Law, Medicine and Ethics*, 2001 Spring;29(1):13-27.

49 Pagan CN, 2018: [When Doctors Downplay Women's Health Concerns](#), *New York Times*, 3 May 2018.

downstream reduced costs and significant benefits, not only in the health system, but for individuals, families/whānau and the community, of improving women's health outweigh the monetary value. It is vital that resourcing for both reproductive health and maternity services, and prevention and reduction of the burden of non-communicable diseases are prioritised in resource allocation. Norton *et al.* find that if a broader, integrated women's health agenda is not adequately resourced, what investment there is in women's health will lead to decreasing returns.<sup>50</sup>

Dr Christine Ngaruiya, Director of Global Health Research, uses an example of how gender disparities in health, impact how resources are allocated. She says that "women have different risk factors and higher morbidity for chronic respiratory disease compared to men but morbidity is shadowed by a penultimate research focus on mortality, which results in less attention to the gap in women's [non-communicable disease] outcomes. This, in turn, affects how resources, programs, and interventions are implemented."<sup>51</sup>

### Addressing the Barriers to Women Seeking Early Care

***The strategy must address the barriers to women seeking early care (which include time, responsibilities, care of other family members, childcare, jobs and transport, as well as financial considerations), and develop and implement strategies to improve timely access to care.***

Despite the fact that we have a socialised universal health care system, accessing health care is not free. Cost is a significant barrier for women in living with the greatest deprivation. If urgent health care is required, either on a weekend when a woman's own GP is unavailable, or if there are no urgent appointments available, there are few options. A woman can do nothing; attend A&E at the nearest public hospital and face, at times, hours long waits (not to mention placing more pressure on a service that is already struggling to cope with demand<sup>52, 53</sup>); or attend a private urgent care provider, where fees are often significantly higher than the GP unless you fall into a high needs group and qualify for a Community Services Card or similar.

However, cost is not the only factor. Women also face difficulties with physical access to available services, social issues such as problems with childcare, accessing transport; language barriers; and many mothers prioritise their children's needs and health over their own.<sup>54, 55</sup>

Studies have shown that disabled women experience multiple barriers when accessing health services (such as cervical and breast cancer screening), such as structural, physical, economic, attitudinal and knowledge barriers.<sup>56, 57</sup> Mirfin-Veitch and Paris concluded in their review of primary health and disability that "for many disabled people, access to primary care is limited at the practice level through inaccessible premises, health information provided in inaccessible formats, and inexperienced health professionals."<sup>58</sup>

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50 Norton R, *et al.*, 2016: *Women's health: a new global agenda*. Oxford: Oxford Martin School.

51 Ngaruiya C, 2022: When women win, we all win – Call for a gendered global NCD agenda, *FASEB Bioadv*; Nov 25;4(12):741-757.

52 Quinn R, 2023: [Ambulances turned away from Auckland Hospital's full emergency department](#), *Radio New Zealand*, 8 March 2023.

53 Frascatore E, 2022: [It's a waiting game in our overloaded and under pressure hospitals](#), *Stuff*, 3 July 2022.

54 Dawson P, *et al.*, 2019: Barriers to equitable maternal health in Aotearoa New Zealand: an integrative review, *International Journal for Equity in Health* vol. 18, Article number: 168.

55 Jatrana S and Crampton P, 2009: Primary health care in New Zealand: who has access? *Health Policy*; Nov;93(1):1-10.

56 Hanlon E and Payne D, 2017: Cervical screening for women with physical disabilities, *Kai Tiaki Nursing New Zealand*, December 2017/January 2018; vol. 23 no. 11: pp22-25.

57 Krahn GL, *et al.*, 2015: Persons with disabilities as an unrecognized health disparity population, *American Journal of Public Health*, 2015 Apr;105 Suppl 2(Suppl 2):S198-206.

58 Mirfin-Veitch B and Paris A, 2013: *Primary health and disability: A review of the literature*, Te Pou o Te Whakaaro Nui.

On top of these barriers, there is a chronic shortage of GPs. According to the Royal New Zealand College of General Practitioners, the number of GPs per 100,000 people is projected to fall from 74 in 2021 to just 70 in 2031 (a shortage of 300 GPs nationwide), further impacting on patient access to care.<sup>59</sup>

### Clinical Trials must Include Proportionate Numbers of Women and Gendered Analyses

***The strategy must require that all medical and health research in Aotearoa New Zealand is appropriately designed to facilitate the inclusion of gendered analyses, and that appropriate and representative numbers of women are included in clinical trials.***

Internationally women tend to be significantly underrepresented in research both as researchers and research participants; they receive less research funding and appear less frequently than men as authors on research publications.<sup>60</sup>

It has been acknowledged in recent decades “that clinical trials have not always adequately enrolled women or analysed sex-specific differences in the data. Such deficiencies have given an often incomplete or incorrect understanding of women’s experience of disease and response to medications.”<sup>7</sup>

For example, despite the fact that cardiovascular disease is one of the leading causes of mortality and morbidity in women, “even in contemporary research, female patients are poorly represented in trials.”<sup>61</sup> UK researchers found that enrolment bias is an important contributing factor, and that “sex-related eligibility criteria, recruitment in ambulatory settings and male chief investigators were associated with underenrolment of women.”<sup>61</sup>

Gender bias in biomedical and health research involves both biological sex differences and sociocultural differences in the way women and men behave, and in the way they are treated.<sup>60</sup>

While we may have no control over research and clinical trials undertaken internationally, research and trials carried out in Aotearoa New Zealand must be done differently; better! The women’s health strategy must prioritise a gendered approach to the collection and analysis of research data, and require that all research approved must include representative numbers of women and include gendered analyses.

### A Consumer and Patient-Centred Strategy

***The strategy must be consumer and patient-centred: consumers must be involved in monitoring and reviewing the progress of the women’s health strategy, and assessing how the health system has performed against the strategy.***

The AWHC strongly believes in the importance of the consumer voice in health care. One of our stated objectives is that ‘women participate in decision-making processes for health care services’.

A patient-centred health system goes well beyond consumer participation or engagement at a policy and governance level, or in the design and delivery of services. Consumers must be at the heart of the health system including the women’s health strategy. We must have a seat at the table at ALL levels of the health system. The women’s health strategy must be informed by the lived experience of women from throughout Aotearoa New Zealand, especially those living with intersectional inequities and the women who are hard to reach.

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59 Grimmond D, et al., 2021: 2021 GP Future Workforce Requirements Report, October 2021, Allen & Clarke, commissioned by the RNZCGP.

60 Ovseiko PV, et al., 2016: A global call for action to include gender in research impact assessment, *Health Res Policy Syst*; Jul 19;14(1):50.

61 Morgan H, et al., 2022: Evaluation of the causes of sex disparity in heart failure trials, *Heart*; Sep 12;108(19):1547-1552.

The women's health strategy must also be monitored and reviewed, not just as required by Section 48 of the Pae Ora (Healthy Futures) Act 2022, but against women's needs and expectations. Reviews and monitoring must involve women health consumers in compliance with The Code of Expectations for Health Entities' Engagement with Consumers and Whānau.

We understand that engaging with consumers takes a lot of time, it makes things messy for advisors, policy makers and legislators who like things nice and tidy, dispassionate, impersonal and nailed down. The reality is that people are messy and difficult and take time. But people are also experts by experience; we know as much if not more about what we need from our health system than the advisors and policy makers do. We know that if consumers don't have a say about issues that affect them it makes for very poor outcomes.

## Critical Issues in Women's Health

There are myriad issues in women's health in Aotearoa New Zealand that need addressing: those needing faster diagnosis and treatment; that require more health practitioners to have better training, knowledge and skills; that require more and better resourcing on multiple levels, among other things. It is not possible to cover them all in this submission, but we wish to briefly outline some of the most important issues.

