

See no Evil - Hear no Evil - Speak no Evil



Medical Rsearch Abuses & Speaking Out



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The Auckland Women's Health Council acknowledge that not all people with breasts, vaginas, and other female organs and anatomy identify as women/wāhine.

We include transgender boys or men, intersex and non-binary people who have female organs and anatomy in the cohort of people our articles are about or aimed at.

In the *Newsletter*, the terms wāhine/women and female are used throughout most articles. It is not our intent to be exclusionary and these terms are used for ease of reading sometimes complex articles.

We know that many "women's health issues" apply to transgender boys or men, intersex and non-binary people and we want those New Zealanders to know that that our articles are for you as well as those who identify as women/wāhine.

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In Medicine, the Morally Unthinkable Too Easily Comes to Seem Normal

By Dr Carl Elliott May 7, 2024

Dr Carl Elliott teaches medical ethics at the University of Minnesota. He is the author of the recently released book The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No, from which this essay is adapted.

This essay was <u>originally published in the New York Times</u> on the 7th of May 2024, and both Dr Elliott and the New York Times have generously allowed us to reprint it in our Newsletter*.

Here is the way I remember it: The year is 1985, and a few medical students are gathered around an operating table where an anesthetised woman has been prepared for surgery. The attending physician, a gynaecologist, asks the group: "Has everyone felt a cervix? Here's your chance." One after another, we take turns inserting two gloved fingers into the unconscious woman's vagina.

Had the woman consented to a pelvic exam? Did she understand that when the lights went dim she would be treated like a clinical practice dummy, her genitalia palpated by a succession of untrained hands? I don't know. Like most medical students, I just did as I was told.

Last month the Department of Health and Human Services issued new guidance requiring written informed consent for pelvic exams and other intimate procedures performed under anaesthesia. Much of the force behind the new requirement came from distressed medical students who saw these pelvic exams as wrong and summoned the courage to speak out.

Whether the guidance will actually change clinical practice I don't know. Medical traditions are notoriously difficult to uproot, and academic medicine does not easily tolerate ethical dissent. I doubt the medical profession can be trusted to reform itself.

What is it that leads a rare individual to say no to practices that are deceptive, exploitative or harmful when everyone else thinks they are fine? For a long time I assumed that saying no was mainly an issue of moral courage. The relevant question was: If you are a witness to wrongdoing, will you be brave enough to speak out?

But then I started talking to insiders who had blown the whistle on abusive medical research. Soon I realised that I had overlooked the importance of moral perception. Before you decide to speak out about wrongdoing, you have to recognise it for what it is.

This is not as simple as it seems. Part of what makes medical training so unsettling is how often you are thrust into situations in which you don't really know how to behave. Nothing in your life up to that point has prepared you to dissect a cadaver, perform a rectal exam or deliver a baby. Never

^{*} the essay is reprinted here verbatim and with the embedded links of the original. The only change we have made is to Anglicise the American spellings of certain words to match the use of British English used throughout the Newsletter.

before have you seen a psychotic patient involuntarily sedated and strapped to a bed or a braindead body wheeled out of a hospital room to have its organs harvested for transplantation. Your initial reaction is often a combination of revulsion, anxiety and self-consciousness.

To embark on a career in medicine is like moving to a foreign country where you do not understand the customs, rituals, manners or language. Your main concern on arrival is how to fit in and avoid causing offense. This is true even if the local customs seem backward or cruel. What's more, this particular country has an authoritarian government and a rigid status hierarchy where dissent is not just discouraged but also punished. Living happily in this country requires convincing yourself that whatever discomfort you feel comes from your own ignorance and lack of experience. Over time, you learn how to assimilate. You may even come to laugh at how naïve you were when you first arrived.

A rare few people hang onto that discomfort and learn from it. When Michael Wilkins and William Bronston started working at the Willowbrook State School in Staten Island as young doctors in the early 1970s, they found thousands of mentally disabled children condemned to the most horrific conditions imaginable: naked children rocking and moaning on concrete floors in puddles of their own urine; an overpowering stench of illness and filth; a research unit where children were deliberately infected with hepatitis A and B.

"It was truly an American concentration camp," Dr Bronston told me. Yet when he and Dr Wilkins tried to enlist Willowbrook doctors and nurses to reform the institution, they were met with indifference or hostility. It seemed as if no one else on the medical staff could see what they saw. It was only when Dr Wilkins went to a reporter and showed the world what was happening behind the Willowbrook walls that anything began to change.

When I asked Dr Bronston how it was possible for doctors and nurses to work at Willowbrook without seeing it as a crime scene, he told me it began with the way the institution was structured and organised. "Medically secured, medically managed, doctor-validated," he said. Medical professionals just accommodated themselves to the status quo. "You get with the programme because that's what you're being hired to do," he said.

One of the great mysteries of human behaviour is how institutions create social worlds where unthinkable practices come to seem normal. This is as true of academic medical centres as it is of prisons and military units. When we are told about a horrific medical research scandal, we assume that we would see it just as the whistle-blower Peter Buxtun saw the <u>Tuskegee syphilis study</u>: an abuse so shocking that only a sociopath could fail to perceive it.

