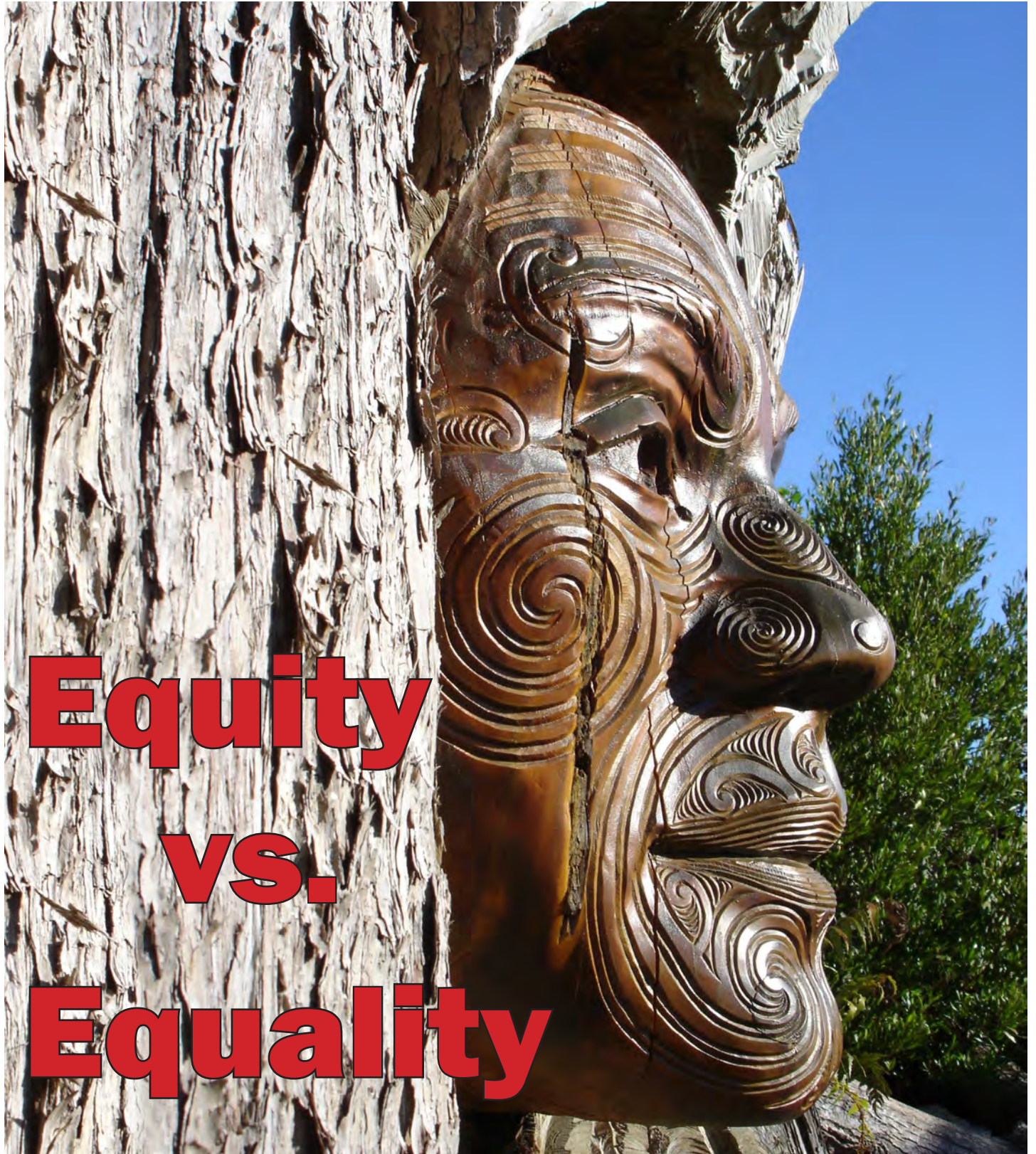




NEWSLETTER

August • 2022

a voice for women's health



Equity
vs.
Equality



**Auckland Women's
Health Council**

PO Box 32-445
Devonport
Auckland 0744

EMAIL:
awhc@womenshealthcouncil.org.nz

WEBSITE:
www.womenshealthcouncil.org.nz

EDITOR:
Sue Claridge

Copyright © 2021
Auckland Women's Health Council

In this Issue...

| | |
|------------------------------------------------------------------|----|
| Equity Vs. Equality | 3 |
| The Barriers to and Possibilities for Indigenising Healthcare | 6 |
| Patient Rights: Informed Consent in our Teaching Hospitals | 10 |
| Birth Injury, ACC and Surgical Mesh | 16 |
| Te Whatu Ora and Consumer Representation | 21 |



Remembering the women who died and those harmed
as a result of the "unfortunate experiment".

Front Cover Photo Credit: © Rick Lippiett | Dreamstime.com

Equity Vs. Equality: Te Aka Whai Ora and Indigenising Health Care

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.¹ 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.

In the context of the current health system reforms the most influential of recent reports was the health and disability system review headed by Heather Simpson.

The *Health and Disability System Review – Interim Report, Hauora Manaaki ki Aotearoa Whānui – Pūrongo mō Tēnei Wā*² found:

- On average, Māori die seven years earlier than non-Māori and are 2.5 times more likely to die from diseases that can be addressed through health care.
- One-third of Māori preschool children receive no oral care, and more than half of 5-year-old Māori children have dental caries (33% higher than for non-Māori children).
- Young Māori have poorer general physical and mental health, are more overweight, have greater substance use, and higher exposure to violence.
- Hospital admissions for self-harm are higher and suicide rates double among Māori aged 15–24 compared to non-Māori.

- Māori develop diabetes up to 10 years younger and progress earlier to more serious disease, yet are less likely to receive appropriate monitoring and testing.
- Despite being significantly more likely to report multiple disabilities, Māori aged 65 and over are much more likely to have unmet need for a disability aid than non-Māori.

In July 2019, the report *A Window on the Quality of Aotearoa New Zealand's Health Care 2019 – a view on Māori health equity*³ was published by the Health Quality & Safety Commission (HQSC). The report focused on Māori health equity and concluded that there are the following health inequities for Māori:

- Inequity in access: services are less accessible for Māori, with health services being less likely to be accessible for Māori compared with non-Māori over the life course, beginning prior to birth,
- Inequity in quality: services are not providing the same benefits for Māori; even when they can access services, the evidence shows inequity in the quality of those health services and treatments for Māori.
- Improvement – efforts to improve quality do not always improve equity for Māori.

Two of the key messages of the HQSC report were that:

- the health system must acknowledge and understand inequities, and commit to equity and Māori health advancement by enabling services where needed, identifying and removing institutional racism from our organisations and services; and
- the health system requires Māori leadership and partnership to improve access, service and treatment.³

One of the most significant recommendations of the Health and Disability System Review was the establishment of a Māori Health Authority as an independent departmental agency, reporting directly to the Minister of Health.²

In the massive health system reform currently being undertaken, this recommendation has been adopted by the Labour Government, and on the 1st of July 2022, Te Aka Whai Ora | Māori Health Authority came into being, sitting alongside Te Whatu Ora | Health New Zealand.

The Pae Ora (Healthy Futures) Act was passed by the majority Labour Government but was not supported by National or ACT, and in particular these parties opposed the establishment of Te Aka Whai Ora | Māori Health Authority. National Leader, Christopher Luxon, has repeatedly said that the Māori Health Authority has to go and opposes Māori co-governance; he plans to repeal Te Aka Whai Ora if National get into Government at the next election.⁴

It is not just the right-wing politicians who oppose Te Aka Whai Ora, but many of the general public. There is a view among a proportion of Pākehā New Zealanders that Māori are getting too much.⁵

Former National MP and Minister for Treaty of Waitangi Negotiations Chris Finlayson has long been a proponent of co-governance – in stark contrast to current National MPs. On the topic of co-governance and in particular a Māori Health Authority, he says:

“Co-governance is not the same as co-government. The [current Labour] government needs to get out and explain that. The creation of a Māori health authority, for instance, is an initiative to see if we can address some long-standing health problems within the Māori community. And if you address those

matters successfully, who benefits? Everybody! The whole economy benefits.”⁵

It is patently obvious that what this country has been doing in Māori health for over 150 years is simply not working. As Martyn Bradbury says “The extraordinary lack of progress in Māori health demands new approaches.”⁶

Minister for Health, Andrew Little, has countered the criticism saying “It’s... one system, working intimately together to make sure that we’re really seriously addressing those inequities.”⁷