### Cancer

1. Increasing cancer incidence, and delays in diagnosis and treatment must be addressed. Hospitals and clinics must be adequately resourced to meet demand in women's services to avoid delays in assessment, diagnosis, and treatment of gynaecological cancers. It is unconscionable that gynaecology at Middlemore, one of Aotearoa New Zealand's biggest hospitals, serving a community with high health needs, must turn women away for serious conditions and symptoms that may indicate cancer. In 2018, a South Auckland GP said that "the real risk is that cancers are missed if these procedures are being delayed." Women were waiting up to six months for procedures to help rule out cancer.<sup>62</sup> More than four years later, during which time the Covid-19 pandemic put more pressure on already overworked and understaffed hospitals, it is hard to imagine that the situation could have improved. In 2020, Medical Director of the Cancer Society, Dr Chris Jackson, said delays were not limited to Counties Manukau or to any one type of cancer, and that any delay is unacceptable, and district health boards (replaced by regions within Te Whatu Ora in 2022) must be able to properly care for their populations.<sup>63</sup>
2. Gynaecological cancers:
  - a) There must be free access to cervical screening, just as breast and bowel screening are free. While the Government announced in May 2021 that the soon to be introduced HPV test will be free, they can only be done at healthcare provider and women will have to pay a normal consultation fee. So, not really free! Despite the reduction in cost, the consultation fee will still be a barrier to access for women already struggling financially.
  - b) The NCSP must adopt home-based self-testing for HPV. A trial in Northland in never- and under-screened women found that women were much more likely to take part if they were in the home-based group, particularly wāhine Māori.<sup>64</sup> Home-based self-testing significantly removed barriers for some of our most vulnerable women and those who are harder to reach, particularly wāhine Māori and Pāsifika. Given that the bowel screening is a self-test at home and the NSU has all the mechanisms in place to make it work, there is no valid reason why it can't be rolled out in cervical screening. As well as reaching more women it would also reduce costs for both the health system

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62 Jones N, 2018: [Cancer warning as delays hit gynaecology services: 'Lives put at risk'](#), *New Zealand Herald*, 22 November 2018.

63 Quinn R, 2020: [Obese people facing delays for gynaecological cancer diagnosis](#), *Radio New Zealand*, 17 December 2020.

64 Bartholomew K, *et al.*, 2021: Recommendations for implementing HPV self-testing in Aotearoa, *NZ Med J*; May 21;134(1535):11-16.

and for consumers. Bartholomew *et al.*, recommend at least an ‘on-request’ service of mailed self-testing kits, leveraging knowledge from local research and approaches used in the National Bowel Screening Programme.<sup>64</sup> However, we see no reason why this should not be a standard screening service for all eligible women.

- c) There must be better education for practitioners and consumers about gynaecological cancers, and better and earlier diagnosis of ovarian and uterine cancer. The five gynaecological cancers – cervical, uterine (including endometrial), ovarian, vulval and vaginal – make up 10% of new cancer diagnoses in women/wāhine, and 10% of the total deaths from cancer in women/wāhine.<sup>65</sup> However, collectively the mortality rate for gynaecological cancers is higher than both breast and colorectal cancers, the two cancers that are statistically in the top ten for morbidity and mortality in women. The mortality rate for ovarian cancer is particularly high. In 2020, 1300 women were diagnosed with a gynaecological cancer, and 497 women died.<sup>65</sup> The two cancers that get most of the attention are breast and cervical, for which there are screening programmes. In the early stages of ovarian cancer (which has the highest mortality rate) symptoms are difficult to detect, and the late stage symptoms are non-specific – fatigue, abdominal bloating, change in bowel habits, more frequent urination, back ache and abdominal or pelvic pain, menstrual irregularities, indigestion, unexplained weight loss or gain. As women age, many conditions can cause these symptoms.
3. There must be compulsory further education for all GPs regarding bowel cancer. There have been far too many cases in which people under the age of 50, presenting with bowel cancer symptoms, have been “fobbed off” by their GP as being too young to have bowel cancer.<sup>66, 67, 68</sup> Researchers from Otago University Medical School found that those under the screening age for bowel cancer (<60 years) were significantly more likely to experience a delay in diagnosis despite presenting to a health care professional with concerns, including symptoms typical of colorectal cancer.<sup>69</sup> Colorectal cancer is the sixth biggest killer of wāhine/women; no health practitioner in this country should remain unaware that bowel cancer can strike at almost any age, and there should be no barriers within the health system to prevent early diagnosis in those presenting with any bowel cancer symptoms.

## Menstrual Health and Periods

1. **Endometriosis:** There must be better education and training for health practitioners regarding abnormal menstrual bleeding and pain. Similarly, there should be better puberty education for girls that includes quality information about what can be considered normal and what should be investigated in a healthcare setting; crippling pain is not normal and must never be passed off as normal by any health care professional.

In Aotearoa New Zealand, “mean diagnostic delay for those with endometriosis [is] 8.7 years, including 2.9 years between symptom onset and first presentation and 5.8 years between first presentation and diagnosis. Five doctors on average [are] seen prior to diagnosis.”<sup>70</sup>

It is estimated that 10% of women suffer from endometriosis, about 120,000 girls and women in Aotearoa New Zealand. Many women with endometriosis are dismissed by their health professionals; they are told what they are experiencing is a normal part of being a woman, it’s “all in their head”, that

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65 Ferlay J, *et al.*, 2020: [Global Cancer Observatory: Cancer Today](#), Lyon, France: International Agency for Research on Cancer.

66 Russell E, 2019: [Cancer: \\$15 million paid to cancer sufferers let down by public system](#), *New Zealand Herald*, 6 May 2019.

67 Russell E, 2019: [Worrying trend: Study shows more young Kiwis getting bowel cancer](#), *New Zealand Herald*, 17 May 2019

68 Broughton C, 2019: [Young cyclist dying of cancer regrets not 'pushing harder' for diagnosis](#), *Stuff*, 26 January 2019

69 Windner Z, *et al.*, 2018: New Zealanders’ experiences and pathways to a diagnosis of bowel cancer: a cross-sectional descriptive study of a younger cohort, *New Zealand Medical Journal*, Vol 131 No 1483: 5 October 2018.

70 Tewhaiti-Smith J, *et al.*, 2022: An Aotearoa New Zealand survey of the impact and diagnostic delay for endometriosis and chronic pelvic pain, *Sci Rep*; Mar 15;12(1):4425.

they are neurotic or that it's just anxiety or stress. It is unacceptable that wāhine/women suffer with endometriosis as long as they do and see as many doctors as they do before getting a diagnosis. The entirely unprofessional behaviour of some doctors in dealing with endometriosis sufferers, and the dismissal of the pain and disability that many women endure with their periods and endometriosis, must be addressed. Endometriosis is a relatively common condition and there is no excuse for any GP to not immediately suspect it when girls and young women present with severe abnormal period or pelvic pain, among a variety of other symptoms.

2. **Period Products:** The cost of period products is a significant issue for many women, especially those living in poverty. Research has found that 12% of students in Years 9 to 13 who menstruate reported difficulty getting access to products due to cost, and that one in 12 girls have missed school during their periods because they don't have access to period products.<sup>71</sup> A 2018 KidsCan survey found "29% of 15-17 year old respondents said they had missed school due to a lack of access to sanitary items. When unable to afford sanitary items, they reported using toilet paper, rags, old cloths, and nappies."<sup>72</sup>

In February 2020, the Labour Government announced that all primary, intermediate, secondary school and kura students will have access to free period products from June 2020.<sup>73</sup> The reality is that the problem is less **period poverty** and more just straight **poverty**. But in the absence of adequately addressing poverty\* far more must be done to ensure that women do not have to make choices between food on the table, paying rent or mortgage or buying period products.