Yet it rarely happens this way. It took Mr Buxtun seven years to convince others to see the abuses for what they were. It has taken other whistle-blowers even longer. Even when the outside world condemns a practice, medical institutions typically insist that the outsiders don't really understand.

According to Irving Janis, a Yale psychologist who popularised the notion of groupthink, the forces of social conformity are especially powerful in organisations that are driven by a deep sense of moral purpose. If the aims of the organisation are righteous, its members feel, it is wrong to put barriers in the way.

This observation helps explain why academic medicine not only defends researchers accused of wrongdoing but also sometimes rewards them. Many of the researchers responsible for the most notorious abuses in recent medical history – the Tuskegee syphilis study, the Willowbrook hepatitis studies, <u>the Cincinnati radiation studies</u>, the <u>Holmesburg prison studies</u> – were celebrated with professional accolades even after the abuses were first called out.

The culture of medicine is notoriously resistant to change. During the 1970s, it was thought that the solution to medical misconduct was formal education in ethics. Major academic medical centres began establishing bioethics centres and programmes throughout the 1980s and '90s, and today virtually every medical school in the country requires ethics training.

Yet it is debatable whether that training has had any effect. Many of the most egregious ethical abuses in recent decades have taken place in medical centres with prominent bioethics programs, such as the <u>University of Pennsylvania</u>, <u>Duke University</u>, <u>Columbia University</u> and <u>Johns Hopkins University</u>, as well as my own institution, the <u>University of Minnesota</u>.

One could be forgiven for concluding that the only way the culture of medicine will change is if changes are forced on it from the outside — by oversight bodies, legislators or litigators. For example, many states have responded to the controversy over pelvic exams by passing laws banning the practice unless the patient has explicitly given consent.

You may find it hard to understand how pelvic exams on unconscious women without their consent could seem like anything but a terrible invasion. Yet

Auckland Women's Health Council & The Health Consumer Advocacy Alliance

present

an evening with Professor Carl Elliott The Occasional Human Sacrifice

CARL ELLIOTT THE OCCASIONAL HUMAN SACRIFICE

MEDICAL EXPERIMENTATION *and* THE PRICE *of* SAYING NO

For more information see our website

Please RSVP to awhc@womenshealthcouncil.org.nz if you plan to come Professor of Bioethics at the University of Minnesota, Carl Elliott will speak about his new book on medical experimentation and the price of saying no.

Monday 5th of August

7pm in lecture theatre AF 116

AUT North, Akoranga Dr Northcote.





a central aim of medical training is to transform your sensibility. You are taught to steel yourself against your natural emotional reactions to death and disfigurement; to set aside your customary views about privacy and shame; to see the human body as a thing to be examined, tested and studied.

One danger of this transformation is that you will see your colleagues and superiors do horrible things and be afraid to speak up. But the more subtle danger is that you will no longer see what they are doing as horrible. You will just think: This is the way it is done. **Editor's Note:** So much of what Dr Elliott writes about in this essay will seem tragically and depressingly familiar to long-time readers of the *AWHC Newsletter*. This is precisely the reason that we sought permission to reprint it. The issues we have faced and continue to face in Aotearoa New Zealand around medical ethics and "morally unthinkable" behaviour in our own health system are not confined to our own country. We must all recognise the morally unthinkable — the abuses in our health system — for what they are, and we must continue to speak up. It is not just the events at National Women's Hospital in the 1960s and '70s, that came to be known as the <u>'unfortunate experiment'</u>; abuses of patient rights continue to this day, and we have regularly published articles on persistent breaches of patient rights, particularly those of informed consent.



WHAKAMAHIA TŌ REO USE YOUR VOICE



Have your say on the review of the Act and the Code at <u>review.hdc.org.nz</u>

Consultation runs from 30 April to 13 August 2024.

The closing date for <u>submissions on the HDC review of the HDC Act and the Code of</u> <u>Patient Rights</u> has been extended to 5pm on the 13th of August. If you haven't yet made a submission and thought you had run out of time, you now have an extra two weeks!

Human Sacrifices and Whistleblowers

The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No by Professor Carl Elliott

Review by Sue Claridge

In his very first sentence in the Introduction of *The Occasional Human Sacrifice*, Carl Elliott characterises himself as a coward, and sets out his credentials as a coward.

As I write this, I have finished reading his book, but not yet met Professor Elliott, although I will in a week's time, when he gives a public talk jointly hosted by the Auckland Women's Health Council and Health Consumer Advocacy Alliance (see page 5).

Despite not having met Prof Elliott, having read his book and about his work, and his own efforts to blow the whistle on abuses in medical research, I'm pretty sure he is not a coward. There is a difference between not being brave enough, as a thirdyear medical student on rotation, to defy the orders of the senior physicians overseeing this critical part of your medical training, and being an actual coward.