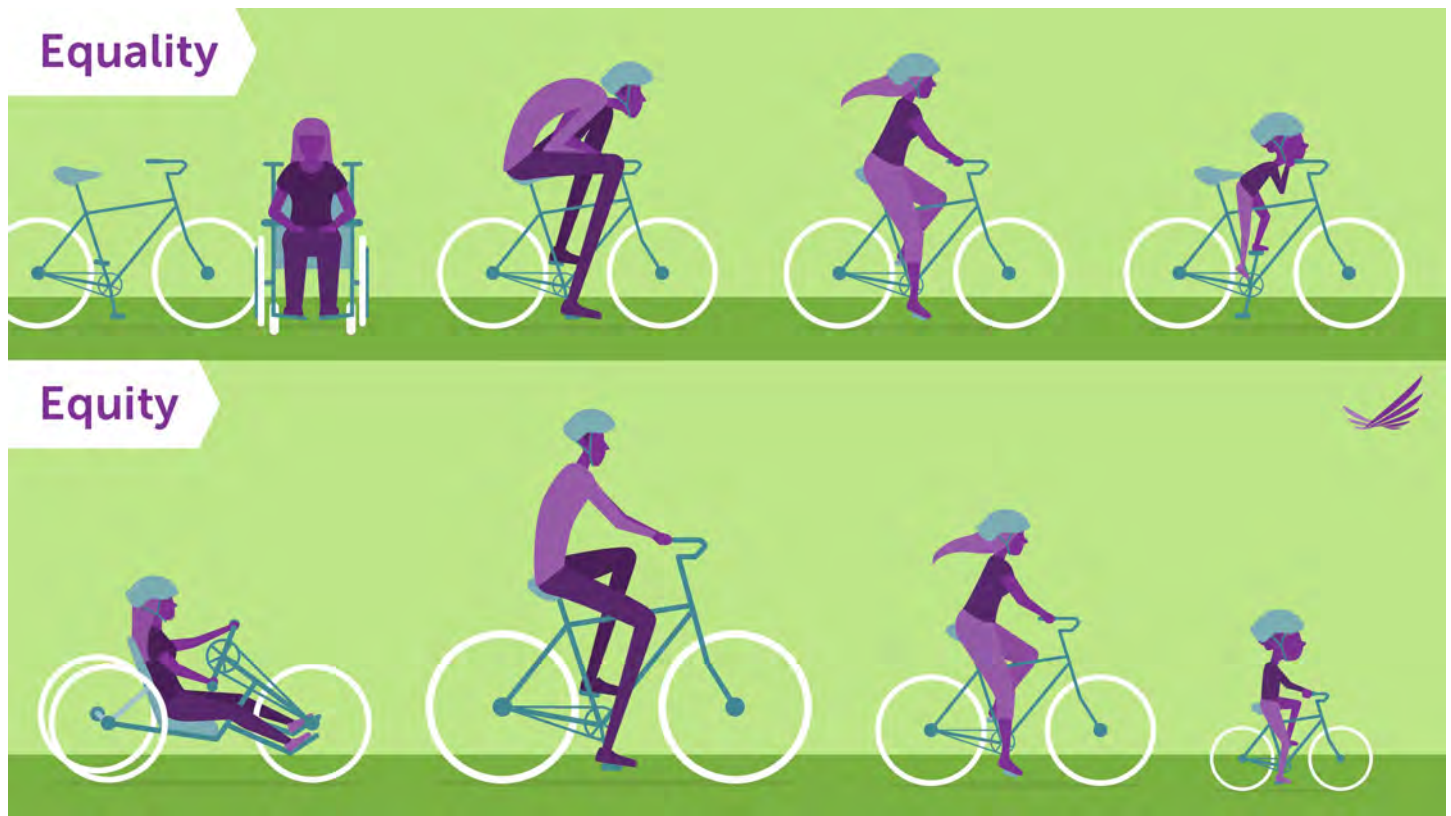
“It’s not about doing their own thing either. The Māori Health Authority is as much a part of the rest of the system. But it is very much the leader for Māori and is very much by Māori for Māori.”⁷

Bradbury says Christopher Luxon “seems to envisage a premium health service for Māori while everyone else gets a second class system.”⁶

This is certainly how some New Zealanders seem to see it, if “letters to the editor” and comments on social media are anything to go by. This is not just an “ugly kind of politics”⁵ on the part of Luxon and his MPs, but in many cases it’s straight-out racism.

The issue is not equality for all New Zealanders; it is equity for all New Zealanders. Leaving the overt racists out of the discussion and focussing on those who seem to harbour a genuine fear that Māori are about to get something that no-one else will get, it is long past time there was a national lesson in equality versus equity.

It is simple really. *Equality* means each individual or group of people is given the same resources or opportunities. *Equity* recognises that each person has different circumstances and allocates the exact resources and opportunities needed to reach an equal outcome.



Visualizing Health Equity: One Size Does Not Fit All (Source: Robet Wood Johnston Foundation)

Equality means providing everyone with the same resources regardless of whether everyone needs them. In other words, each person receives an equal share of resources despite what they already have, or don't have.

Equity is when resources are shared based on what each person needs in order to adequately level the playing field.

One part of the solution to inequities and disparities in Māori health is the indigenising of health care. Indigenising health care will prioritise Māori voices, and enable health care to be provided through a Māori lens, instead of through the experience and perspective of Pākehā.

The following article – *The Barriers to and Possibilities for Indigenising Healthcare* – was originally written as an essay for a third-year Geopolitics paper at the University of Auckland. While its original purpose was for assessment and written for an academic audience, it explains the importance of indigenising healthcare in Aotearoa New Zealand and is particularly pertinent in the context of our radically changed health system, comprising Health New Zealand | Te Whatu Ora and the newly established Te Aka Whai Ora | Māori Health Authority. We hope that by developing an understanding of the issues around the ongoing impacts of colonisation

on the health of Māori, and the importance of indigenising health care institutions and practice, New Zealanders will see that it is equity not equality that must be addressed; why, far from being racist, Te Aka Whai Ora is possibly the most important step towards equity of health and wellbeing for Māori that Aotearoa New Zealand has ever seen.

References

- 1 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.
- 2 Health and Disability System Review, 2019: [Health and Disability System Review - Interim Report, Hauora Manaaki ki Aotearoa Whānui – Pūrongo mō Tēnei Wā](#), Wellington: HDSR.
- 3 HQSC, 2019: [A Window on the Quality of Aotearoa New Zealand's Health Care 2019 – a view on Māori health equity](#), Health Quality & Safety Commission, 29 July 2019.
- 4 Smith X, 2022: [Christopher Luxon insists Māori Health Authority has to go](#), *New Zealand Herald*, 20 April 2022.
- 5 Wilson S, 2022: [David Seymour stoking the fires of a culture war](#), *New Zealand Herald*, 12 Jul 2022.
- 6 Bradbury M, 2022: [The extraordinary lack of progress in Māori health demands new approaches](#), *Waatea News*, 26 April 2022.
- 7 Neilson M, 2022: [Health sector shake-up: Minister Andrew Little and National's Dr Shane Reti on the major reforms](#), *New Zealand Herald*, 1 July 2022.



The Barriers to and Possibilities for Indigenising Healthcare

By Stephanie Claridge

Settler-colonialism has left a significant legacy on the healthcare of Māori. Traditional healthcare practices have been undermined by western healthcare, resulting in an inequitable effect and treatment of ailments, diseases, and disabilities in Indigenous communities. Indigenisation, and its concurrent decolonisation, is the solution as it prioritises Indigenous voices to promote Indigenous paradigms and ontologies while abolishing colonialist systems.

Decolonisation is but one part of the goal and is required to promote Indigenisation. However, because decolonising healthcare in Aotearoa is a slow, obstructed process, Indigenisation is also inhibited. Indigenisation of healthcare is lacking as it relies on the initial Indigenisation of other societal sectors such as government and education: Indigenisation of only healthcare is restricted by law, policy, and the education of the wider community.

Practices — such as those around pregnancy, medicines, body autonomy, and mental health — face fewer barriers in indigenisation once the medical institution itself (e.g. the hospital or clinic) is indigenised, along with the indigenisation of the

education that medical practitioners receive. These Indigenised practices and institutions can ultimately be accessed better due to decolonisation.

Indigenous peoples have more complications from surgeries, including higher mortality rates.¹ Often the blame for this is placed entirely on the colonial legacy and cycles of lower socioeconomic status, a lack of education, and overarching racist and supremacist pedagogies that limit accessibility to culturally appropriate healthcare. However, should these socioeconomic factors be addressed and corrected, high rates of complications and mortality among Indigenous peoples remain, as they are being treated with settler-colonial practices in settler-colonial spaces.²

Childbirth and pregnancy practices are one example where indigenisation has shown a distinct improvement in the health of both the parent and the child. For example, for Indigenous peoples in Canada, childbirth and pregnancy is a community-oriented practice where the community is involved in the spiritual, emotional, and physical care of the parent and infant.³ This, along with ceremonies,

strengthens relationships, connections, and identity within the community and family. Western hospitals limit the incorporation of such practices, especially when an expecting parent experiences perinatal complications; however, Indigenous doulas and midwives can be used when parents are limited to settler-colonial hospitals, such as in the Northern Manitoba Doulas Project.³

Community-driven pregnancy practices can be inaccessible to Indigenous parents that live far from Indigenous communities, as they may need to travel greater distances to reach the appropriate Indigenous clinics. This is further complicated by the need for temporary childcare, job stability, and financial security. Thus, healthcare indigenisation cannot be restricted to reservations and Indigenous communities, but must also be available across the entire nation so that Indigenous people have accessible and appropriate healthcare everywhere. To limit indigenised healthcare is to allow the continued genocide of Indigenous peoples.

Many western practices are needlessly invasive and threaten bodily autonomy due to the clinical manner in which they are conducted. Indigenous – and non-Indigenous – are encouraged to undergo humiliating, uncomfortable, and potentially traumatic practices due to an apparent lack of alternatives. Many Indigenous people do not see the violation worthy of a second visit⁴, and opt to forgo non-critical procedures, such as annual tests and check-ups. Where applicable, indigenisation of these procedures is required so Indigenous peoples may access essential healthcare, testing, and treatments that do not disregard cultural values, such as privacy.

For example, Canada has successfully indigenised cervical cancer screening through self-sampling⁵, rather than allowing a non-Indigenous practitioner to perform the invasive sampling. HPV self-sampling for cervical cancer screening will be introduced in Aotearoa New Zealand in July 2023.

This success can be applied to similar testing procedures, whether through self-sampling or by being undertaken by trusted Indigenous practitioners when necessary, instead of perpetrating trends of non-Indigenous practitioners acting on Indigenous patients. Fortunately, as the indigenisation of these practices can benefit non-Indigenous people, there are fewer barriers in financing, developing, and promoting indigenised alternatives and educating Indigenous people on their options. However, there are historical trends of products and practices originally made for Indigenous peoples being appropriated and co-opted by their colonialists⁶ (e.g. through policy and exploiting physical barriers).