Only months after our Government put free period products into schools, Scotland became the first country in the world to approve free period products for anyone. The Scottish Parliament unanimously voted in favour of making it "a legal duty on local authorities to provide free items such as tampons and sanitary pads to 'to anyone who needs them'".<sup>74</sup> The ideal in Aotearoa New Zealand is also for period products to be free for anyone who needs them. Failing that, we should either be removing GST from them or they should be re-evaluated by Pharmac for subsidy as an essential health product.

\* As this submission is being written, it was revealed that scant progress had been made in reducing child poverty in the four years Aotearoa New Zealand began measuring and reporting on material hardship, and the newly released figures only go to June 2022 before the current cost of living crisis.<sup>43</sup>

## Maternity and Postnatal Health Issues

Aotearoa New Zealand's Model of Maternity Care has been described as the envy of women around the world, and supposedly gives women the opportunity to make choices about their pregnancy, including their lead maternity career (LMS) and their place of birth. Ady Priday, a South Auckland Lead Maternity Care midwife, says "Our system is the envy of the world in terms of good outcomes and yet not everyone here seems to value it."<sup>75</sup>

Most importantly our Government doesn't seem to value it.

Years of under resourcing of the maternity services sector has seen midwives leaving the profession in their droves,<sup>76</sup> women struggling to find a midwife at all let alone one of their choosing, and women being

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71 Fleming T, et al., 2020: [Youth19– Period Poverty Fact Sheet](#), Youth19 A Youth 2000 Survey.

72 KidsCan, 2020: [More action needed to combat young people's experiences of period poverty](#), 20 February 2020.

73 Ardern J and Tinetti J, 2020: [Free Period products to be available in all schools and kura](#), Ministerial Press Release, 18 February 2020.

74 Diamond C, 2020: [Period poverty: Scotland first in world to make period products free](#), *BBC Scotland News*.

75 Emma Espiner E, 2019: [Time to recognise midwives](#), *Newsroom*, 19 December 2019

76 Meier C, 2018: [Thousands of women unable to find midwife for Christmas holiday births](#), *Stuff*, 16 February 2018

discharged from maternity wards before they are ready to leave.<sup>77</sup> The role of midwives is so undervalued that many are leaving the profession, and some independent midwives effectively work for as little as \$7 to \$12 an hour.<sup>78</sup> In addition, the closure of provincial birthing units has put the lives of mothers and babies at risk.

A number of small provincial birthing units have closed forcing women to have to travel long distances – sometimes for two hours or more – to have their babies. According to the Ministry of Health 2017 report on maternity, 11 primary birthing facilities have closed around the country.<sup>79</sup> Since this report was written a further unit, Lumsden, was downgraded to a “hub” forcing local women to travel to Southland or Dunedin hospitals.<sup>80</sup> The MoH *Report on Maternity* isn’t published in that format any longer, however, online research has revealed that since 2019 a further five primary birthing units have closed.

Another issue is that, although women are entitled to 48 hours postnatal in-hospital care, women have been asked to leave within 12 hours because beds are needed.<sup>81</sup>

Even if sufficient resourcing is provided right now, it is going to take years to undo the harm done by chronic under-resourcing of the maternity sector. It will take years to graduate sufficient numbers of new midwives to address the current chronic shortage, and raise staffing to levels that will ensure that mothers and babies are safe and well cared for during pregnancy, labour and in the post-natal period that is so critical for the contributing to life-long health.

We are doing no better in maternal mental health. In their 2021 annual report, the Perinatal and Maternal Mortality Review Committee (PMMRC) reported on maternal suicide. Between 2006 and 2018 there were 30 maternal deaths by suicide reported by the PMMRC.<sup>82</sup> In comparison with the UK, we have five times the maternal suicide rate, while the differences in other causes of maternal death between the two countries were statistically insignificant.<sup>82</sup>

While the majority of maternal suicides occur in the postpartum period (56%), a significant proportion occur during pregnancy (41%). The PMMRC said that “in contrast to previous thinking, pregnancy is not necessarily protective of death by suicide.”<sup>82</sup>

In 2022, the report *Āhurutia Te Rito It takes a village*<sup>83</sup> was released. Author, Holly Walker was driven by her own experiences to ask “how mothers and birthing parents are supposed to cope with the myriad stresses and challenges that can accompany the birth of a new baby in contemporary Aotearoa.”

She wrote in her ‘Author’s Note’ that in 2019 she attended a meeting at which Professor Sir Peter Gluckman said that maternal mental health (particularly during pregnancy) was emerging as perhaps the single biggest factor in determining long term child health and wellbeing.

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77 NZCOM, 2020: [Midwives Baffled and Disappointed by Lack of Govt Financial Support](#), Press release, 21 April 2020

78 Midwives march: ‘I’ve never seen such a level of hopelessness’, Checkpoint, *Radio New Zealand*.

79 MoH, 2019: [Report on Maternity 2017](#), Wellington: Ministry of Health

80 Johnston, M, 2019: [Mothers-to-be fear roadside births in frosty Southland after maternity service downgrade](#), *New Zealand Herald*, 9 June 2019

81 Keogh, B: [Shortage of maternity beds at Middlemore Hospital when new mum broke leg hours after giving birth, report finds](#), *New Zealand Herald*, 23 June 2018

82 PMMRC, 2021: [Fourteenth Annual Report of the Perinatal and Maternal Mortality Review Committee | Te Pūrongo ā-Tau Tekau mā Whā o te Komiti Arotake Mate Pēpi, Mate Whaea Hoki: Reporting mortality and morbidity 2018](#), Health Quality & Safety Commission.

83 Walker H, 2022: [Āhurutia Te Rito | It takes a village: How better support for perinatal mental health could transform the future for communities in Aotearoa New Zealand](#), the Helen Clark Foundation 26 April 2022.

She wrote in response “Wait, so we need to support mothers and birthing parents better? ... Well, blow me down with a feather.”

She goes on to say “in most modern, English-speaking, so-called ‘Western’ nations like Aotearoa New Zealand, healthcare and maternity policies and services have come to be strongly dominated by a focus on the baby, sometimes at the exclusion of the birthing parent. It’s as if we think the baby’s interests and needs can somehow be separated from those of their whānau.”

*Āhurutia Te Rito* | *It takes a village* found that:

- perinatal distress in Aotearoa is widespread, complex, and linked to systemic inequities such as poor housing, low income, food insecurity and domestic abuse;
- 55% of Māori and 30% of non-Māori report significant life stress in late pregnancy;
- disabled women face multiple barriers to appropriate maternity care and many feel ill-prepared and unsupported to manage their pregnancies and births;
- making sure parents and whānau have access to support is the best way to protect perinatal mental health, and contributes directly to wider whānau well-being;
- better support for perinatal mental health would be transformational for whānau and communities in Aotearoa New Zealand.<sup>83</sup>

The report stated that “perinatal distress can have myriad other severe consequences. It can impede emotional and physical wellbeing, healthy parenting, family functioning, employment status, and household financial wellbeing”, and that having a parent experience perinatal distress – even before they are born – can have lifelong implications for babies.<sup>83</sup>

Research, including some undertaken in this country, has found that “symptoms of maternal distress during pregnancy can have a significant negative impact on child brain development. Antenatal distress can impede both the structure and connectivity of a child’s brain, and functional outcomes for that child, like working memory, attention, and sensory processing.”<sup>83</sup>

Perinatal distress disrupts critical attachment bonds between parents and children (including fathers) and the results can “lock in intergenerational disadvantage.” Impaired executive functioning, sub-optimal brain development, insecure attachments with caregivers, and early health disadvantages all have lifelong consequences.” Conversely, warm supportive and attentive parenting is strongly protective of lifelong health and well-being.<sup>83</sup>

Clearly, the mental health of women has a critical impact on the long-term health of their children, whānau and communities.