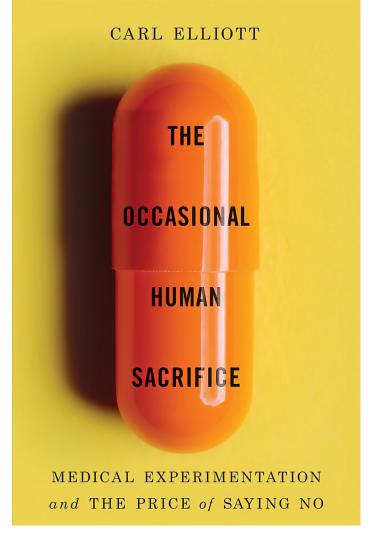
The difficulties that medical students face in speaking out against breaches of patient rights that they observe happening in our teaching hospitals – and no doubt in the teaching hospitals in the US – are well documented. New Zealand research published in 2022 revealed that medical students found it very difficult to stand up to senior physicians and supervisors over issues of ethics, patient rights and consent.

Dr Phillipa Malpas, Honorary Associate Professor in Clinical Medical Ethics at the University of Auckland, when interviewed for a 2022 article in the <u>AWHC Newsletter</u> on this issue, said:

"[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."

If this is still the case in the relatively "enlightened, post-Cartwright early 21st century of Aotearoa New Zealand, imagine how much harder it must have been to speak up in Elliott's time as a medical student in the 1980s in the US.



Required Reading

The Occasional Human Sacrifice should be required reading for:

- All medical students.
- All medical researchers and medical practitioners who have any involvement at all in medical research, including those who recommend participation in clinical trials to patients.
- The staff and management even peripherally involved in medical research at all institutions that undertake medical research.
- All current and future members of medical ethics committees and our Health and Disability Ethics Committees.
- Any patient or health consumer considering participating in medical research.

Elliott's description of his time as a medical student is an excellent introduction to the main subject of his book — the moral struggle and experience of whistleblowers in a medical context. *The Occasional Human Sacrifice* is less about the depraved and unethical treatment of human beings in medical experiments, than it is about the principled human beings who were determined to blow the whistle on abuses of patients in those medical experiments; medical experiments that patients neither consented to participate in, nor were even aware that they had somehow been caught up in.

After describing his own experience as a whistleblower on unethical psychiatric research at the University of Minnesota (where he still works), in which a young man lost his life, Elliott devotes a chapter to each of six notorious stories of shocking abuses of patients in medical research:

- the Tuskegee syphilis experiments on poor black men;
- the Willowbrook hepatitis experiments on intellectually disabled children;
- the Fred Hutchinson Cancer Research Center lethal bone marrow transplant experiments;
- the University of Cincinnati lethal total body irradiation experiments;
- New Zealand's National Women's Hospital experiments on women with carcinoma *in situ*; and
- Paolo Macchiarini's lethal synthetic tracheal transplant experiments at the Karolinska Institute.

With relative restraint, Elliott gives us just enough detail about the excruciating harm — and often death — suffered by people on whom qualified and senior doctors experimented; just enough detail to understand how truly depraved and unconscionable these experiments were.

It is hard not to be affected by the agonising deaths of almost 90 cancer patients who had total body irradiation having been told it was a new treatment for their cancers. In fact, they were unwitting 'guinea pigs' in experiments for the US military to better understand what would happen to soldiers exposed to nuclear radiation.

It is hard not to be affected by the intellectually disabled children living in abject squalor at Willowbrook – a state-sponsored institution that was overcrowded and had poor sanitation, and where hepatitis A was rife with between 30 and 53% of children contracting the disease. Children not already infected, were fed chocolate milk contaminated by faeces collected from other child-



Bioethicist, Professor Carl Elliott.

ren at Willowbrook, to test whether gamma globulin protected against hepatitis A. Other children were deliberately injected with the much more dangerous hepatitis B - a disease they would not otherwise have been exposed to at Willowbrook - in order to test a hepatitis B proto-vaccine.

Then there is Yesim Cetir, a young Turkish woman who died after 191 surgical procedures over five years, as the result of a horrifically botched exploratory thoracotomy at the Karolinska Institute that left her with a burst trachea and one lung so damaged it was removed. She received two defective synthetic tracheal transplants a year apart, both of which failed, and she required unrelenting medical attention for years, including multiple organ transplants in the US. By the time she died she had suffered two strokes, had lost part of her vision and couldn't walk.

And "Phoebe", one of Herbert Green's research subjects. Over a period of years Green had refused to accept that her condition was malignant despite the clinical evidence and pathology. When whistleblower Dr Ron Jones took over her care while Green was overseas, she haemorrhaged so badly from an enormous tumour that she had to be transfused with 12 units of blood — more than her entire blood volume. Dr Jones operated, but by that time the surgery was only palliative. No matter how difficult it is to read about these, and the many other people who were unwitting, unconsented 'experimental subjects', they provide critical context to the stories of the whistleblowers. The book is, throughout its pages, an in-depth look at what characterises whistleblowers, what drives them to speak out against colleagues, medical practitioners and researchers more powerful and well connected than they. It is a story about what happens to whistleblowers, who are typically pilloried, vilified and ostracised. Some lost their jobs. In the Karolinska case, the whistleblowers were declared guilty of scientific fraud alongside Paolo Macchiarini.