Such a scenario must be carefully avoided by maintaining Indigenous-led healthcare movements, so Indigenous people retain accessible healthcare.

Medicines and treatments under the settler-colonial system are granted authenticity due to the vigorous processes they are created under and the lack of flexibility in their use. However, many Indigenous peoples (such as those in the Philippines and Brazil⁷) have altered the use of medicines to mirror natural medicines (such as applying the medicine to the skin rather than ingesting it), thus realigning them with Indigenous paradigms. This cultural reinterpretation⁷ occurs once a medicine is in high use and has been in the community for an extended period.

The indigenisation of medicine is as important as the western education of these medicines, as it circumvents the continued imposition of settler-colonial knowledge and practices, and ensures the usage by the Indigenous people. However, the weaponisation of science to promote supremacist ideas poses barriers to the indigenisation of medicines in settler-colonial countries.

Settler-colonialists do not currently occupy countries like the Philippines and Brazil to the extent that Aotearoa New Zealand and Canada are occupied, so indigenisation is not as hindered by the settler-state. The settler-colonial states in Aotearoa New Zealand and Canada are heavily involved in Indigenous affairs and assumes that deviations from western medicine cannot produce viable and effective results⁸; this is seldom the case.⁹ Thus, minimal further western research is conducted into alternative uses (although Indigenous research may occur), and settler-colonial medical institutions do not formally recognise alternative medicines or practices (e.g. Rongoa Māori in Aotearoa New Zealand¹⁰).

Indigenous peoples are subjected to high rates of intergenerational trauma and resultant poor mental health due to settler-colonialism.¹¹ This is worsened by a lack of culturally appropriate support and treatment, so Indigenous people are often restricted to settler-colonial clinics or are forced to forgo mental health care altogether. Indigenous perspectives of mental health are holistic and interconnected.

For Māori, mental health care relies on spiritual, cognitive and emotional, physical, and familial dimensions¹² (see top of page 8) rather than the western model that focuses predominantly on the cognitive and emotional dimensions. Subjecting Indigenous peoples to atomistic and disconnected mental health care is particularly damaging for those who have experienced acute trauma and intergenerational trauma in response to colonial



The Māori Health Model: Te Whare Tapa Whā, developed by Mason Durie

practices, such as forced relocation, assimilation, and removal of children.¹³

Affordable and indigenised mental healthcare is severely lacking, so an ideal (but temporary) solution is the education and training of specialised Indigenous practitioners in Indigenous communities where intergenerational trauma is rampant. Eventually, indigenised mental health care must be taught to non-Indigenous psychologists, therapists, counsellors, and psychiatrists; this is where issues arise because such holistic worldviews are often portrayed as misguided and unsubstantiated in the western world, so Indigenous initiatives are underfunded. Indigenous peoples cannot be expected to be treated by the same system that caused them such harm, and yet that is the standard in mental health.

Indigenising the medical curriculum and medical research involves recruiting and promoting Indigenous educators and practitioners to positions of influence and power so Indigenous knowledge and paradigms may be accurately incorporated into the curriculum. Medical research lacks Indigenous input and assumes white, western bodies as the default. This has resulted in a lack of education on how symptoms present in different ethnicities, leading to misdiagnosis and mistreatment of patients. When paired with hostile or dismissive attitudes from non-Indigenous practitioners, Indigenous peoples are placed at a higher risk for complications, long-term and repeated issues, and death.¹⁴

The medical curriculum requires more Indigenous scholars and educators to provide Indigenous input and perspectives and incorporate spiritual, emotional, and familial worldviews (as well as physical worldviews) into healthcare.¹² However, the specific recruitment of Indigenous peoples to positions of power creates concern among non-Indigenous people who may no longer be among the majority. Such a change is perceived as a threat as they believe that they, the new minority, will be treated as they treated the Indigenous minority: dismissed

and disregarded. This creates a compelling argument for non-Indigenous administrators to limit the promotion of Indigenous peoples; this is Indigenous inclusion and tokenism rather than indigenisation.^{15, 16} Indigenous inclusion is a poor compromise for indigenisation as non-Indigenous practitioners cannot guarantee adequate healthcare for Indigenous patients while simultaneously disavowing their sovereignty.

Incorporating Indigenous healthcare into the medical education curriculum impacts both non-Indigenous practitioners and Indigenous practitioners. Educating non-Indigenous practitioners on Indigenous practices creates non-hostile spaces for patients, resulting in the reduced responsibility of indigenisation on Indigenous practitioners and educators.¹⁷ Such practitioners should not be limited to Indigenous institutions, but also be the majority in non-Indigenous institutions to ensure culturally appropriate healthcare.¹⁸

However, incorporating this level of encompassing education in Aotearoa and Canada has been slow; these classes were condemned in Aotearoa New Zealand throughout the 1980s due to assumptions that they would reduce the time spent learning traditional western healthcare practices, and thus graduates would have a diminished quality of education.¹⁹

In reality, this “compromise” served only to minimally raise the focus on Indigenous healthcare, while the priority remained non-Indigenous healthcare. Indigenisation requires compulsory adequate and informative education for practitioners; this includes teaching practices (such as Indigenous pharmaceuticals²⁰ with the same level of detail and respect that settler-colonial practices are given. Indigenised healthcare education is dictated by the policy of the academy and those of influence. Came *et al.*, found that many Māori and Pāsifika leaders were repeatedly undermined and dismissed when advocating for healthcare equality.²¹ Ultimately, educating non-Indigenous practitioners on Indigenous healthcare is required for them to respectfully advocate for the transition from cultural competency to decolonisation to indigenisation.

An unfortunate reality is that the eventual support of the governing settler-state is required for indigenisation across all levels of healthcare and to create dual systems and institutions that allow a sustainable partnership between the settler state and the Indigenous peoples. Without this relinquishment of control, the Indigenous peoples have limited ability to abolish colonialist systems and regain autonomy and sovereignty in healthcare.

The settler government provides opportunities through policy changes, enforcement of favourable laws, and restructuring of healthcare institutions. Without legal requirements for incorporating Indigenous healthcare, there will be an inconsistent and underwhelming acceptance and utilisation of Indigenous practices.²²

Dual institutions promote top-down indigenisation and grant autonomy to Indigenous peoples to be treated with their own cultural practices, with appropriate cultural attitudes, by Indigenous practitioners. Such dual structures have been established in Canada (Indigenous Services Canada)²³ to grant non-insured health benefits to Indigenous peoples, and the newly established Te Aka Whai Ora | Māori Health Authority in Aotearoa New Zealand (1 July 2022).

Regardless, such an Indigenous authority has only as much power as the settler state allows it. A dual institution may exist under one governing party of the settler state and be removed by the next. Despite the benefits of a dual healthcare institution to Indigenous peoples and the advances in indigenisation, it is ultimately under the law of the settler state. Thus, a sustainable, long-term, and stable Indigenous sovereignty in healthcare is impossible without the indigenisation of the governing settler state.

Currently colonialism exists in a socially and politically acceptable state that promotes continued injustices and inequities, and denies the sovereignty and autonomy of Indigenous people, reinforcing the need for indigenisation and decolonisation. Indigenisation is not a compartmented movement, but instead involves holistic relationships and connections between practices and institutions, along with overlapping and dynamic barriers. Indigenising healthcare requires collaboration between Indigenous leaders, practitioners, and patients, and non-Indigenous practitioners and policy-makers across multiple sectors of society to promise Indigenous institutions and practices. Non-Indigenous peoples must provide support and engagement to ensure the well-being of Indigenous peoples, while also stepping aside for Indigenous leadership. To inflict colonialist systems upon Indigenous peoples is to disadvantage them directly and indirectly and further reduce autonomy and power over themselves.

References

- 1 Büyüm AM, *et al.*, 2020: Decolonising global health: if not now, when? *BMJ Global Health*, 5(8), e003394.
- 2 Chakanyuka C, *et al.*, 2021: Appraising Indigenous cultural safety within healthcare: Protocol of a scoping review of reviews. *Journal of Advanced Nursing*, 78(1), 294–299.
- 3 Hayward A & Cidro J, 2021: Indigenous Birth as Ceremony and a Human Right. *Health and Human Rights*, 23(1), 213–224.