The report finds that responsibility for reducing perinatal distress should not fall on individuals. As the drivers of perinatal distress are systemic, so must be the solutions: “social determinants of mental health – poverty, racism, gender disadvantage and other structural inequalities, food insecurity, gender-based violence, poor housing, limited education and social networks – are all of critical importance for women in the perinatal period.”<sup>83</sup>

There must be a strong commitment to supporting maternity services in the women’s health strategy if we are to have a maternity model that really can be the envy of the rest of the world. Most importantly we need to ensure that our babies have the very best start in life, no matter where in the country they are born and into what family or social circumstances, and that their mothers get the very best of care and support from conception to the critical few weeks after their births.

## Patient Safety

Patient safety is a significant concern for the AWHC, and there is ample evidence that women are disproportionately harmed in their interactions with and treatment within the health system.

In the US, preventable medical error is the third biggest killer behind heart disease and cancer. A 2016 study by Johns Hopkins University calculated that more than 250,000 deaths per year in the US are due to medical error.<sup>84</sup> In a New Zealand study published in 2006, Auckland University School of Population health lecturers Mary Seddon and Alan Merry found more than 1500 people were killed or permanently disabled annually in this country through preventable medical error. They wrote:

“The evidence is incontrovertible—we are inadvertently harming an unacceptable number of our patients by the very healthcare intended to help them.”<sup>85</sup>

An earlier New Zealand study<sup>86</sup> found that “up to 30% of public hospital expenditure goes toward treating an adverse event”, and that does not take into account the cost to individuals in both direct and indirect costs, loss of quality of life etc., and to the community in loss of productivity and participation. Brown *et al* found in 2002 that “adverse events are estimated to cost the medical system \$NZ870 million, of which \$NZ590 million went toward treating **preventable** adverse events.”<sup>86</sup> [our emphasis]

Given the harm caused by surgical mesh alone in the last decade or more, that cost has only gone up. ACC payments for surgical mesh injuries have increased from \$500,000 in 2017 to \$5.1 million in 2021.<sup>87</sup>

The enormous harm done by surgical mesh in this country, as so clearly demonstrated in the Restorative Justice report,<sup>88</sup> makes clear how deficient our patient safety and protection regulations and agencies are, and women continue to be harmed.

Between October 2018, when Government officials ordered hospitals to take action to minimise the harm from surgical mesh procedures, and August 2022, at least another 38 women were injured severely enough to have claims accepted.<sup>89</sup> ACC said that the total number of women harmed since October 2018 is expected to be higher than 38 because “not all claims included the date of operation and those that didn’t were left out of the dataset” and “many women don’t experience surgical mesh complications until several years after surgery and some don’t know they are entitled to lodge an ACC treatment injury claim.”<sup>89</sup>

Modern medicine is littered with examples of the catastrophic harm inflicted on people – often disproportionately impacting women – by inadequately tested and inadequately regulated drugs, medicines and procedures. Thalidomide. Diethylstilbestrol. Primodos. Contraceptive coils. Vioxx. Fenfluramine-Phentermine (Fen-phen). Essure contraceptive device. Breast implants. Lung sealant. Pacemakers. Deep brain stimulators. Endometrial ablation. Surgical mesh.

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84 Makary MA and Daniel M, 2016: Medical error - the third leading cause of death in the US, *British Medical Journal*, May 3; 353: i2139.

85 Merry A and Seddon M, 2006: Quality improvement in healthcare in New Zealand. Part 2: are our patients safe - and what are we doing about it? *New Zealand Medical Journal*, 2006 Jul 21; 119(1238): U2086.

86 Brown P *et al.*, 2002: Cost of medical injury in New Zealand: a retrospective cohort study. *Journal of Health Services Research and Policy*, 2002 Jul; 7 Suppl 1: S29-34.

87 Russell E, 2022: [In Her Head: Women’s health - Surgical mesh investigation, claims surgeons harmed women](#), *New Zealand Herald*, 30 June 2022.

88 Wailling J, Marshall C & Wilkinson J, 2019: *Hearing and responding to the stories of survivors of surgical mesh: Ngā kōrero a ngā mōrehu – he urupare*, A report for the Ministry of Health. Wellington, New Zealand: The Diana Unwin Chair in Restorative Justice, Victoria University of Wellington.

89 Russell E, 2022: [In Her Head, surgical mesh: Another 38 women harmed after Govt warning to hospitals](#), *New Zealand Herald*, 18 August 2022.

University of Massachusetts and Harvard Medical School researchers reviewed the historical background of sex and gender in clinical research policy and described several approved drugs and devices targeted for use in women that have caused major morbidity and mortality. They write: “A large number of medications and medical devices removed from the market by the US Food and Drug Administration over the past four decades specifically posed greater health risks to women.”<sup>90</sup>

Carey *et al.*, point out that a number of approved drugs and devices that were targeted for use in women have caused major morbidity and mortality, going on to say that “historically, women have been under represented in clinical trials, with resulting research predominantly being performed on male animals and men.”<sup>90</sup>

“In many cases, this inherent bias in research design has led to catastrophic consequences for women.”<sup>90</sup>

The issue now is to minimise further harm and harm from future drugs, devices and procedures. The disproportionate impact of medical injury and harm caused by treatment must be addressed in the women’s health strategy. It is critical that the women’s health strategy includes mechanisms to address past harm in those still suffering the impacts of dangerous or harmful medical treatment, and ensure robust harm minimisation responses when it occurs in the future.

## Menopause

There is a vital need for both health practitioners and women to better educated about perimenopause and menopause. It is hardly surprising that both women and the primary health care providers have gaps in their knowledge; there is not even an agreed upon definition of menopause. On Aotearoa New Zealand health websites for consumers, menopause is defined as a single moment in time 12 months after her last period,<sup>91</sup> and also an extended period of time during which a woman stops having regular periods.<sup>92</sup>

“Menopause is often referred to as a taboo topic”<sup>93</sup>, and the lack of open discussion of menopause no doubt contributes to the lack of knowledge among women about perimenopause and menopause.

Many women under 40 have limited education on menopause. A UK study found that “perimenopausal women are overwhelmingly uneducated on the menopause and angry that they had to experience it with such little knowledge.”<sup>94</sup>

MacPherson and Quinton say that neither healthcare professions nor patients initiate conversations around the subject, and the “discourse around menopause is a symptom of wider issues in women’s health, with lack of understanding of physiology, treatment options and impact on some women.”<sup>93</sup> Despite a recent surge in the discourse in society and the media about menopause, there is “little dialogue in medical schools and in the postgraduate curriculum.”

In their scoping review on how menopause is understood and taught within the education of healthcare professionals, they found that “there is a disappointing paucity of taught menopause content reported across medical education.”<sup>93</sup>

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90 Carey JL, *et al.*, 2017: Drugs and Medical Devices: Adverse Events and the Impact on Women's Health, *Clin Ther*; Jan;39(1):10-22.

91 [Menopause, on Health Navigator New Zealand.](#)

92 Weadon P: [Menopause – a patient’s guide](#), Women’s Health, Family Doctor.

93 MacPherson BE and Quinton ND, 2022: Menopause and healthcare professional education: A scoping review, *Maturitas*, vol. 166, December 2022; pp 89-95

94 Munn C, *et al.*, 2022: Menopause knowledge and education in women under 40: Results from an online survey, *Womens Health (Lond)*; Jan-Dec;18:17455057221139660.

“The way menopause is presented in textbooks and taught is too simplistic.”<sup>93</sup>

Researchers from the Society for Women's Health Research in the US, found that there are “knowledge gaps among healthcare providers concerning menopause” and that “training in menopause is not a routine part of medical school curricula or residency training.”<sup>95</sup> Research on the knowledge of nurses found that nurses working in primary care had limited knowledge regarding the definition of menopause and characteristic signs and symptoms.<sup>96</sup>

There appears to be no research on the menopause knowledge of primary healthcare providers in Aotearoa New Zealand. However, anecdotal evidence of individual women's experiences suggest that there are considerable gaps in the knowledge of some GPs, and many inconsistencies in their approach to women presenting with perimenopausal and menopausal symptoms that worry them or are impacting on their lives.