Elliott met with the whistleblowers and spent time with them, in an effort to understand what drove the whistleblowers to speak out about the abuses they witnessed while so many others kept quiet. As an academic – a bioethiscist – and a whistleblower himself, he takes a deep dive into the literature on whistleblowers, not just those in a medical or health setting.

A recurring theme is the relative naïveté that many of the whistleblowers set out with; a belief that

Whistleblowers in Aoteroa New Zealand

The Protected Disclosures (Protection of Whistleblowers) Act 2022, which came into force on 1 July 2022, can protect people when making disclosures about serious wrongdoing in or by their organisation. It should almost always protect them from being identified if they make their disclosure to their organisation, and in a medical or health context, to the Ministry of Health and/or the Health or Disability Commissioner, and likely if they disclose to the Medical Council.

Christian Poland says, in the HCAA report <u>Are Our</u> <u>Medical Harm Reporting Systems Effective? Are</u> <u>People Safe?</u> that a medical professional is unlikely to be protected under the Act when reporting harm caused by a colleague at a different hospital/ institution, even if they have reasonable grounds to believe the serious wrongdoing occurred.

This is because, in order for a disclosure to be "protected", the serious wrongdoing must be "in or by the discloser's organisation": s 9(a).

"So that was probably one of the most shocking things, that nobody really gave a shit. And I wasn't prepared for that."

 John Pesando on his efforts to expose lethal bone marrow transplant experiments at the Fred Hutchinson Cancer Research Center

if they only exposed what was going on, those in a position to address such shocking abuses of patients would sit up and take notice. Even if they didn't expect to be thanked, many whistleblowers expected that the perpetrators of the six unethical experiments would be held to account, would be stopped. The reality was that, while many of the whistleblowers sacrificed years of their lives, sometimes their careers and their reputations, suffered inordinate levels of stress, and lost friends and family, the perpetrators were rarely punished, and some were – and still are – held up as heroes.

The six case studies are all quite different from each other in many aspects, although the experiences of the whistleblowers substantially overlap. However, the fallout from 'unfortunate experiment' in Aotearoa New Zealand has some quite unique aspects.

<u>Dr Ron Jones</u> is the sole surviving whistleblower from a group of three that included Dr William McIndoe, cytologist and colposcopist, and Dr Malcolm (Jock) McLean pathologist. Together with statistician Peter Mullins, Jones, McIndoe and McLean published a paper in 1984 in the journal *Obstetrics and Gynecology*. This paper exposed Herbert Green's research, which involved withholding treatment from women with abnormal cervical smears that ultimately led to many women developing invasive cervical cancer; 33 women died.

Were it not for Sandra Coney and Phillida Bunkle's <u>Metro article in 1987</u>, what was revealed in the 1984 Obstetrics and Gynecology paper may never have properly seen the light of day. The Metro article came about as a direct result of the paper and Sandra Coney's introduction to Clare Matheson, one of Green's 'guinea pigs'.

The public response to the revelations in the *Metro* article was outrage; the Government's response was to very quickly – within ten days – establish a judicial inquiry headed by [then] District Court Judge Silvia Cartwright.

Of all the stories in *The Occasional Human Sacrifice*, the uncovering of New Zealand's own unethical medical experiment has probably led to the most significant and widespread change in our health system and our attitudes to both medical research and patient rights, especially informed consent, than in any other case in Elliott's book.

While there are still some who deny the facts, repudiate the outcomes of the Cartwright Inquiry, and seek to all but canonise Herbert Green, by and large, the 'unfortunate experiment' has been a lesson reasonably well learned and has changed the ethics around medical research in this country. RANZCOG, the former Auckland District Health Board and former Prime Minister Jacinda Ardern all issued public apologies.

What is missing from Carl Elliott's book is that the victims of Herbert Green's unethical and abhorrent experiments - and the whistleblowers who ensured that what he did was exposed and addressed in a formal inquiry - are not forgotten, even 36 years after the Inquiry. Unlike many victims in the other stories, the legacy that whistleblowers Ron Jones, Jock McLean and Bill MacIndoe (together with Sandra Coney and Phillida Bunkle) have left, is that the victims are remembered. They are remembered every year on the 5th of August, the anniversary of the release of the Cartwright Report. The Auckland Women's Health Council and the Cartwright Collective, and other organisations such as the Maternity Services Consumer Council, have, over the last 36 years, made a pilgrimage to the old National Women's Hospital to remember what the women endured, the loss of life, and the sacrifice of their families, and of the men who tried to stand up to Herbert Green and who ultimately spoke out irrespective of the impact that might have on their lives and reputations.

Each year we hold space for those who were so badly affected by Herbert Green's unethical medical experiment.

Carl Elliott knows of our pilgrimage to the old National Women's Hospital at Greenlane every year. He told me in an email discussing his *New York* *Times* essay (see page 3), his book and talk on the 5th of August (see page 5) that one of our Committee members had sent him some photos and told him about our annual gathering and commemoration. He said:

"I found it incredibly moving. I don't know of anything like that happening anywhere else in the world."