- 4 Whop LJ, *et al.*, 2021: Achieving cervical cancer elimination among Indigenous women. *Preventive Medicine*, 144, 106314.
- 5 Bromhead C, *et al.*, 2021: Human Papillomavirus (HPV) Self-Sampling among Never-and Under-Screened Indigenous Māori, Pacific and Asian Women in Aotearoa New Zealand: A Feasibility Study. *International Journal of Environmental Research and Public Health*, 18(19), 10050.
- 6 Thi Nguyen C & Strohl M, 2019: Cultural appropriation and the intimacy of groups. *Philosophical Studies*, 176(4), 981–1002.
- 7 Haak H & Hardon A, 1988: Indigenised Pharmaceuticals in Developing Countries: Widely Used, Widely Neglected. *The Lancet*, 332(8611), 620–621.
- 8 Allen L, *et al.*, 2020: Indigenous-led health care partnerships in Canada. *Canadian Medical Association Journal*, 192(9), E208–E216.
- 9 Etkin NL, *et al.*, 1990: The indigenization of pharmaceuticals: Therapeutic transitions in rural Hausaland. *Social Science & Medicine*, 30(8), 919–928.
- 10 Koia JH & Shepherd P, 2020: The Potential of Anti-Diabetic Rākau Rongoā (Māori Herbal Medicine) to Treat Type 2 Diabetes Mellitus (T2DM) Mate Huka: A Review. *Frontiers in Pharmacology*, 11.
- 11 Kim PJ, 2019: Social Determinants of Health Inequities in Indigenous Canadians Through a Life Course Approach to Colonialism and the Residential School System. *Health Equity*, 3(1), 378–381.
- 12 Durie M, 2011: Indigenizing mental health services: New Zealand experience. *Transcultural Psychiatry*, 48(1–2), 24–36.
- 13 Carrier L, *et al.*, 2020: Two-Spirit Identity and Indigenous Conceptualization of Gender and Sexuality: Implications for Nursing Practice. *Creative Nursing*, 26(2), 96–100.
- 14 King M, *et al.*, 2009: Indigenous health part 2: the underlying causes of the health gap. *The Lancet*, 374(9683), 76–85.
- 15 Hayward A, *et al.*, 2021: Addressing the need for indigenous and decolonized quantitative research methods in Canada. *SSM Population Health*, 15, 100899.
- 16 Gaudry A & Lorenz D, 2018: Indigenization as inclusion, reconciliation, and decolonization: navigating the different visions for indigenizing the Canadian Academy. *AlterNative: An International Journal of Indigenous Peoples*, 14(3), 218–227.
- 17 Davis G & Came H, 2022: A pūrākau analysis of institutional barriers facing Māori occupational therapy students. *Australian Occupational Therapy Journal*.
- 18 Curtis E, *et al.*, 2019: Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *International Journal for Equity in Health*, 18(1).
- 19 Papps E & Ramsden I, 1996: Cultural Safety in Nursing: the New Zealand Experience. *International Journal for Quality in Health Care*, 8(5), 491–497.
- 20 Min J, *et al.*, 2020: Creating a pharmacy elective course in Indigenous health. *Currents in Pharmacy Teaching and Learning*, 12(8), 1004–1013.
- 21 Came H, *et al.*, 2019: Māori and Pāšifika leaders' experiences of government health advisory groups in New Zealand. *Kōtuitui: New Zealand Journal of Social Sciences Online*, 14(1), 126–135.
- 22 Lokugamage AU, *et al.*, 2020: Decolonising ideas of healing in medical education. *Journal of Medical Ethics*, 46(4), 265–272.
- 23 Rand, M., *et al.*, 2019: Evaluation of the Aboriginal Relationship and Cultural Competency Courses among a sample of Indigenous Services Canada nurses. *International Journal of Indigenous Health*, 14(1), 29–41.



Patient Rights: Informed Consent in our Teaching Hospitals

By Sue Claridge

Informed consent is a pillar of our interaction with health practitioners and the health system. It is entrenched in New Zealand law by way of the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 under the [Health and Disability Commissioner Act 1994](#).

[The Code of Health and Disability Services Consumers' Rights](#) (the Code) establishes the rights of consumers, and the *obligations and duties* of providers to comply with the Code. Patients don't know what they don't know; the consent rights of patients must be facilitated by adherence of practitioners to their obligations under the Code.

Informed consent was a central issue in the Cartwright Inquiry and is central to the legacy of the recommendations in the Cartwright report. Judge Silvia Cartwright discusses the issue of informed consent widely in her report in Chapter 7: Ethics and Patient Rights.¹ Her recommendations led directly to the establishment of the HDC and the Code of Rights, a document that sets out patient rights in plain language for patients and practitioners alike.

The right and obligation of patients to provide informed consent is multi-faceted; it is more than just consent, and carries with it the right to say no; the right to be informed (or not know information*), and to choose about all aspects of one's health care and interaction with practitioners; and includes the right to know and consent to the practitioner that is providing the treatment.

Further, all informed consent rights extend to teaching and medical research situations.

* for example, to not be told a prognosis, or expected time left in a terminal diagnosis.

For our regular readership, many of whom are well versed in the rights and responsibilities involved in informed consent in the context of health care and medical treatment, it may seem that I am preaching to the converted. However, it is clear from anecdotal evidence, reports in the media, complaints to the HDC and studies published in the medical literature, not all New Zealanders are aware of what informed consent entails or their legal rights and responsibilities. Of particular concern is the apparent (wilful) ignorance of some, or perhaps many, health practitioners regarding their obligations to patients.

One needs to look no further than the Annual Reports of the Health and Disability Commissioner to gain an appreciation for the scale of the problem of breaches of informed consent rights. When all issues raised in complaints are considered, consistently one of the most common complaint categories is informed consent; over the last four years that this data has been provided in the [HDC annual reports](#), informed consent issues have been involved in between 14 and 19 percent of complaints.

New Zealand Research on Informed Consent

The journal paper that precipitated this article was published in the *New Zealand Medical Journal*³ in May this year. It was the latest of a several of papers since 2011 that has investigated or discussed informed consent in New Zealand teaching hospitals.

This most recent paper found that with regard to medical students under supervision in hospitals "Adherence to the national consensus statement on obtaining informed consent for sensitive examinations is unsatisfactory."

Bhoopatkar and colleagues³ write that "Extra care is required regarding the need for informed consent

Breaches of the Code at North Shore Hospital

In December 2019, Radio New Zealand broke news of ongoing serious breaches of informed consent rights at North Shore hospital. A complaint had been laid with the HDC regarding “junior doctors, midwives and paramedics observing or performing obstetric and gynaecological surgeries on patients under anaesthetic who have not consented to it.”²

While we reported on this issue in our Newsletter in [March 2020](#) and again in [February 2021](#), referring only to the “public domain” articles available at the time, I had actually spoken to the theatre nurse at the heart of the complaint and met with her in the days before the RNZ report. AWHC chose to keep that information confidential to protect the nurse.

Theatre nurse Ali* no longer works at North Shore Hospital.

Over a period of six years Ali observed numerous instances in which patients informed consent rights were being breached. These breaches were typically in women’s health, and often involved a teaching situation with trainee and not fully qualified doctors. Many of the breaches involved intimate examinations and procedures such as vaginal examinations. Some of these instances were detailed in the RNZ report.¹

Ali knew very well what the Code of Rights sets out in terms of informed consent, and knew that North Shore being a teaching hospital did not absolve the doctors, trainee doctors or the hospital management of their obligation to uphold patient rights. She repeatedly brought these breaches to the attention of doctors and surgeons in the course of her work, and formally raised her concerns with her charge nurse and unit manager, hospital and Waitemata DHB management, and then the chair

for student involvement in teaching and learning activities, especially for sensitive examinations (breast, rectal, genital, and pelvic examinations).” They go on to point out what should be patently obvious to anyone who has done any work in the area of patient rights, that “Performing unconsented sensitive examinations, particularly under anaesthesia, is now considered unethical and indefensible.”

Ninety-three out of 265 final year medical students at the University of Auckland responded to the study survey, which collected data on compliance with informed consent requirements and asked students about challenges they faced performing sensitive examinations.

of the WDH Board, all with the support of Kate Weston, Professional Nurse Advisor with New Zealand Nurses Organisation.

Ali ‘blew the whistle’ under the Protected Disclosures Act 2000, yet at work she was increasingly under threat from the senior medical staff with whom she worked. Her position became so tenuous that North Shore Hospital stood her down; her safety at work could not be guaranteed by hospital management and she was being bullied and threatened by the doctors and surgeons she had to work with.

Ultimately, Ali was forced to resign. Without a job and without an income, she couldn’t pay her mortgage and was forced to sell her house. All because she repeatedly spoke up in defence of patients at North Shore Hospital whose rights to informed consent were being breached. The Protected Disclosures Act 2000[†], designed to provide protection for employees and other workers who report concerns, appeared to offer her little practical protection.

Ali is at peace with her decision to pursue her significant concerns about breaches of informed consent rights. Despite all she has been through, she says she would do it all again; she sleeps well at night knowing that what she did was right. She believes it is vital that those who are in a position to do so, should speak up for patients.

* Ali is not her real name, but a pseudonym used to protect the nurse as much as possible.

† The [Protected Disclosures Act 2000](#) has since been replaced by the [Protected Disclosures \(Protection of Whistleblowers\) Act 2022](#)

One of the most illuminating parts of the study is the qualitative responses to the survey in which students related factors that reduced adherence to the national consensus statement, in particular those factors that related to the student’s supervisor. Comments from students included:

“I explained the University policy, but he [supervisor] wasn’t concerned...”

“Many of the senior doctors were unaware of the universities policies placing a large amount of the responsibility upon the students.”

“Due to the hierarchy in 4th year often felt unable/unwilling to question seniors even though I was aware the consent process was not followed.”

The 2015 Consensus Statement

In 2015, a consensus statement on medical students and informed consent was jointly prepared by the:

- Faculty of Medical and Health Science of the University of Auckland,
- Faculty of Medical and Health Science of the University of Otago,
- Chief Medical Officers of District Health Boards,
- New Zealand Medical Students' Association,
- Medical Council of New Zealand.⁴

The consensus statement discussed the Code of Rights and obligations of practitioners to obtain informed consent, the background to the situations that medical students find themselves in in a teaching environment with real patients. Eighteen principles pertaining to informed consent for the presence of a medical student during the care of patients were set out in some detail and with multiple examples.

"I was forced to perform an unconsented DRE [digital rectal examination] examination in theatre while a patient was under general anaesthetic. I objected to this but was coerced into performing it anyway by the urologist."

This student felt abandoned by their University, even after making formal complaints:

"Essentially I felt like the medical school didn't care when I contacted them about being forced to perform a male DRE under general anaesthetic WITHOUT consent... Even quite senior staff were contacted about this and simply were either unsure or unconcerned with this behaviour. I was essentially brushed off."

In response to publication of this paper, Health and Disability Commissioner, Morag McDowell, said she was deeply concerned and very disappointed that the issue is continuing after earlier research published in 2018 highlighted the same problem⁵ (see below).

She went on to say that "a lack of clinical and ethical leadership is a system failure."

"These students have not been supported. Leadership from senior doctors and nurses must be shown in rectifying this."