Adding to issues of lack of knowledge is the prevailing attitude in the medical community; “menopause continues to be represented through dominant culturally infused ‘failure’ discourses and is portrayed as a ‘precursor to disease’.”<sup>99</sup>

Menopause “was redefined as a deficiency disease by physicians in the 1960s, when synthetic oestrogen became widely available.”<sup>97</sup>

Dr Patricia Niland and Professor Antonia Lyons also write that “lay and medical texts portray menopause primarily as a deficiency disease”. They go on to say that medical textbooks from the 18<sup>th</sup> to the late 20<sup>th</sup> century portrayed women's bodies as a “‘female-brain-hormone-ovary system’ ‘controlled’ by a ‘central processor’ (the hypothalamus)” and that at menopause “this authority system breaks down due to ‘ovarian failure’ which leads to ‘failure’ throughout the system whereby the “members of the system decline: ‘breasts and genital organs atrophy’, ‘wither’, and become ‘senile’”<sup>99</sup>

Dr Jerilyn Prior writes that “the pervasive medicalisation of perimenopause and menopause is related to a lack of accurate, woman-centred information.”<sup>98</sup>

Women need more information and education on menopause well before they experience perimenopause, and they need their primary health care providers to have better knowledge and training as well. Women who experience debilitating perimenopausal and menopausal symptoms, that impact their ability to undertake normal everyday activities, must have access to specialist menopause services within the public health system for advice and support on the diagnosis and management of menopause.

## Attitudes to Women and Women's Health Conditions

Women/wāhine are not just faced with combatting centuries of medical ignorance, discrimination and parochialism, in the 21<sup>st</sup> century the often face the same issues when they interact with their health care providers.

Bonita and Beaglehole write that “gender, but not age, race, or social class of a patient significantly influenced doctors' diagnostic and management activities in a study that controlled for these variables simultaneously.

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95 Aninye IO, *et al.*, 2021: Menopause preparedness: perspectives for patient, provider, and policymaker consideration, *Menopause*, Jun 28;28(10):1186-1191.

96 Ferreira Campos P *et al.*, 2022: Climacteric and menopause: knowledge and conduct of nurses working in Primary Health Care, *Rev. Enferm. UFSM*, v.12, p.1-21.

97 McCrea F, 2004: The politics of menopause: The discovery of a “deficiency” disease, in *Health, Disease, and Illness: Concepts in Medicine* (Eds: Caplan A, *et al.*). Georgetown University Press. pp. 187-200.

98 Prior JC, 2015: Perimenopause and menopause as oestrogen deficiency while ignoring progesterone, *Nature Reviews Disease Primers*; vol1: 15031.

Women were asked fewer questions, received fewer examinations, and had fewer diagnostic tests ordered for coronary heart disease. These differences are a reflection of the strong gender bias against equitable prevention and treatment of women.<sup>22</sup>

Sex bias against female patients is a constant battle for many women. For example, Hoffmann and Tarzian reported in 2001 in the *Journal of Law, Medicine and Ethics*, that “that women are more likely to be given sedatives for their pain and men to be given pain medication. Speculation as to why this difference might exist has included the following: Women complain more than men; women are not accurate reporters of their pain; men are more stoic so that when they do complain of pain, “it's real”; and women are better able to tolerate pain or have better coping skills than men.”<sup>99</sup>

In a more recent meta-analysis of 77 studies, researchers found that women with pain are more likely to be perceived as hysterical, emotional, complaining, not wanting to get better, malingerers, and fabricating pain, as if it is all in her head, and that women with chronic pain are assigned psychological rather than physical causes for their pain.<sup>100</sup> Additionally, “women, compared to men, received less and less effective pain relief, less pain medication with opioids, and more antidepressants and got more mental health referrals.”<sup>100</sup>

An Aotearoa New Zealand study found that for female patients with male doctors there was an increased likelihood of the practitioner doubting the diagnosis and believing that the female patient had a hidden agenda that she failed to present in the consultation; male practitioners were also more likely to diminish the perceived seriousness of the condition in female patients.<sup>101</sup> Gross *et al*, conclude that their findings “suggest a need to raise male physicians' awareness to possible biases when treating female patients. The findings also suggest the need to empower female patients to take an active partnership role to improve their communication with male physicians.”<sup>101</sup>

Even in the Covid pandemic, implicit sex biases against women were evident. Julio Ancochea and colleagues found that women were more heavily impacted by Covid infection than men, in part because most frontline health care professionals are women and also more women are primary care-givers. The researchers found that “both hospitalisation and ICU admission were less frequent outcomes in females than males. Unfortunately, basic diagnostic tests such as blood tests or imaging were less used in women.”<sup>102</sup>

It is not just discriminatory attitudes and beliefs that women face; they face poorer outcomes and higher risk of death, particularly if they have male surgeons.

Research from Canada, published in *JAMA Surgery* in 2022,<sup>103</sup> found that women patients with male surgeons suffered significantly worse outcomes than women patients with female surgeons. The same disparity was **NOT** seen in male patients treated by female surgeons compared with male patients treated by male surgeons.

Researcher Dr Angela Jerath and colleagues wrote that “In primary care, sex or gender discordance between patients and physicians (particularly among male physicians and female patients) is associated with worse

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99 Hoffmann DE and Tarzian AJ, 2001: The girl who cried pain: a bias against women in the treatment of pain, *Journal of Law, Medicine and Ethics*, Spring 2001;29(1):13-27.

100 Samulowitz A, *et al.*, 2018: "Brave Men" and "Emotional Women": A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain, *Pain Research and Management*, 2018 Feb 25;2018:6358624.

101 Gross R *et al.*, 2008: The association of gender concordance and primary care physicians' perceptions of their patients, *Women and Health*, 2008;48(2):123-144.

102 Ancochea J, *et al.*, 2020: Evidence of gender bias in the diagnosis and management of COVID-19 patients: A Big Data analysis of Electronic Health Records, COVID-19 SARS-CoV-2 preprints from medRxiv and bioRxiv, July 26 2020.

103 Wallis JD, *et al.*, 2022: Association of Surgeon-Patient Sex Concordance With Postoperative Outcomes, *JAMA Surgery*, 2022 Feb 1;157(2):146-156.

rapport, lower certainty of diagnosis, lower likelihood of assessing patient's conditions as being of high severity, concerns of a hidden agenda, and disagreements regarding advice provided."<sup>103</sup>

Female patients were 15% more likely to experience adverse outcomes following common surgical procedures when treated by a male rather than a female surgeon, and 32% more likely to die in the 30 days following the procedure. For male patients there was no difference in outcomes whether they were treated by female surgeons or male surgeons.<sup>103</sup>

Gender discrimination in the provision of healthcare is part and parcel of a global medical system that:

- does not value women's health enough to learn more about women's bodies, their symptoms and how they experience ill-health;
- does not value women's health enough to learn more about how they experience pain;
- assumes that if it isn't immediately obvious what is causing her symptoms then it must be all in her head, or caused by rampant hormones, or that she is a hypochondriac, has a hidden agenda or is malingering or seeking drugs;
- undervalues women doctors and subjects them not only to discrimination in training, research, leadership, and pay, but sexually harasses them and forces them to work in an environment where other doctors and patients (including some women) disrespect them and assumes that they are inadequate in comparison with male doctors.<sup>104, 105, 106, 107</sup>

In Aotearoa New Zealand wāhine/women face the ongoing inclination of health practitioners to diagnose somatic, functional and/or mental health disorders in women who present with complex physical conditions. Or they are ignored, turned away, accused of being drug seekers or given ridiculous advice, such as the advice one doctor gave a 15 year old girls, that getting pregnant could cure her severe abdominal pain and heavy vaginal bleeding.