I would like to think that medical research abuses such as those Carl Elliott covers in his book are well in the past and could not happen today. However, the horrific events at the Karolinska Institute occurred quite recently, between 2011 and 2016. We must stay vigilant; we must not be complacent, thinking that it would be impossible for such shocking abuses of patients to happen again, even in Aotearoa New Zealand. While patient rights have improved since the Cartright Inquiry, there are still grey areas regarding the involvement of patients in medical research, especially patients that are unconscious or incapacitated, and this very issue is included in the current Health and Disability Commissioner review of the Act and Code of Health and Disability Services Consumers' Rights.

Since the Helsinki Declaration in 1964, which is a statement of ethical principles for medical research involving human subjects, the participation of human beings in medical research without their knowledge or consent has been prohibited. Yet, formalised, ratified prohibition at an international level has not prevented such abuses from happening here and overseas.

We must remain vigilant.

"Let not anyone pacify his conscience by the delusion that he can do no harm if he takes no part, and forms no opinion. Bad men need nothing more to compass their ends, than that good men should look on and do nothing."

— John Stuart Mill, 1867



Dr Ron Jones

The plaque honouring Dr Bill McIndoe and Dr Jock McLean at Greenlane

Sandra Coney and Phillida Bunkle (far left) with AWHC members, at Greenlane.

Celebrating Wāhine Toa

Wāhine Māori, Emma Rawson-Te Patu is the First Indigenous Woman to Head the World Federation of Public Health Associations

By Sue Claridge

In May this year, Emma Rawson-Te Patu became the first New Zealander and first indigenous woman to head the World Federation of Public Health Associations (WFPHA) in its 57-year history.

Emma Rawson-Te Patu (Ngāti Ranginui, Ngāi Te Rangi, Raukawa, Ngāti Hauā), a public health advocate and researcher, was elected vice president and president-elect to the global body in May 2022.1 She is the Director of ManuKahu Associates, Indigenous Consultancy in Aotearoa New Zealand, and specialises in addressing institutional racism using indigenous frameworks for public health. She currently consults to the New Zealand Human Rights Commission and develops training and frameworks for developing culturally responsive public health approaches and socially/culturally conscious business strategy and organisational development based on indigenous knowledge.² She was also the Public Health Equity Lead at Whakauae Research Services in 2022 and 2023.

The WFPHA represents more than five million academics, researchers, physicians and health promoters in more than 100 public health organisations around the world, and is the only worldwide professional society representing and serving the broad field of public health internationally.^{3, 4}

Ms Rawson Te-Patu's inauguration on the 16th of May 2024 was attended by Director-General of Health, Dr Diana Sarfati, and Deputy Director-General of the Public Health Agency Dr Andrew Old.

She has said that the "immediate priority for her two-year tenure was decolonising public health globally."¹ She told Moana Ellis, Local Democracy Reporter, "The United Nations and World Health

Organisation have declared the importance of indigenous knowledge and traditions. Our federation is well positioned to show leadership globally by leaning into this responsibility."¹

"Inequities for indigenous people are still as significant as they have ever been. Public health is about reducing inequities across the board.

"This is an opportunity for the global public health community to authentically understand how they can implement solutions to address indigenous inequities that will also support the health and wellbeing of the total population."

In her inaugural speech, Ms Rawson-Te Patu said:

"This space needs to look outside of what it traditionally has always been, which is Public Health Medicine. [I'm] absolutely not downing the value all of that — the evidence and the practice — but the colour isn't there that's required. The colour needs to touch the places where it needs to be to support the people that need things that [they] aren't getting... There is a majority of indigenous populations across this planet that are not getting what they need and they are dying sooner — too soon — than they should be in this day and age."¹

This work, this role is clearly personal to her; she pauses, collecting herself, emotional as she continues.

"I lost two just this past week. Friends and family members... from cancer, from diabetes, from preventable diseases. They were younger than 50 and they had children, they had families, and they are dying, and they need not die."⁵

Ms Rawson-Te Patu doesn't pull any punches and it's obvious that she thinks it's well past time that the health of indigenous people around the world, and the institutionalised racism that they experience, was properly addressed. She has no intention of being quiet about what needs to change.

"As far as I'm concerned, as long as I'm here, and my friends are here, and my mates are here, my family are here, our tribes are here, we will do the work and we will push for the work that's required to make the change that is needed. People will see and begin to understand how incredible it is the gifts that we bring as indigenous peoples, because it's going to benefit everybody. But you need to listen, and you need to have patience and have time and make time to understand what we're talking about, because I'm a little bit sick of repeating myself."⁵

"I know health diplomacy requires you to be quite careful... but sometimes you just have to say it straight. So, I am a bit of that. I'll use it when it's required."⁵

Before her inauguration as President of the WFPHA, Emma Rawson-Te Patu was interviewed by the Global Governance Project and was asked about the progress that had been made in Aotearoa New Zealand in decolonising public health.

She acknowledged the global leadership role that Aotearoa New Zealand has had in race relations, but said that "the reality is the systemic issues remain and are rife."⁶

She said that "efforts to understand and highlight the places where institutional racism exists and how to address it have increased", then references the recent major health system reforms that "acknowledge and address the ongoing systemic barriers and to reflect the authentic Tiriti relationship that our government is bound to honour through Te Tiriti o Waitangi," referring to the establishment of Te Aka Whai Ora (the Māori Health Authority.