"This requires positive and ethical role modelling, and students must feel empowered to question any examination if a patient has not given informed consent."⁵

Breaches of informed consent rights continue to be an issue in a teaching environment. Malpas *et al.*

One of the most salient statements in the paper was:

"The above text is a consensus statement that was agreed by multiple stakeholders, after careful and considered consultation to provide a guideline. The paper is not intended to set standards but rather to outline New Zealand's existing legal and regulatory requirements in a practical way."

It is clear that this was not a set of guidelines that students and supervising medical practitioners could choose to implement or not. It was a statement clarifying expectations for informed consent in the training of medical students in New Zealand today. In other words, there was little room for ambiguity regarding the obligations on medical students and their medical supervisors in obtaining informed consent where student were present or taking part in providing care to a patient.

published the results of a 2016 study in September 2018.⁶ It resulted in similar quotes from medical students regarding failures to obtain consent from patients in a teaching situation:

One student reported that "I felt compelled to not waste further theatre time or challenge the consultant."

When another queried whether they needed consent to undertake a sensitive examination the consultant brushed off the question saying, "oh it's fine, don't worry about it"

A male student was told by his supervising clinician in an obstetrics and gynaecology setting that informing the particular patient of the procedure "would take forever to explain to someone that is uneducated." When he queried whether the clinician could ask for consent for him to be present, "this was not done either with the excuse that the patient would not know what that [consent] was and would say yes anyway."

Another student said, "It appeared the consultant had no intention of asking for consent or explaining to the patient what I was going to do." (The student refused to undertake the examination when the patient said he would rather not.)

This research also reported on the difficulty students have refusing to do examinations without consent, knowing that their supervisors determine their grade at the end of their rotation.

One of the co-authors of both research papers and the 2015 consensus statement is Dr Phillipa Malpas,

Honorary Associate Professor in Clinical Medical Ethics at the University of Auckland. She published a paper in 2011 in the *Journal of Medical Ethics*, discussing her findings from an ethics assessment of senior medical students at the University.⁷ The ethics assessment was a broad reflection by students on the ethical dimension of a clinical case or situation in which they had been involved.

Among other issues that students discussed, “many of the students’ reports concerned the issue of consent; in particular, when students had not gained consent from patients for them to participate in the patient’s care.”

Despite the introduction of the Code of Rights in 1996, and the fact that medical students are taught medical ethics and about patient rights, and despite these issues in the New Zealand context being discussed in the medical literature for at least the last 11 years, issues around informed consent in a teaching situation persist. It leaves advocates of the Code of Rights speechless and exasperated, and wondering what it will take to effect change in our hospitals.

Dr Phillipa Malpas shares that frustration and disbelief.⁸

Interview With a Medical Ethicist

Dr Phillipa Malpas consented to be interviewed for this article (done by email) and AWHC is hugely appreciative of the time she took to answer our questions and her candour on the subject of informed consent.

Right from the start, Dr Malpas’ exasperation is evident. In her first email she says that she thought that “shining a light on [the issue of informed consent] within the contexts of patient rights, medical training, professionalism, and the implications of the Cartwright Inquiry recommendations, would start a conversation that would result in change. If change is happening, it’s glacially slow!”

Then, we asked Dr Malpas a number of questions:

How do you feel about the issue of continuing breaches of patients’ rights, 34 years on from the Cartwright Inquiry, 26 years since the establishment of the Code of Rights, and seven years since the consensus statement on medical students and informed consent?

Personally, I feel disappointed and frustrated that patient’s rights continue to be breached within the context of informed consent. The Cartwright Inquiry marked a seminal turning point within the health care system in Aotearoa. In the Inquiry

Report¹, [Chapter 9](#) is crystal clear: “Any patient who is to be examined or to undergo any procedure related to teaching, must be informed of the nature of the procedure, the number of students to be present as observers and the names of those who are to participate actively”.

In the Consensus Statement the issue of informed consent sits front and centre. The paper was a collaborative project with a number of stakeholders, whose main objective was to provide guidance to medical students and supervisors, to engender discussion within hospitals and universities, and clarify expectations. Point 13 is clear: “Sensitive examinations (includes breast, rectal, vaginal examinations and those of the external genitalia) in competent awake patients require explicit consent. This can be verbal but should be documented in the patient’s notes. It is essential that there should be no possibility for the consent to have any element of coercion.” Point 14 concerns sensitive examinations under anaesthesia – they require “formal written consent obtained in advance and signed by the patient”.

What do these persistent breaches say about our ability to change the culture within medical practice over time?

There are many health professionals who discuss issues such as consent and the involvement of medical students in their treatment and care carefully and thoughtfully. Informed consent is done well. However, the persistent breaches that my research showed (and what others’ research has also mirrored) suggests our ability to change the culture within medical practice faces an uphill battle.

Given the gulf between what students are taught about their obligations regarding informed consent, and what they experience in practice in their hospital rotations, it appears that the significant power imbalance between trainee doctor and senior supervising doctor, results in a perpetuation of an attitude that patient rights simply don’t matter.

Certainly, I think the significant power imbalance between students and their seniors is a factor in why some medical students struggle with speaking up and instead, ‘do what they are told’ – often against the students’ wishes. Students have stated that they have been belittled and criticised by seniors when they do find the courage to speak up and say ‘no they won’t undertake a sensitive examination on a patient who has not given their consent’. I think the majority of supervising doctors do respect patient’s rights by seeking their consent, introducing the students they are supervising to patients by name, and ensuring that patients feel comfortable with the involvement of medical students in their treatment and care. However, there is a core of doctors who do

not respect the patient's right to be informed about who will be involved in their medical treatment and care (observation or otherwise).

Do you feel the issues go beyond informed consent to poor attitudes of health professionals towards patients, and perpetuates the significant power imbalance particularly between male doctors and female patients.

Without wanting to excuse poor attitudes towards patients (male or female), I do think time and work pressures impact on how patients are sometimes treated as well as fatigue, and a lack of staff at times. But yes, power imbalances exist and some attitudes towards patients are callous and appalling.

The fact that supervisors and consultants have all the power and can influence the assessment of medical students clinical performance, and therefore their academic results, is effectively teaching students that silence and acquiescence is necessary in order to complete their studies and graduate. What are the implications of this in terms of efforts to change culture and train better, more empathetic doctors who understand, acknowledge and value the rights of patients?

I think there needs to be greater emphasis on patients (and whānau) being better informed about their rights; to speak up when they are dissatisfied, to complain when they are not provided with the treatment and care they are entitled to, and to be proactive in understanding their own bodies. But I also think medical training needs to be routinely reviewed to ensure that students' experiences and complaints are acted on. Supervisors write (and submit) reports on a student's performance, their attitudes, the ways they interact and approach their patients, and their knowledge and understanding of medicine. Medical students do not assess their experiences with their supervisors, including their attitudes towards patients and staff. However, this could be done ethically, appropriately and confidentially by third parties (peers and seniors) whereby students are protected from the consequences of

reporting (their) adverse experiences, and supervisors given the opportunity to respond in a fair manner to critical reports.

Do you think the lack of awareness of university policies on informed consent in senior doctors is genuine or wilful ignorance? And if it is genuine, how is it that senior doctors, in the aftermath of the consensus statement on medical students and informed consent, can be unaware of the importance of informed consent in any situation including teaching? What does this say about the quality of both medical training in Aotearoa New Zealand, professional competence and further professional education, and oversight by teaching hospitals and universities?



Dr Phillipa Malpas

I believe the ethics teaching in the UoA medical programme is thorough, specifically in relation to how important consent is within medicine; when I was teaching we discussed the Cartwright Inquiry, and consent was discussed across several years. For several years I had Ron Jones discuss [his book] *Doctors in Denial* and the issue of informed consent with senior medical students. In further professional education, and the role of hospitals and other medical institutions, consent needs to be a priority in the ongoing training of all health professionals.

If it is possible for one doctor to properly obtain informed consent for the presence and involvement of student doctors then surely it must be possible for all doctors to adhere to the Code of Rights and the consensus statement? Are doctors in breach of patient rights suggesting that it is too difficult for them to understand the rules or undertake a simple task of obtaining consent from a patient?

It shouldn't be difficult and this point is made in the Consensus Statement. Without wanting to minimise the importance of communication, it often simply amounts to a conversation with a patient and a doctor or nurse (and may also involve a medical student).

Breaches of patient rights have been documented recently at North Shore Hospital in the WDHB. When this issue was exposed by a theatre nurse, the WDHB said that there was a need for clarity and that lack of consistent national guidance is partly at fault. It is hard to understand how the Code of Rights or the consensus statement could be seen to be confusing, inconsistent or unclear; your thoughts?

I agree. I believe this issue needs to be driven from the top. It's all about leadership and developing a culture of inclusivity! The experience of theatre nurse Ali clearly shows how difficult it is to effect positive change when it is not led and supported from the top. In regard to medical students, we cannot expect those who are situated at the bottom of the hierarchal ladder to be the ones changing the attitudes and behaviours of their seniors. The 'trickle' up' effect seems doomed to fail.

Chief Medical Officer Dr Jonathan Christiansen at WDHB said that "consent was a two-way street," "that women needed to be proactive and ask more questions if they felt they did not have enough information." What do you make of these comments?

I take his point that consent isn't just one sided, and that practitioners need to help patients understand information so that they can make an informed decision. But patients have responsibilities too. I don't think it's fair to lump everything in the lap of health practitioners. But I agree that health practitioners need to do more to help their patients understand, and that is a powerful argument for why we need diversity in our doctors so that they represent their patients. Patients, especially female patients, undergoing sensitive examinations are uniquely vulnerable, and the power imbalance between doctors and their patients couldn't be starker.

Medical Council chairman, Dr Curtis Walker, said "I wouldn't suggest there's a problem so much as an ongoing conversation as to how much [informed consent] is enough and how much might be too much, and certainly also how much is practical in any given clinical situation." How is it possible to have "too much" informed consent?