In 2022, *New Zealand Herald* health journalist, Emma Russell researched and wrote a series of articles under the banner, 'In Her Head: fighting for better women's health care'.<sup>108</sup>

Many of the stories are about surgical mesh, but there are also other issues: ovarian cancer, endometriosis, birth trauma, gall bladder disorders.

A woman in one of the stories in the series, complained of severe abdominal pain and was given laxatives and diet advice when she went to the emergency department. Over a two-year period, she had visited two medical centres several times complaining of pain in her abdomen and saying she was gaining weight despite exercising more and eating less. Every time, she was told there was nothing wrong with her and that she was just overweight and needed to change her diet and live a healthier lifestyle. The doctor finally agreed to do a scan which revealed a three-litre tumour growing in and around her organs; she had ovarian cancer!<sup>109</sup>

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104 Bennett CL, *et al.*, 2020: The Gender Gap in Surgical Residencies, *JAMA Surgery*, 2020;155(9):893-894.

105 Xepoleas MD, *et al.*, 2020: The experiences of female surgeons around the world: a scoping review, *Human Resources for Health*, vol. 18, Article no.80.

106 Lyons NB, *et al.*, 2021: Gender Disparity Among American Medicine and Surgery Physicians: A Systematic Review, *American Journal of the Medical Sciences*, Feb;361(2):151-168.

107 Lim WH, *et al.*, 2021: The unspoken reality of gender bias in surgery: A qualitative systematic review, *PLoS One*, Feb 2;16(2):e0246420.

108 Russell E, 2022: [In Her Head: fighting for better women's health care](#), *New Zealand Herald*.

109 Russell E, 2022: [In Her Head: Women's health - Kelly's ovarian cancer fight ignored for two years](#), *New Zealand Herald*, 7 May 2022.

The surgical mesh restorative justice process heard from mesh injured women who had been further harmed by the attitudes of their doctors to the debilitating pain and disability that was caused by mesh procedures. In particular, women were humiliated by doctors' advice when the damage caused by mesh was so bad they could no longer have sex, because the mesh had eroded through the vaginal wall and it was causing pain to the women and their partners. One woman was told by her female doctor she should buy a vibrator, and another told by her young male doctor that she should masturbate.<sup>88</sup>

The gender bias and appalling attitudes of some health care providers towards women must stop! The medical training curriculum in our medical schools must include compulsory women's health (not just obstetrics and gynaecology) to the highest level. This must include education in gender bias, and healthcare professionals acknowledging and addressing bias and discrimination in their practice. The clearly deep-seated and entrenched bias and discrimination against women on multiple levels must be eradicated and this should be a clear, non-negotiable expectation within the women's health strategy.

## Better Health Education for Women

The women's health strategy must advocate for better health education for girls and women, so that they have a better understanding of their own bodies and how to achieve and maintain health.

There is an astonishing lack of knowledge about women's bodies and how they work... even among those with female reproductive organs. In a survey of 1000 British women in 2016, only half could locate the vagina on medical diagrams and fewer than one third could correctly label six different parts (typically people think the terms vulva and vagina are interchangeable and that the clitoris, and labia are part of the vagina). Only one in seven women could name a single one of the five gynaecological cancers.<sup>110</sup>

This was not the first study to ascertain how limited is the knowledge of women's reproductive organs. A 2013 paper in the *Journal of Paediatric and Adolescent Gynecology* found that among 236 US university students 74 percent of men and 46 percent of women questioned were unable to identify the cervix, while 80 percent of men and 62 percent of women in the study were unable to locate the vagina correctly.<sup>111</sup>

A 2021 US survey of women's understanding of women's health revealed alarming gaps in their knowledge.<sup>112</sup>

- 91% didn't know heart disease is the leading cause of death in women;
- 91% didn't know the Pap test only screens for cancer of the cervix;
- 73% didn't know that lack of sleep can damage the brain;
- 69% didn't know drinking alcohol increases breast cancer risk.

How can women be expected to know when something is not normal, and advocate for themselves in a health care setting if they don't know what parts of their bodies are what, much less how they work.

## Disproportionate Impact of Pandemics and Climate Change on Women's Health.

Severe global or national events, such as pandemics and weather/environmental events caused by climate change, disproportionately affect women in ways that can significantly negatively impact on their health.

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110 Cockburn H, 2016: [Nearly half of British women cannot identify the vagina, study finds](#), *The Independent*, accessed at

111 Volck W, *et al.* 2013: Gynecologic knowledge is low in college men and women, *Journal of Paediatric and Adolescent Gynecology*, 2013 Jun;26(3):161-6.

112 MDVIP, 2021: [New Study Finds Alarming Gaps in Women's Health Knowledge and Healthcare Experiences](#).

While an increasing volume of research has investigated the impacts on women’s health in low and middle-income countries, there is a dearth of quality research on the impact of pandemics and climate change on women’s health in Aotearoa New Zealand. Kim van Daalen and colleagues write that “Despite obvious disparities between genders, gender-disaggregated health data are often either under-represented or non-existent as a variable when assessing the health effects of climate change in medical research, environmental research, and strategic planning of mitigation and adaptation policies. This disregard for gender differences is particularly concerning as climate change is predicted to worsen existing social and economic inequalities between and within countries.”<sup>113</sup>

It is vital that the women’s health strategy address these issues, as the evidence is clear that such events will increase in frequency. There must be a change in our culture to ensure that women do not suffer a greater loss in health as the result of pandemics and weather events, and the women’s health strategy must incorporate a blueprint for bringing about that change.

## Pandemics

Dr Lieberman Lawry, an Associate Professor in Preventive Medicine and Biostatistics, and colleagues found that “despite decades of understanding that sex and gender impact health, public health and disease, these impacts are routinely overlooked during pandemics.”<sup>114</sup> Pandemics exacerbate existing gender inequalities and Lieberman Lawry *et al.* say that “inclusive gender assessment that covers sex and all genders is necessary at baseline, early recovery, and post-disaster phases” so that policy, programmes and interventions properly respond to different needs of people.<sup>114</sup>

The changes in the way we lived as a result of the Covid-19 pandemic, and the restrictions imposed, disproportionately impacted on women’s health and wellbeing. As Chloe Cooney noted: “Pandemics expose and exacerbate the existing dynamics of a society — good and bad.”<sup>115</sup>

The pandemic response and lockdowns involved a radical revision of “home” as an intense site of practically everything. Many government responses assumed home as a safe space to retreat to. We know that home is a privileged location for some, and for others a place of dispossession, disconnection, violence and loss. Our homes were invested with enhanced capacity where governments and employers assumed free and amenable space (and time) for work, leisure, sustenance, care, childcare and education.<sup>116</sup>

We are facing a ‘care crisis’,<sup>117</sup> which could lead to profound and long-lasting shifts in women’s work and life outside the home. Rates of anxiety and stress among women are reactions to their position as frontline workers and care providers, and to the impossible choices they can face regarding childcare, education, and their economic and personal security.

New findings linking ‘long COVID’ symptoms to women’s reproductive capacity suggest that COVID infection may have an ongoing impact on women’s health, quality of life and ability to carry out the paid and unpaid work that is expected of them. For example, women seem to experience less severe symptoms short-term but suffer worse long-term COVID complications, including depression, reduced physical activity, and

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113 van Daalen K, *et al.*, 2020: Climate change and gender-based health disparities, *Lancet Planet Health*, Feb;4(2):e44-e45.

114 Lieberman Lawry L, *et al.*, 2023: Overlooked sex and gender aspects of emerging infectious disease outbreaks: Lessons learned from COVID-19 to move towards health equity in pandemic response, *Front Glob Womens Health*; 2023 Feb 20;4:1141064.