However, it was clearly galling for her, as the President Elect of the WFPHA, with a stated priority of decolonising public health globally, that the Government in her own country has chosen to buttress existing institutionalised racism in our health system by disestablishing Te Aka Whai Ora before it had a chance to prove its value in addressing disparities and equities for Māori.

"Unfortunately, the groundbreaking model for health services and delivery recently established by the previous government, which gave Māori the closest model of co-governance within a centralised system of healthcare infrastructure, workforce capacity, service delivery and commissioning, was swiftly deconstructed by a new government with an agenda and politics that are more than demonstrating a significant shift away from evidence-based policy and action, and executing what could be described as contemporary breaches to our Tiriti."⁶

Change is happening for indigenous people, but it is often tragically and devastatingly slow. In Aotearoa New Zealand alone, Māori live shorter, less healthy lives, and inequities and disparities are still not being adequately addressed.

Emma Rawson-Te Patu's appointment as President of the World Federation of Public Health Associations is something all New Zealanders should be proud of. It is not just recognition of her work and achievements but of the importance of the indigenising of health systems in countries where indigenous peoples continue to face racism, and inequities and disparities in health and health outcomes.

"The biggest challenge to the efforts to decolonise our society or elements of it is the appetite of individuals to bravely understand and educate themselves on the necessity of this process, and how and why inequities exist — and that it is very possible to address these through this process. It is multifaceted and requires the collective efforts of many. This work has been happening for decades, and will continue for many more to come. However, the more allies we have, the greater the efforts will be and the more success we will have...

Never more than now do we need to value the place and wisdom of Indigenous populations. A commitment to decolonise public health is a start to valuing our craft of public health differently and truly addressing health inequities and increasing life success for some of our most affected populations."

— Emma Rawson-Te Patu⁶

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More Evidence That You Are Better Off With a Female Surgeon

By Sue Claridge

Two recent studies have added to the growing evidence that patients are better off either with a female surgeon, or a gender diverse surgical team, with a lower risk of dying and a lower risk of postoperative morbidity and being readmitted to hospital.

In 2022 we reported¹ on Canadian research published in *JAMA* that found that women patients with male surgeons suffered significantly worse outcomes than women patients with female surgeons.² The same disparity was *NOT* seen in male patients treated by female surgeons compared with male patients treated by male surgeons.

They found 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 i n the 30 days following the procedure.¹¹

The researchers concluded that "In primary care, sex or gender discordance between patients and physicians (particularly among male physicians and female patients) is associated with worse rapport, lower certainty of diagnosis, lower like-lihood of assessing patient's conditions as being of high severity, concerns of a hidden agenda, and disagreements regarding advice provided."²

In one of the recent studies, published in the *British Journal of Surgery*, Canadian researchers (that included two of the researchers who co-authored the 2022 JAMA study), found that "greater anaesthesiasurgery team sex diversity was associated with better postoperative outcomes."⁴ The proportion of women anaesthetists and surgeons in surgical teams over 35% was associated with a 3% lower risk of major post-operative illness within three months of surgery. The association was greater when operations involved a female surgeon or female anaesthetist.

The study considered a wide range of surgery types, including cardiac, gastrointestinal, genitourinary, gynaecological, head and neck, neurosurgery, orthopaedic, spinal, thoracic and vascular.

It is not just health care in which this effect of gender diversity is seen, with the 35% threshold echoing business findings in various countries including the USA, Italy, Australia, and Japan, which showed better performance with more balanced teams.²

Despite the clear benefits of gender diversity in health care, Hallet *et al.*, said that "inclusion of women in operating rooms remains challenging. This is evidenced in the present study by the slow rise in the median percentage of female anaesthetists and surgeons by only 5% over 10 years, with half of the hospitals studied having less than 35% women in 2019."²

In the second study involving 458,108 female and 318,819 male patients, Japanese and American researchers found that "patients have lower mortality and readmission rates when treated by female physicians, and the benefit of receiving treatments from female physicians is larger for female patients than for male patients."⁵

The researchers said that there could be several different reasons for the difference in outcomes.

"Female physicians spend more time with patients and spend more time engaging in shared medical decision making and partnership discussions than male counterparts," said Dr Lisa Rotenstein, a coauthor of the study and an assistant professor and medical director at the University of California San Francisco.⁶

She went on to say that in outpatient care, women doctors spent more time on the electronic health record and deliver higher quality care, while in surgery, they spend longer on a surgical procedure and have lower rates of postoperative readmissions. "We need to be asking ourselves how to provide the training and incentives so that all doctors can emulate the care provided by female physicians."⁶

Dr Arghavan Salles, a clinical associate professor of medicine at Stanford University in California who was not involved in either study, said "I would love for male physicians to look at these data seriously and interrogate their own practices. There is often a tendency to discount data like these because they are uncomfortable or may feel threatening. However, that kind of response will not help patients."⁶

Dr Salles referred to another recent study of surgeons performing gall bladder surgery, that found patients had better outcomes when their surgeon was female, rather than male.