This quote perhaps reflects back an earlier comment about uneducated patients, and possibly also includes those who are fearful and anxious about their health, their prognosis, and the future – some patients may be completely thrown by a diagnosis,

or be vulnerable for other reasons, or be distrusting of health practitioners. My point is that some doctors will have patients who require a lot of time and patience to understand and still may not be clear about the options available to them. Some patients don't want to know and would prefer to be told what to do ("doctor what would you do if you were me", or "if you were in my mother's shoes, what would you do?"). Some patients don't follow their doctor's advice, some are non-compliant with their treatment. I absolutely don't want to push any blame on patients; however, I can see the complexity of some patients and their lives that result in doctors viewing informed consent as a hurdle too great to jump. Are these patients the exception? I simply don't know. But my own personal view is that seeking informed consent from patients (or their whānau) shouldn't be so difficult that doctors see it as problematic, unobtainable or not worth the investment of time.

References

1. Cartwright S, 1988: [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](#), 1988.
2. Pennington P, 2019: [Nurses say gynaecology patients' rights were breached](#), *Radio New Zealand*, 5 December 2019.
3. 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).
4. Bagg W, *et al.*, 2015: Medical Students and informed consent: A consensus statement prepared by the Faculties of Medical and Health Science of the Universities of Auckland and Otago, Chief Medical Officers of District Health Boards, New Zealand Medical Students' Association and the Medical Council of New Zealand, *New Zealand Medical Journal*, 15 May 2015, Vol 128 No 1414.
5. HDC, 2022: [We must do better on informed consent](#), Health and Disability Commissioner, Press release, 23 May 2022.
6. 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.
7. 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.
8. Malpas P, 2022: Personal Communication.

Birth Injury, ACC and Surgical Mesh

By Sue Claridge



“Whenever and wherever you intend to give birth, your experience will impact your emotions, your mind, your body, and your spirit for the rest of your life.”

- Ina May Gaskin

Having a baby is, for most women, incredibly painful. Fortunately, for most women, much of the pain subsides immediately after the baby is born. Despite this, it can take days to weeks for many to recover from the physical effects and damage from the birth. However, no woman goes into labour and birth expecting that the physical effects of bringing their baby into the world leave them with a severe birth injury, and ongoing pain and debilitation that may take years to resolve, if ever.

Over the last year a significant amount of work has been undertaken by individuals, NGOs and some members of Parliament, to ensure that women harmed in giving birth are able to get the care, treatment and rehabilitation that they need.

In the [February-March 2022 edition of the Auckland Women’s Health Council Newsletter](#), we reported on the work being done in this space and on the Accident Compensation (Maternal Birth Injury and Other Matters) Amendment Bill.

In September 2021, ACC Minister, Carmel Sepuloni announced “Amongst a suite of changes, we’re proposing to amend ACC legislation to cover more injuries experienced by women during childbirth.”

Among many other individuals, health professionals and organisations, [AWHC made a submission](#) on the proposed bill. While in principle we supported the Bill and the expansion of ACC cover to include birth injuries, we were adamant that the Bill did not go far enough. We submitted in the strongest possible terms that **ALL** birth injuries should be covered by ACC and retrospectively, so all women can receive the medical care they deserve.

The Accident Compensation (Maternal Birth Injury and Other Matters) Amendment Bill has been through the select committee process and in July had its second reading in Parliament. The Bill is currently at the fifth stage of the legislative process, the ‘Committee of the whole House’, in which the bill will be considered part by part, and MPs have the chance to debate it in detail.

Possibly the most important aspect of the legislative process for women with birth injuries, are the amendments that the Select Committee made in response to the written and oral submissions. The original Bill listed the specific birth injuries that ACC would cover. This is in stark contrast to existing ACC legislation that does not list the injuries covered by the AC Scheme, and includes only broad definitions and some specific examples.

AWHC and other submitters argued that the proposed legislative amendment was inconsistent. We saw no reason why coverage of birth injuries should be treated any differently from other injuries, and failed to see why some birth injuries were to be covered and not others.

The Select Committee agreed – to a certain extent – and in addition to those listed in the original Bill, found that following injuries should also be covered:¹

- obstetric anal sphincter injury tears and urethral tears,
- anterior wall and posterior wall prolapses,
- post-partum uterine inversion,
- coccyx fracture or dislocation,
- pubic ramus fracture,
- symphysis pubis capsule or ligament tear.

The Select Committee also recommended regular review of the list of maternal birth injuries to be covered to ensure appropriate and comprehensive coverage.

Changes to ACC cover to include maternal birth injuries and associated issues, including mental trauma and injury and injury to newborns, was strongly advocated for by the Green Party, in particular by Jan Logie. While the Green Party have said they will support the amended legislation, they remain disappointed “at the limitations of this reform, and the model chosen to extend cover for birth injuries.”¹

In particular, they were disappointed that the legislation included a closed list of injuries to be covered, rather than a general category of birth injuries, and the lack of retrospective cover for women injured prior to the Act coming into force (October 2022) who still need support, treatment and rehabilitation. They were also disappointed that mental injury due to a traumatic birth, whether or not there is also a physical injury, and injuries to the baby, whether or not this meets the threshold of treatment injury, were also excluded from the Bill.

The Green Party went on to say:

“There is a \$1 billion annual pay-out difference between men and women from ACC. The costs of this bill are estimated to be around \$25 million per annum. The costs to women with significant existing injuries that are untreated has never been recorded and is not considered within this legislation. By failing to listen to calls of submitters that the bill needed to go further, the Government is signalling that they’re not serious about addressing gender equity with ACC.”

AWHC also discussed this issue of equity in our submission, and we are also disappointed that given an opportunity to, in part, address what are by ACC’s own admission significant biases and discrimination against women in ACC coverage, the Select Committee chose not to do as much as they easily could have.

“Giving birth should be your greatest achievement, not your greatest fear.”

- Jane Weideman

Treatment for Birth Injury and the Use of Surgical Mesh

The Accident Compensation (Maternal Birth Injury and Other Matters) Amendment Bill is due to be enacted soon and comes into effect on the 1st of October 2022. ACC expects to support 28,000 women per year to access the support and treatment they need.²

Consumer and patient advocate, Charlotte Korte, is concerned that after the bill passes and ACC covers birth injuries, there will be an increase in the number of women presenting to gynaecologists needing treatment and repair of birth injuries.³

Among other health issues that Charlotte works on, she is a member of APHERM (Advocating for Pelvic Health Empowerment and Rehabilitation for Mothers), a multidisciplinary group of healthcare professionals and consumers who came together out of concerns about increasing pelvic floor disorders and injury occurring pre and post birth.

APHERM submitted on the Accident Compensation (Maternal Birth Injury and Other Matters) Amendment Bill and strongly advocated for the changes in ACC cover for birth injuries, and like AWHC had concerns that the bill did not go far enough.

Like so much in health, many initiatives are a double-edged sword, offering positives and negatives. While we all celebrate the fact that many New Zealand mothers will now get the treatment and support they deserve for injuries incurred during birth, it is vital that those injuries are properly treated, that treatment does not cause further harm, and that prevention of birth injuries is properly and adequately addressed.

APHERM advocate for better education, screening, and treatment during pregnancy and after delivery by all multidisciplinary maternity care providers (pelvic health physiotherapists, continence nurses, midwives, practice nurses and GPs).

However, implementing such a programme of preventive action and care may take years to achieve; in the meantime, the fear is that many women will be recommended procedures that involve the use of surgical mesh, significantly exacerbating the surgical mesh crisis that we have been experiencing in Aotearoa New Zealand since at least 2012.

Charlotte fully supports Sally Walker's petition for a suspension vaginally-inserted surgical mesh procedures for stress urinary incontinence (see below), but she is also concerned about the rising number of injuries sustained from surgeons now providing alternative non-mesh surgical procedures.³



Patient advocate, Charlotte Korte

"The majority of surgeons in New Zealand have not done these procedures for some time, nor had the training required to do these proficiently. Urgent upskilling for surgeons undertaking non-mesh procedures is vital and strict monitoring by the Ministry of Health is essential, as happened in the United Kingdom after they paused surgical mesh in 2018," she told AWHC.³

The UK Mesh Clinical Advisory Group, made up of UK specialists in urogynaecology, stated that that few surgeons now have the skills for alternative non-mesh procedures. In recommendations to medical directors and surgical

teams, the Advisory Group said "It will therefore be essential to mitigate this by including non-tape procedures for SUI in the high vigilance scrutiny: e.g. colposuspension, fascial sling procedures, and periurethral injectable treatments. This should apply for the duration of the pause."⁴

Aotearoa New Zealand lags behind other countries, such as Scotland and England. While we have made progress – the restorative justice process in 2019, and ACC's review of previously declined claims for surgical mesh injury – women are still being harmed. Since June 2022, *New Zealand Herald* health reporter, Emma Russell, has shone a light on the horror of surgical mesh and what happens to women when such procedures go very, very wrong.*

Put Your Name to Saving More Women From Harm

Can you sign Sally Walker's [petition to Parliament](#)?

Sally was seriously injured by a surgical mesh procedure for urinary incontinence and prolapse. But her surgeon didn't tell her about the risks or the alternatives. Since the mesh operation she has had multiple operations, has had to have her bladder removed, her vagina sewn shut and lives with chronic pain and disability.⁴

Sally doesn't want this to happen to any other women, but because mesh is still being used in this way in New Zealand other women are at risk of having their health and their lives destroyed, leaving them with severe pain and disability.

She wants the Government to suspend the implantation of vaginally-inserted surgical mesh for stress urinary incontinence. Signing the petition only takes a couple of minutes and by signing it you may help other women avoid what Sally, and thousands of other New Zealanders harmed by mesh, have been through.