115 Cooney C, 2020: [The Parents Are Not All Right](#). *GEN*, 6 April 2020.

116 Jenkins F, 2020: [Did our employers just requisition our homes?](#) *Canberra Times*, 4 April 2020.

117 Smith J., *et al.*, 2021: More than a public health crisis: a feminist political economic analysis of COVID-19. *Global Public Health*, Aug-Sep;16(8-9):1364-1380.

deteriorating lifestyle habits.<sup>118, 119, 120</sup> In addition, differences in women's innate immunity lead to women consistently reporting more adverse reactions than males in response to vaccines including COVID-19.<sup>114</sup>

Gender inequality is an ongoing social, economic, political and **health crisis**, which has been exacerbated by the pandemic.<sup>120</sup> [our emphasis]

One of the biggest impacts on women as a result of the pandemic and measures to control it, is increased domestic violence,<sup>121</sup> with an increase in frequency and severity of violence against women and children.<sup>122</sup> So pronounced has that increase been that it has been labelled the 'shadow pandemic'.<sup>123</sup> "Increases in intimate partner violence were described as rising in parallel with the lock-down, with the police and Women's Refuge reporting surges in family harm related calls."<sup>124</sup>

In 2020, the government of Aotearoa New Zealand received advice from the Ministry for Women that support and recovery measures to date had not been designed with gender equity in mind, and ran the risk of exacerbating Covid-19 impacts, particularly for Māori and Pāsifika women.<sup>125</sup> It advised government to develop a cross-government gender-Covid response, including meaningful specific actions to mitigate the disproportionate effects on women in Aotearoa New Zealand.

It is absolutely vital that a gendered response to future pandemics is developed before we face the next one.

### Climate Change and Extreme Weather Events

It is clear that as climate changes, and accepting that even addressing this now will take decades to see effective and positive change, we must consider human health in all our environmental and climate change decisions.

Women and girls often face disproportionately high health risks from the impacts of climate change when compared to men and boys. Globally women are more affected by health impacts associated with climate change than men, and are more likely to die or suffer injury from extreme weather particularly cyclones and heatwaves; experience food insecurity; and suffer poor mental health and partner violence.<sup>126</sup>

Pregnant people will be particularly vulnerable:<sup>127</sup> "climate change might also affect women's ability to seek reproductive and maternity health services, and pregnancy-related outcomes can be affected by changes in infectious diseases, temperature, and nutritional status."<sup>113</sup>

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118 Bucciarelli, V., *et al.*, Depression pandemic and cardiovascular risk in the COVID-19 era and long COVID syndrome: gender makes a difference. *Trends in Cardiovascular Medicine*, Jan;32(1):12-17.

119 Torjesen, I., 2021: Covid-19: Middle aged women face greater risk of debilitating long term symptoms. *BMJ*, Mar 25;372:n829.

120 PAHO, 2021: *Gendered Health Analysis Covid-19 in the Americas*, Pan American Health Organization, Washington DC: US.

121 Bettinger-Lopez C, and Bro A, 2020: A Double Pandemic: Domestic Violence in the Age of COVID-19, *Domestic Violence Report*, Vol 25, No. 05, June/July 2020 , pp.85-86(2). Civic Research Institute.

122 Koziol-McLain J, *et al.*, 2023: Impact of COVID-19 on the Health Response to Family Violence in Aotearoa New Zealand: A Qualitative Study. *Inquiry*. 2023 Jan-Dec;60:469580221146832.

123 Sri AS, 2021: COVID-19 and the violence against women and girls: 'The shadow pandemic', *Int J Soc Psychiatry*, Dec;67(8):971-973.

124 Every-Palmer S, *et al.*, 2020: Psychological distress, anxiety, family violence, suicidality, and wellbeing in New Zealand during the COVID-19 lockdown: A cross-sectional study, *PLoS One*, Nov 4;15(11):e0241658.

125 Ministry for Women. [COVID-19 Advice to Minister](#). 2020.

126 Sellars S, 2016: *Gender and Climate Change: A Closer Look at Existing Evidence*, Global Gender and Climate Alliance, November 2016.

127 Pandipati S and Abel DE, 2023: Anticipated impacts of climate change on women's health: A background primer, *Int J Gynaecol Obstet*; Feb;160(2):394-399.

While many of the worst effects of climate change will have the greatest impact on under-developed and impoverished nations, and therefore have the greatest gendered impact on women and girls of such nations, Aotearoa New Zealand is far from immune to the disproportionate impact on women's health.

As with the Covid-19 pandemic, the severe weather events that devastated parts of New Zealand in February 2023, particularly cyclone Gabrielle, resulted in an increase in reports of domestic violence.<sup>128</sup> This is not a new phenomenon; the 2004 Manawatu floods also resulted in increases in domestic violence.<sup>129, 130</sup>

Food security is a world wide issue, one that many New Zealanders might consider to be the least of our country's climate change problems. Again, however, the devastation of cyclone Gabrielle has had a significant impact on the availability and cost of fruit and vegetables<sup>131</sup> adding to the already soaring cost of food over the last year.<sup>132</sup> With the destruction of orchards and farms in the Hawkes Bay, we can expect fruit costs, at least, to remain high for several years while these horticultural areas are re-established.

Reductions in global food availability, and fruit and vegetable consumption in particular, are estimated to result in 500,000 climate-related deaths worldwide by 2050.<sup>133</sup> In Aotearoa New Zealand reduced availability and high cost may not result in direct deaths, but in significantly reduced health measures and an increase in diet-related conditions, such as cardiovascular disease, diabetes and cancer. With the existing cost of living crisis already putting pressure on those living in areas of higher deprivation, reduced availability of healthy food will disproportionately affect those with lower incomes and living in poverty.

In their report *Human Health Impacts of Climate Change for New Zealand*, the Royal Society Te Apārangi state that "the effects of climate change will not be spread evenly across the population, exacerbating existing socioeconomic and ethnic health inequalities," but that the "adaptability and resilience of health and welfare systems are important factors in minimising the effects of climate change on human health."<sup>133</sup>

## Other Considerations for the Women's Health Strategy

### The Code of Health and Disability Services Consumers' Rights

The Code of Rights must underpin all aspects of the strategy, in particular it must address breaches of consumer rights, particularly informed consent in the delivery of women's health services.

Throughout history, women's predominant relationship with the medical profession has been one of "having things done to them" rather than being in a partnership in which, with the guidance of a health professional, they work towards achieving health and wellness. Consent is a concept that has long been ignored, and at best is often only paid lip service. This was brought into stark relief with the "unfortunate experiment" involving Herbert Green, National Women's Hospital and women found to have cervical abnormalities in the 1960s and 70s.<sup>2</sup>

The Cartwright Inquiry specifically addressed the lack of informed consent in health services provision and as a direct result the Code of Health and Disability Services Consumers' Rights was written and enacted under

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128 Iasona S, 2023: [Hawke's Bay family violence support service hears from whānau 'we've never heard of before'](#), *NewsHub*, 21 February 2023.

129 Houghton R, 2009: 'Everything Became a Struggle, Absolute Struggle': Post-Flood in *Women, Gender and Disaster: Global Issues and Initiatives* (Eds. Enarson E, & Chakrabarti PGD), Chpt 8, SAGE Publications India Pvt Ltd.

130 Houghton R, 2010: "We had to cope with what we had": *Agency perspectives on domestic violence and disasters in New Zealand*. Victoria University of Wellington, Wellington.

131 Kitchin T, 2023: Cyclone Gabrielle's impact on New Zealand's 'fruit bowl', *Radio New Zealand*, 9 March 2023.

132 Prasad A, 2023: [Cyclone Gabrielle: Fresh produce prices likely to rise, experts say](#), *New Zealand Herald*, 16 February 2023.