"One of the findings in that study was that surgery took just a few minutes longer when performed by female surgeons. Was that additional time spent double checking, making sure everything was fine before the end of the procedure? Was that time spent performing more careful dissection to try to prevent complications?" she asked.⁶

In the gall bladder surgery study, 150,509 patients were operated on by 2553 surgeons; female surgeons had significantly fewer surgical complications than male surgeons, including fewer bile duct injuries, they operated more slowly, they converted to open surgery less frequently, and their patients had shorter hospital stays.⁷

Sex-discordance (male surgeon-female patient or female surgeon-male patient) has also been found to have an impact in complex cancer surgery. In a study of 495,628 patients who had surgery for lung, breast, hepato-pancreato-biliary, or colorectal cancer between 2014 and 2020, sex discordance between surgeon and patient was associated with a decreased likelihood of optimal post-operative outcomes, with a higher risk of complications and death within 90 days.⁸ Female patients treated by male surgeons had slightly worse outcomes than male patients treated by female surgeons but both pairings had a decreased likelihood of optimal post-operative outcomes.

The Take Home Messages

There is substantial and increasing evidence that as a woman, you are more likely to have poorer outcomes from surgery performed by a male surgeon or a male dominated surgical team, than if you have a female surgeon or more gender diverse surgical team. While there is evidence of poorer outcomes for female surgeon-male patient sex discordance in some studies, it is not as strong.

So, how does this affect New Zealand women/ wāhine?

There are no medical papers that suggest any research on sex discordance has been done in Aotearoa New Zealand, so we are reliant on research done internationally, although there is no reason to think that research would not be applicable here.

If you must have surgery in our public health system you are highly unlikely to have any choice about your surgeon or surgical team. The best you can do is make sure you are well-informed about your surgery, ask plenty of questions including about the benefits and risks of surgery, make an informed decision about your treatment and take responsibility for being as healthy preand post-operatively as possible. If, after surgery you are worried about adverse events or complications, ensure that you speak up, ask your surgeon or GP about your symptoms as soon as you can and seek a second opinion if you are not happy.

In the private sector, you have more choice about your surgeon, depending, in part, on the surgical specialty and where you live/your access to a private practitioner. However, there is far more to the success of surgery than just the gender of your surgeon, including how skilled and experienced your chosen surgeon is, how complex the surgery and your general health. Again, making informed decisions is critical and there are many pieces of information to weigh up when making a decision about your surgeon or any treatment suggested by a medical practitioner.

The more important message is around how we train our doctors. As Dr Lisa Rotenstein said "We need to be asking ourselves how to provide the training and incentives so that all doctors can emulate the care provided by female physicians."

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Help Us Continue Our Work

Auckland Women's Health Council relies on community funding grants and donations to keep our organisation functioning and to pay for operating expenses.

We need your help to continue our important work for the women/wāhine of Aotearoa New Zealand.

For many years we charged a small membership subscription; members received our *Newsletter* as part of this fee. In 2021, we decided to make subscription to our *Newsletter* and membership of the Council free. People can subscribe to the *Newsletter* without becoming a member and receive the *Newsletter* directly into their email inbox. We continue to make it freely available on our website from the date of publication. We strongly believe in the importance and value of the information that we provide, the analysis and gendered perspectives on health, and we want all women/wāhine to have access to this without the burden of cost.

Membership applications remain subject to the approval of the Executive Committee, as set out

in our constitution, but we no longer ask for the payment of membership fees or a subscription. We hope that those who believe in our work and are able to, will support us with a donation when they can. However, we don't want financial considerations to limit membership.

We have made <u>donating to the Auckland Women's</u> <u>Health Council</u> easier for those able to support us financially. We don't ask for a specific amount, but because we are a registered charity, any donations of \$5 or over are eligible for a New Zealand charitable giving tax credit.

There are two ways that you can donate money directly to the AWHC: through internet bank transfer or via Givealittle using your credit card. <u>Information on making a donation through either of these methods is provided on our website.</u> Thank you in advance to all those who can support us through a donation.

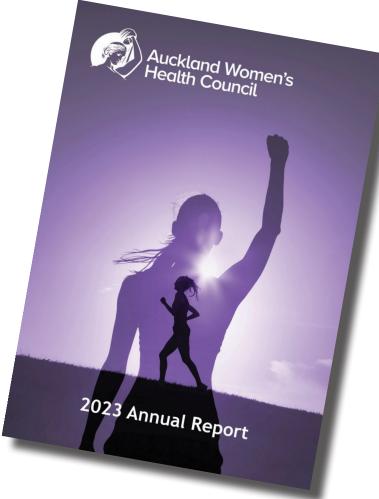


From Our Annual Report

We presented our 2023 Annual report at our AGM in May 2024, and reprint here our reflections on 2023 and our thoughts for the future. Since we presented our report, the health system has sunk deeper into what could easily be described as chaos and despair. I have heard from people in other health related organisations that many people in our health workforce are despondent, distressed and burnt out.