* Links to many of Emma Russell's articles can be found in "In Her Head, surgical mesh: Another 38 women harmed after Govt warning to hospitals"⁴, but unfortunately are premium content and behind a subscription paywall.

If you thought that after the restorative justice process and ACC's review, and the years of work by mesh injured women like Charlotte Korte, women in Aotearoa New Zealand were safe from the debilitating injuries caused by surgical mesh used for stress urinary incontinence (SUI) and pelvic organ prolapse (POP)... you were wrong.

Just this month, new data has revealed that in the four years since Government officials ordered hospitals to take action to minimise the harm from these surgical mesh procedures, at least another 38 women have been injured severely enough to have claims accepted by ACC.⁵

ACC reported that those 38 women have "received large taxpayer-funded pay-outs amounting to \$650,000 to compensate for the harm obtained through a treatment intended to fix childbirth injuries."

ACC also 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."⁵

AWHC acknowledges that not all those who have procedures involving surgical mesh are harmed by them, and that, in particular, the use of mesh for hernia repair can be highly successful. [Urologist, Dr Chris Hawke](#), says that "modern hernia surgery is, without any exaggeration, 10 times less likely to fail than in the past" because of the use of mesh. However, he goes on to say that it is problematic in flexible tissues, and he makes clear that surgical mesh is misused in gynaecology, although perfectly reasonable when used appropriately, such as in hernia repair.

Herein lies the problem; it is still being used for gynaecological procedures.

It is not just NGOs like AWHC, and mesh injured women who harbour substantial concerns about the ongoing use of surgical mesh. Health and Disability Commissioner, Morag McDowell has also spoken about her concerns, particularly around issues of informed consent – many women have told of expressing their concern and reluctance to their surgeon about having mesh used, or had it implanted without being told – and regulatory issues including credentialing and training of surgeons.⁵

Another major issue is attitude of Minister of Health, Andrew Little and Associate Minister of Health, Ayesha Verrall to the continuing harm caused by surgical mesh.

On the 4th of July 2022, National's health spokesperson, Shane Reti, asked Health Minister Andrew Little "How many people, if any, have been diagnosed with pelvic mesh related complications per year in the past 5 years?"⁶

Little replied saying that "The level of detail requested has not historically been reported to, or recorded by, the Ministry of Health" and that he considers "that the time, and hence the expense, of answering the Member's question *is not in the public interest*."⁶ (our emphasis)



HDC, Morag McDowell



Health Minister, Andrew Little



Associate Health Minister, Ayesha Verrall

It is outrageous that data on complications/adverse outcomes from a medical implant that has caused so much harm, the use of which has been widely banned or suspended internationally, is not collected or recorded by the Ministry of Health and its agencies. This is an absolute abrogation of responsibility and that information is absolutely in the public interest.

In August, Associate Minister of Health Dr Ayesha Verrall, was asked by the *New Zealand Herald* if she was confident women were no longer being harmed by surgical mesh, she responded:

“The Government has taken this issue seriously and already undertaken steps to ensure past wrongs are rectified, including an apology by ACC, as well as changes to ACC’s processes.”⁵

“Where care isn’t to an acceptable standard, they’ve been treated unfairly or harm has occurred, they have the right to be heard,” she said.⁵

Charlotte Korte is appalled at this statement:

“I am now a disabled women after suffering a mesh injury, I cannot describe what I have lost as a result of having surgical mesh implanted. I am in contact every day with New Zealander’s who have had their lives utterly destroyed by these procedures, the harm is significant, I do not believe that credentialing surgeons to implant and remove mesh will keep people safe.”

“I do not believe that Ayesha Verrall’s comment accurately describes the situation. Where is the apology from the Government for allowing the harm to continue? ACC may have apologised, and yes there may be a few more who have had their claim accepted, but the fight only just begins once your claim has been accepted; in fact, it is much harder now dealing with ACC than it ever was. How does setting up mesh specialist centres* help to rectify the problem if you are still implanting mesh? Sadly, these centres will be needed for a very long time.”³

Saying that the Government is taking this seriously, then following up with irrelevancies about ACC reviews and apologies does not answer the question, and does not prevent more harm happening to women. As far as AWHC are concerned this isn’t good enough. Apologies and cover by ACC are not

* The MoH is working to establish specialist service centres for mesh complications in Christchurch and Auckland. The centres will have a focus on pelvic floor procedures. A person experiencing mesh harm can be referred to one of the centres or can self-refer. The centres will offer wrap-around services – physiotherapy, pain specialist, psychological help – as well as the option of mesh removal by credentialled surgeons.

enough. What the women of Aotearoa New Zealand need is for further harm to be prevented. Right now!

To say that mesh injured have a right to be heard demonstrates a complete failure to understand the issues and severity of the harm experienced, and the urgent need to stop further harm. It is the absolute epitome of “ambulance at the bottom of the cliff” mentality and does an enormous disservice to the mesh-injured women who have been fighting for ten years to halt the harm from mesh. The time to be heard is long past; now is the time for decisive action on the part of our ministers of health and our Chief Medical Officer.

However, given such an indecisive and weak response from the Government and health agencies over the gynaecological use of surgical mesh in this country, it is essential that those seeking treatment for birth injuries inform themselves about surgical mesh, including knowing:

- the alternative names for surgical mesh,
- the questions to ask your doctor if you are thinking about having a surgical mesh implant,
- the symptoms of surgical mesh complications,
- the steps to take if you start experiencing any of these symptoms,
- questions to ask your doctor when discussing mesh removal.

Charlotte Korte has provided AWHC with practical information on surgical mesh, including information on the points above. You can find [this information on our website](#) along with articles on surgical mesh, resources and links.

References

1. [Accident Compensation \(Maternal Birth Injury and Other Matters\) Amendment Bill](#), Government Bill, 103–2, As reported from the Education and Workforce Committee
2. Manch T, 2022: [More birth injuries set to be covered by ACC as expanded bill passes second reading](#), *Stuff*, 28 July 2022.
3. Korte C, 2022: Personal Communications.
4. Mesh Pause Clinical Advisory Group, 2018: *Recommendations of the Mesh Pause Clinical Advisory Group to Medical Directors and Surgical Teams*, in a [letter to Regional Directors, Trust Medical Directors, and clinicians from the NHS, UK](#).
5. Russell E, 2022: [In Her Head, surgical mesh: Another 38 women harmed after Govt warning to hospitals](#), *New Zealand Herald*, 18 August 2022.
6. New Zealand Parliament, Written Questions: [22887 \(2022\). Dr Shane Reti to the Minister of Health](#).
7. Russell E, 2022: [In Her Head women’s health: Sally Walker’s surgical mesh trauma - ‘My body was breaking down’](#), *New Zealand Herald*, 30 June 2022.

MANAGING EXPECTATIONS



By Sue Claridge

“CONSUMER REPRESENTATION” IN TE WHATU ORA

The concept of consumer representation that is organised, formalised and recognised by the Ministry of Health and health entities is not new. From the mid-1990s there had been an increasing number of calls for public and private agencies in the health and disability sectors to engage with consumers and to involve consumers in their decision-making and/or governance.¹ Then, in 2004, a discussion document written by Sandra Coney for the New Zealand Guidelines Group (NZGG) was published: *Effective Consumer Voice and Participation for New Zealand: A Systematic Review of the Evidence*.¹

Among 12 recommendations from the report, Sandra recommended that:

- NZGG advocate to the Ministry of Health with regard to the need for a consumer focus in the Ministry of Health.
- NZGG advocate to the Ministry of Health on the need to national policy around consumer participation, expanding on the New Zealand Health Strategy principle for active involvement of consumers at all levels.
- The standards, performance measures or similar tools for measuring consumer participation be developed.

Despite the amount of work undertaken to enable an effective consumer voice within the health system, it never really got off the ground. A national consumer group – the Consumer Collaboration – was established after a national hui in October 2005 (hosted by HDC), but was ultimately disbanded.

In 2013, Auckland Women’s Health Council Committee member, member of the Cartwright Collective and long-term consumer advocate and representative, Jo Fitzpatrick, gave the plenary address at a seminar on the Legacy of Cartwright marking the 25th anniversary of the Cartwright Report. She titled it [*In the Valley of the Missing Link: the Consumer Experience*](#).²

Early in her address, she related a story of how, having provided a consumer perspective at a clinical meeting, one of the clinicians approached her and complimented Jo on her contribution. She also quizzed Jo on her credentials as a consumer advocate – which in 2013, went back some 12 years and stood up to scrutiny.

“That’s when the kicker came,” said Jo.

“‘Oh’ said the specialist, ‘you’re not a real consumer advocate. You know too much. It’s probably time for you to step aside and let a real consumer take your place.’”

Jo said that she politely asked the clinical specialist “So, how long have you been a specialist?”

“Twenty years,” she answered proudly.

“Goodness,” said Jo, “that’s longer than I’ve been a consumer advocate. So, when do you plan to stand aside?”

Looking startled the specialist said “Oh, now that’s given me something to think about. I may need to revise my assumptions about consumer advocates.”

Nine years on from that seminar, and 18 years since the publication of *Effective Consumer Voice and Participation for New Zealand: A Systematic Review of the Evidence*, consumer advocates and consumer representatives would have to wonder if consumer representation has, in reality, come very far. It seems we either 'know too much' and therefore can't really, truly represent consumers, or as consumers we know nothing at all, and 'how dare we' aspire to tell the exulted medical and health professionals what is in consumers best interests.