133 Royal Society Te Apārangi, 2017: *Human Health Impacts of Climate Change for New Zealand, Evidence Summary*, Royal Society Te Apārangi, October 2017, Wellington: NZ.

the Health and Disability Commissioner Act 1994. The Code enshrines consumer rights to be fully informed and to make an informed choice and give informed consent.

Despite this, informed consent is all too often glossed over, ignored and outright denied female patients. For example, in investigations into the surgical mesh debacle, there have been numerous reports of women:

- not being told that their procedures for urinary incontinence or prolapse involved the use of mesh and did not know that mesh had been used until complications arose;
- being told that they had no choice but to have mesh;
- and not being given alternative options or not being told of the risks. In addition, some patients reported only being asked for consent after being administered pre-op drugs, or consent being sought by non-medical personnel.<sup>88</sup>

Several research papers published in the last twelve years have investigated or discussed informed consent in New Zealand teaching hospitals.<sup>134, 135, 136</sup> Many informed consent breaches occur in women's health and obstetrics and gynaecology.<sup>137, 138</sup>

The women's health strategy must uphold and promote the rights of women to make informed decisions and provide informed consent in health care in all situations. For a variety of reasons (age, ethnicity, education and imbalance of power between health care provider and patient), women carry a greater vulnerability in their interactions with health care providers. An important means to protect women's safety and improve outcomes in health is to resolutely uphold their rights.

## The LGBTQI+ Community Need Their Own Health Strategy

There must be a separate LGBTQI+ health strategy. The LGBTQI+ community has specific unmet health needs that cannot be adequately addressed in the women's, Māori, Pāšifika or disabled health strategies despite the natural overlap and intersectional nature of all health strategies.

While it is vital that the women's health strategy takes an intersectional approach and consider the needs of wāhine Māori, Pasifika, gay women, women with disability, trans, intersex and gender diverse people who have health needs that are in common with those whose assigned birth gender is female, that is not enough to ensure that members of the LGBTQI+ community have their health needs adequately met.

LGBTQI+ New Zealanders face inequities and disparities in access to health services and outcomes from health care, yet are neglected by policy-makers. Despite advances in the rights and legal status of LGBTQI+ New Zealanders, social prejudice and bias that extends deep into our health system negatively impacts on members of the LGBTQI+ community.

A 2013 report found that "Rainbow communities, especially those of diverse gender identity (transgender) and diverse biological sex (Intersex) have a troubled history of interaction with the health system. This can

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134 Malpas P, 2011: Reflecting on senior medical students' ethics reports at the University of Auckland, *Journal of Medical Ethics*, 2011 Oct;37(10):627-30.

135 Malpas P, *et al.*, 2018: Medical students, sensitive examinations and patient consent: a qualitative review, *New Zealand Medical Journal*, 21 September, Vol 131 No 1482.

136 Bhoopatkar H, *et al.*, 2022: Adherence to a national consensus statement on informed consent: medical students' experience of obtaining informed consent from patients for sensitive examinations, *New Zealand Medical Journal*, 2022 May 20; 135(1555).

137 Pennington P, 2019: [Nurses say gynaecology patients' rights were breached](#), *Radio New Zealand*, 5 December 2019.

138 RNZ, 2020: [Patient furious about audience at gynaecological operation](#), Morning Report, *Radio New Zealand*, 22 December 2020.

lead to health problems becoming more complex and expensive to manage as people delay engaging with the health system out of fear.”<sup>139</sup>

Health issues include, but are not limited to, greater levels of suicide, depression and substance abuse, as well as higher levels of obesity, and certain forms of cancer. In addition, the “lack of targeted research means the health needs of the Rainbow community are hidden from and thus excluded from current public health policy.”<sup>139</sup>

*Counting Ourselves*, a 2019 report on the health and wellbeing of trans and non-binary people in Aotearoa New Zealand found that transgender and non-binary New Zealanders<sup>140</sup> had particularly negative interactions with the health system and suffered significant barriers to adequate and culturally appropriate health care. The report found:<sup>140</sup>

- high numbers of transgender and non-binary New Zealanders wanting but not being able to access gender-affirming healthcare;
- in the 12 months prior to the report, 13% of participants were asked unnecessary or invasive questions about being trans or non-binary, that were unrelated to their health visit, when they were trying to access healthcare;
- 17% reported they had experienced conversion therapy: that is, a professional had tried to stop them from being trans or non-binary;
- 36% of participants had avoided seeing a doctor because they were worried about disrespect or mistreatment as a trans or non-binary person;
- 71% aged 15 and older reported high or very high psychological distress, compared with only 8% of the general population in Aotearoa New Zealand;
- 56% had seriously thought about attempting suicide in the last 12 months; 37% had attempted suicide at some point and 12% had made an attempt in the last 12 months.

The Government Inquiry into Mental and Addiction, He Ara Oranga, found that there are unmet mental health needs for LGBTQI+ New Zealanders,<sup>141</sup> While the Health and Disability System Review report found that “patterns of use for both inpatient and community mental health specialist services show higher rates for people who identify as LGBTQIA+ (among other minority groups)”.<sup>141</sup>

A 2018 Masters of Health Sciences dissertation on LGBT community mental health needs, found:

“that the LGBT community are exposed to unique social stressors that have a direct impact on their mental wellbeing... the LGBT community have specific needs when accessing and engaging mental health services for these needs. The community is exposed to essentially a heterosexist international health system, and is frequently pathologised by health professionals because of the cultural differences, in particular when engaging with mental health services. The LGBT community’s [sic] are generalised as a whole community, and not as individual cohorts, which creates additional barriers for specific needs, in particular those of the transgender community.”<sup>142</sup>

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139 Stevens MW, 2013: *Rainbow Health: The Public Health Needs of LGBTTI Communities in Aotearoa New Zealand with Policy Recommendations*. Auckland: Affinity Services

140 Veale J, et al., 2019: *Counting Ourselves: The health and wellbeing of trans and non-binary people in Aotearoa New Zealand*. Transgender Health Research Lab, University of Waikato: Hamilton NZ.

141 Government Inquiry into Mental Health and Addiction. 2018. [He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction](#), pp25-27 Wellington: Government Inquiry into Mental Health and Addiction.

142 Rees S, 2018: *The Lesbian, Gay, Bisexual and Transgender (LGBT) community’s mental health care needs: An integrative literature review*, unpublished dissertation for Masters of Health Sciences for Nursing – Clinical, University of Otago.

Samuel Rees recommended that health care systems review their role in improving the health disparities of this minority population, and reduce the stigma and discrimination currently experienced by improving health policy and education development.<sup>142</sup>

In research for this submission, it was very difficult to find figures on how many New Zealanders identify as members of the LGBTQI+ community. Stats New Zealand, in their 2021 Household Economic Survey, found that only 4.4% of New Zealanders identify as “LGBT+”.<sup>143, 144</sup> However, Ministry of Health data collected in the New Zealand Health Survey for the year ended 30 June 2022 found that 11.6% of New Zealand adults (15+ years of age) identify as gay, bisexual or other (not heterosexual).<sup>145</sup> This data did not include transgender New Zealanders.

How can our health agencies begin to address the unmet health needs of the LGBTQI+ community if there are such vast discrepancies in the understanding of how many New Zealanders identify as LGBTQI+? Based on just these two datasets, the number of LGBTQI+ New Zealanders might be somewhere between 226,000 and 597,000... or perhaps more.

As Michael Stevens writes in his report, “This represents a significant segment of the wider population whose health needs are generally invisible or ignored by the health system.”<sup>139</sup>

Clearly, the LGBTQI+ community need their own health strategy!

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143 Stats NZ, 2021: [1 in 20 adults identify as LGBT+ in major social survey](#)

144 In the Stats NZ survey “LGBT+” included those who identify as non-binary.

145 MoH, 2022: [Sexual identity of New Zealand adults](#), as presented on Figure.NZ (Figure NZ Trust) 17 November 2022.