On the 22nd of July, the Health Minister, Dr Shane Reti sacked the Board of Health NZ and replaced it with a Commissioner, Dr Lester Levy, who had only recently been appointed chair of the Board. It remains to be seen whether or not taking that "strongest ministerial intervention available" under the Pae Ora Act will pull our health system out of the mire.

— Sue Claridge, Editor



Reflecting on 2023...

In our last annual, report written in April 2023, we commented on the state of the nation's health system, noting that it "is in crisis and our health workforce is under significant stress."

In the year since, the health system crisis has deepened, and the political landscape has changed dramatically. We addressed these issues in an article in our November 2023 *Newsletter*, discussing the health system reforms and where we were then, more than a year on from the passing of the Pae Ora (Healthy Futures) Act. We had:

- A 'new' health system that is not functional, equitable or whole.
- A 'new' half-renovated health system that is worse than what we already had.
- A health system, parts of which the National Party has said it will dismantle as well as rescinding some of the legislation that underpins it.

Since last November, the National-led coalition Government has dis-established Te Aka Whai Ora – the Māori Health Authority – without having given it a chance to address the intrenched disparities and inequities in Māori health and health outcomes. The concept of "by Māori for Māori" has been thrown out under the guise of "unifying" the country.

We are losing qualified health practitioners, particularly nurses, in droves and primary health care is so strained and "under the pump" that many New Zealanders have to wait weeks for appointments with GPs, and have no continuity of care as they see a different GP every time. Increasing numbers of New Zealanders are forced to attend hospital emergency departments because they can't access primary health care in a timely manner.

In our last report, we said that "Never has the ability of people to take responsibility for their own health and well-being been so important." Not only has there been no improvement, but this observation becomes more pertinent as every week passes.

The pressure on the health system, and the uncertainty, inadequacies and failures that very many health consumers are experiencing within it, have increased the importance of NGOs such as the AWHC.

The consumer voice, consumer representation and advocacy have never been so important... and

we know that it works, even if only in very slow, incremental ways. Health consumer/patient rights remain an issue and cultural changes in the system and among health professionals are also slow to change. New Zealanders need help and support, and access to quality independent, evidence-based information now as much as at any time in the past.

Since 1988, Auckland Women's Health Council has provided a strong voice on women's health issues for the greater Auckland region, and has been actively involved at a national level. It is tragic that our organisation is not only still needed, but that the issues that led to its foundation continue to be raised, often in barely changed forms, more than 35 years on.

A highlight of our year has been effective collaboration with some of our closest allies that has led to change, in particular calls for a suspension of mesh procedures for stress urinary incontinence. The value of our networks with other NGOs working to improve the experience of health consumers has been reinforced. We are committed to expanding those connections with others who are working towards ensuring that barriers to accessing affordable and available, as well as culturally appropriate, acceptable and beneficial health services are removed for our women/wāhine.

Looking Forward

We continue to value our relationships with our allies and collaborators, and look forward to joining forces with them to effect change in the coming months and years. We have formal memberships of health consumer forums and coalitions to which we contribute on behalf of women/wāhine, and will continue to keep the health issues that women face at the forefront of those discussions.

At the time of writing, the Health and Disability Commissioner has just launched public consultation on its review of the Code of Health and Disability Services Consumers' Rights and the Health and Disability Commissioner Act 1994. AWHC has had a sustained interest in the office of the Health and Disability Commissioner and the Code of Rights since its very first submission on the Health and Disability Commissioner Act 1994. In 2023 we were invited to provide early input on the HDC review and will also take part in the current public consultation.

These opportunities to be involved in consultation at many levels throughout the health system, and the legislation and policy that underpins it, are vital. They enable us to turn up the volume on women's health issues, and ensure that women are heard and can contribute to creating the sort of health system they want and need.

As is the case with very many non-profit organisations, we are always in need of more voices on our own Committee, and particularly more diversity. We welcome new members and eagerly look forward to more women joining us to help share the load and bring their unique experiences and viewpoints to our table, so that we can continue to work towards providing a voice for all women/ wāhine.

One of the issues that looms largest in the health system is that Māori and tagata Pāsifika continue to be disproportionately affected by inequities and disparities in access to and outcomes from health care. The current political landscape in Aotearoa New Zealand threatens to exacerbate this rather than improve it.

The Executive Committee of the Auckland Women's Health Council have had numerous discussions about what role we might play in addressing these issues. We are working towards being tangata tiriti – to stand in partnership and solidarity with Māori – and will continue to raise awareness and include commentary on the inequities and disparities in health and health outcomes for Māori, and racism in the health system, through our Newsletter articles, submissions and the website.

As difficult and dispiriting as the current situation in health in Aotearoa New Zealand is, we know that AWHC is not alone in our efforts to make a difference. We take heart from all the wāhine toa around the motu who work so hard behind the scenes, all of us pulling in the same direction to make Aotearoa New Zealand a healthier place for all our women/wāhine; a place where all women/wāhine have accessible, equitable, affordable, available, accountable and culturally appropriate health care services.

We remain a voice for women, and a voice for change.

The full 2023 Annual Report can be found on our website.