In her address, Jo went on to consider the Ministry of Health's 2013 to 2016 *Statement of Intent*, in which then Minister of Health, Tony Ryall, said that the New Zealand public health service was driving an "integrated approach that puts the patient and user at the centre of service delivery."³

The document went on to advise that that it will "ensure patients and carers are at the centre of service delivery"; that they are planning a "health system that is people-centric and more convenient. A high-quality health system ... that meets people's health needs and their legitimate expectations."³

Regarding the 2013 to 2016 *Statement of Intent*, Jo said:

"The rhetoric is rampant but is it reflected in reality? So much in health is about us. Without us, the whole enterprise becomes somewhat pointless! With today's emphasis on patient-centred care, patient portals, patient journeys and patient-directed care pathways, has the power in medicine shifted towards consumers as partners in care?"²

Let's take a leap forward in time to October 2021. The Health Quality & Safety Commission (HQSC) invited New Zealanders to join Health Forum Aotearoa. They say on their [website](#) that they support consumers being actively involved in decision-making for their health, *at all levels*. [our emphasis] The forum is part of their vision for the future to deliver a people and whānau centred health system.

At the time that they asked New Zealanders to join the forum they said that the aim was to "support the health system to tap into the diverse voices of consumers and communities to ensure consumer and whānau voices are prioritised at all levels of service set up and delivery."

AWHC signed up as members of the forum, albeit with a few niggling concerns and reservations. For example, it was concerning that the list of 'areas of interest' in the sign-up form did not include women's health. We hoped that this was not an indication that women's health was not on their agenda, despite ample evidence in the medical literature that women's health is poorly catered to,

from medical research through to accessing health-care and equity in health outcomes.

The first consultation that Health Forum Aotearoa undertook was for feedback on a draft code of expectations for how health entities must work with consumers, whānau and communities in the planning, design, delivery, and evaluation of health services; a document that is required by the Pae Ora (Healthy Futures) Act 2022 and is underpinned by the health sector principles. All health entities must act in accordance with the code and are required to report annually on how the code has been applied.⁴

AWHC made a submission, and we were generally supportive and optimistic, with some provisos. In total, 169 submissions were received by HQSC and the finalised Code of Expectations is dated 1st of August 2022.⁴

In reviewing the final Code, AWHC were particularly pleased to see recognition of the importance and value of lived experience, and use of the phrase "experts by experience". Far too often consumers are dismissed and/or condescended to or patronised because they don't have a medical degree, yet in the areas of health that impact upon them (often negatively), they can often know more than the health practitioners they are dealing with, especially GPs and practice nurses.

While 'on paper' the Code of Expectations generally looks good, we have reservations about how it will be applied in reality.

Will engagement, consultation and participation be just a box-ticking exercise? Will health entities just engage with the stock-standard consumer representatives or will they genuinely and effectively consult with hard to reach New Zealanders: those who are elderly and/or not tech savvy; those who don't have ready access to the internet for online surveys and forums; those who are geographically isolated making in person engagement and participation more difficult; those with language/literacy barriers; and those who have entirely lost trust in the health system as a result of their experiences and resist direct engagement with health entities?

In the past, consultation with those who are health literate, engaged, educated, articulate and very willing to provide feedback, is stymied by ridiculously short time frames within which to make submissions. There are numerous instances of consultation/discussion documents being released, for example, in the week or two before Christmas with submissions closing mid-January. It is hard to believe that such consultations are anything more

Experts by Experience - the Consumer Advocacy Alliance

The [Consumer Advocacy Alliance](#) (CAA) is a collective of experienced health care advocates who share a common passion for creating positive, effective and lasting change. Their founders have a common standpoint; that health care as it is now is not working, that the experience of New Zealanders in the health system is not what it should be. By working together and pooling their experience they plan to identify areas and opportunities where they can facilitate change within the healthcare system and ensure that the consumer voice is heard.

CAA was founded by long-time consumer and patient advocate, Charlotte Korte; Denise Astill of Foetal Anti-Convulsant Syndrome New Zealand (FACSNZ); Kat Gibbons of Pelvic Dysfunction Support NZ (PFDNZ); and Sue Claridge of Auckland Women's Health Council.

The Consumer Advocacy Alliance was founded by consumers for consumers, and their tagline is '**experts by experience**'. Their [first campaign](#) is in support of a strong consumer voice in the development of the women's

health strategy within Te Whatu Ora | Health New Zealand as legislated for in the Pae Ora (Healthy Futures) Act 2022.

They are asking the Government and the Ministry of Health to involve women health consumers at ground level in the development of the Women's Health Strategy. CAA believe that setting key priorities to address current inequities that would improve healthcare for women must be done in co-design with consumers; that women and experienced health advocates deserve more than just being 'consulted', they need to be part of the solution.



than lip service to the concept of engaging with consumers and true consumer representation.

Where are the Women?

Where are the Consumers?

In reviewing the Code of Expectations, we note that in the examples of groups that suffer inequity, women are left out, yet women make up slightly more than half the population. While we recognise that the inequity suffered by Māori, in particular, is significant and egregious, on a purely numbers basis, gender inequity within the health system affects more New Zealanders than any other; thus the inequity suffered by Māori and Pāšifika women and women with disabilities is multiplied.

Sandra Coney has expressed similar concerns, saying it was "interesting" that women have disappeared.⁵

"The women's health movement in the 1980s and 90s fought for women to be recognised as both leaders and consumers, independent of their family role. There was recognition that because of gendered discrimination and social stereotypes, inequities and fewer resources, women both needed greater inclusion in decision-making in health and resourcing to achieve this."⁵

She fears we are going backwards and says "women are invisible in any kind of capacity or role."

Sandra substantiates this saying, "There are specific issues for women in the health sector, including judgements made based on stereotypes of women (as we are seeing with the mesh issue), particular needs of women as patients with women specific diseases/injuries, women accessing health services as well-women (e.g. screening, maternity), violence against women as a health issue. I don't see any recognition of this in the Code of Expectations. Women are not recognised as a group that needs priority."⁵

This sort of omission is not a one-off. Consider the National Cervical Screening Programme – a programme that was born of the Cartwright Inquiry and women's health movement of three decades ago. In the same way that women are invisible in the Code of Expectations, consumers are completely 'missing in action' in the NCSP Advisory and Action Group.

The NCSP impacts on every New Zealander with a cervix over the age of 25, yet they have not seen fit to include a single consumer representative in the 14-strong Advisory and Action Group. This group consists entirely of medical/health professionals and no representatives of women's health consumer organisations or women consumers. The "refreshed" NCSP Advisory and Action Group was announced in the 3rd of August NCSP update, over a month after the Pae Ora (Healthy Futures) Act came in to force and after the Code of Expectations for

consumer engagement was finalised; certainly long after all health entities should have known about their obligations regarding engagement with consumers.

Members of the Federation of Women's Health Councils (FWHC) were sufficiently horrified and outraged about the lack of consumer representation on the NCSP Advisory and Action Group – the one group that history would seem to dictate would be the first to embrace the need for consumers to be actively involved – that the FWHC's co-convenors have written to the NCSP.⁶

In the letter, it was acknowledged that the focus of the Advisory and Action Group is “primarily on achieving equity for women in the immediate future” but also argued that “there is much new programme service activity occurring within NCSP that needs consumer voice at the table.” They also reminded the NCSP that there is an “expectation in the Pae Ora (Healthy Futures) Act that health entities will engage with consumers” and that the associated Code “expects this engagement to occur at every level.”⁶

The FWHC concluded that its members “ask that this situation is reviewed urgently and a consumer member is duly appointed.”⁵ The FWHC has yet to receive a reply.

Another example of the lack of genuine consumer voice in the new health system, was the appointment of Claire Braatvedt, as lead advisor of the consumer voice project in the Transition Unit.⁸ According to her LinkedIn page, Claire is a qualified medical doctor with broad commercial experience across health insurance and digital health technology. So, exactly how is she representative of consumers?

Nine years ago, in 2013, in talking about consumer representation Jo Fitzpatrick² concluded that on the plus side:

- There are health professionals eager to work with consumers as partners in care.
- There are a million opportunities to get involved.

BUT on the negative side:

- There has been very little ceding of power to consumers in health in the last 25 [now 35] years.
- Gatekeeping is alive and well in the health sector. Most often it comes from health professionals

and health managers, but it also comes from other consumers.

- Consumer participation remains an act of good will by the medical system and subject to its patronage and control.
- While not exactly an afterthought, achieving real progress for consumers is hard work, as clinicians and clinical priorities dominate.
- The transition from a medical model to a model of shared care that includes health consumers as active partners will be a long hard road. We have the rhetoric, the reality will be much more difficult.
- We need more consumer advocates in many more places in health. Consumer representation is not a competitive sport, we can all bring our experiences and advocacy to the role.

One of Jo's negatives has been left off that list: “that there is no systematic structure to ensure consumer participation. We need to join up consumers and work collaboratively. We need an independent and functioning consumer collaboration working as it was originally intended.”

Health Forum Aotearoa wears the ‘colours’ of a systematic structure to ensure consumer participation although, as the HQSC is a health entity and part of the system, it is hard to say that Health Forum Aotearoa is independent.

Only time will tell if it is a ‘functioning consumer collaboration working as it was originally intended’.

References

1. Coney S, 2004: [Effective Consumer Voice and Participation for New Zealand: A Systematic Review of the Evidence](#), New Zealand Guidelines Group, October 2004.
2. Fitzpatrick J, 2013: [In the Valley of the Missing Link: the Consumer Experience](#). Plenary Address at the Legacy of Cartwright Seminar, 27 September 2013.
3. MoH, 2013: [Statement of Intent 2013 to 2016: Ministry of Health](#). Wellington: Ministry of Health, May 2013.
4. [Code of expectations for health entities' engagement with consumers and whānau](#), 1 August 2022.
5. Coney S, 2022: Personal Communications.
6. NSU, 2022: [National Cervical Screening Programme Sector Update - August 2022](#), National Screening Unit, August 3 2022.
7. Robson B and Holland B, 2022: Personal Communications.
8. Health and Disability Review Transition Unit, 2021: [Update from the Transition Unit - Wednesday 4 August 2021](#), News and Notices 4 August 2021.