

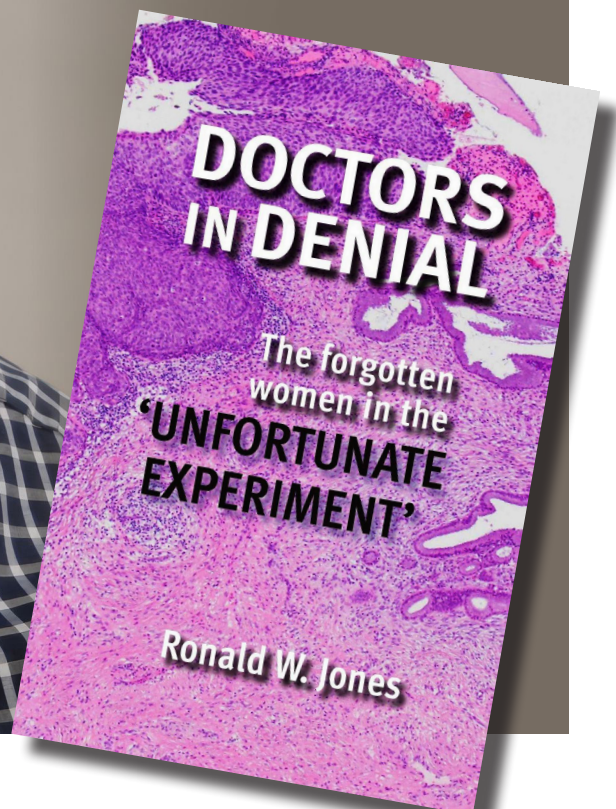


NEWSLETTER

April • 2025

a voice for women's health

Dr Ron Jones CNZM 1939—2025





In this Issue...

Farewell Dr Ron Jones	3
What Health Care is Teaching Our Little Girls	6
Bev Lawton: Champion of Women's Health Honoured	8
Where is our Health System Heading?	9
Ashley Bloomfield on the Health System Crisis	11
Bowel Cancer: Reflecting our Health System Crisis	12
Recommendations from the HDC Review of the Act and Code of Rights	15
The HDC's Odd Lack of a Complaints Process	18

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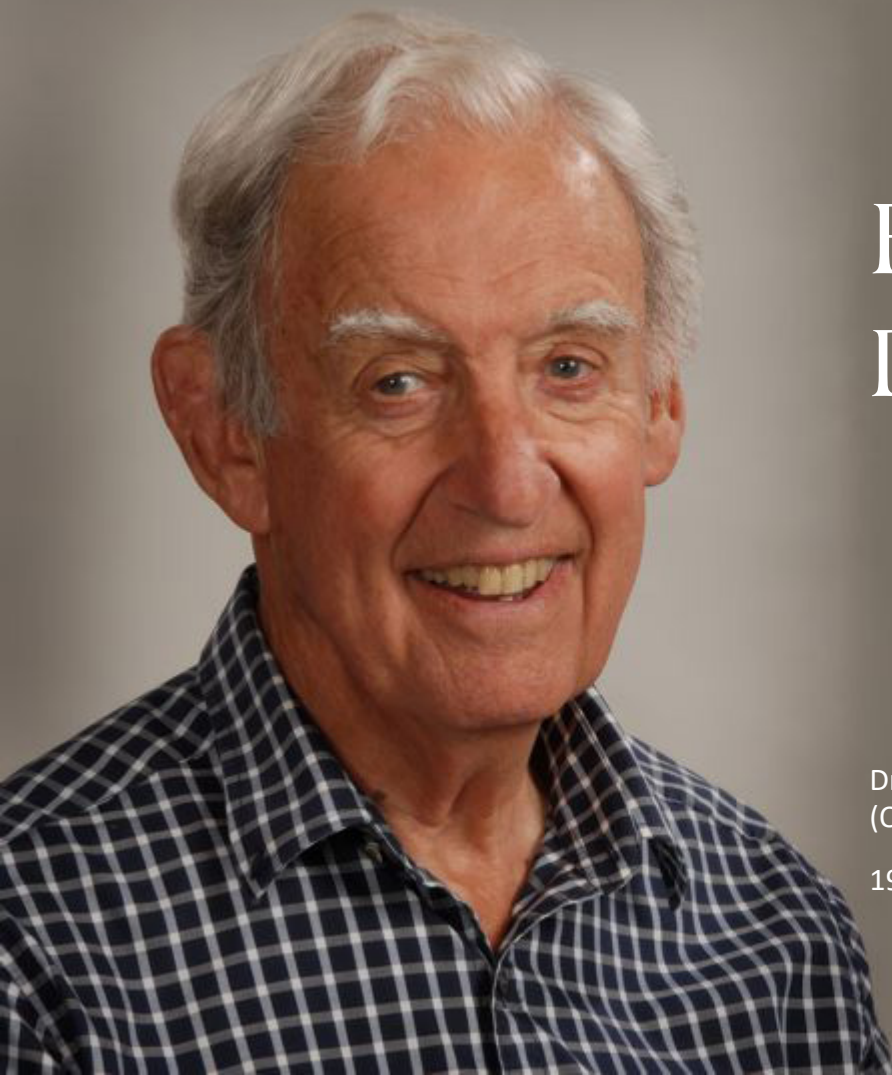
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Farewell Dr Ron Jones

Dr Ronald William Jones CNZM, MB ChB, MD
(Otago), FRCS (Ed.), FRCOG., FRANZCOG

1939-2025

by Sue Claridge

Retired gynaecologist, obstetrician, and former professor at the University of Auckland. A man of great moral fortitude and honour.

Dr Ron Jones died unexpectedly but peacefully, surrounded by his family on the 31st of March 2025.

We had long considered Ron an Honorary member of the Auckland Women's Health Council, and it was with great sadness that we learned of his death. Less than a week prior, I had been engaged in an email conversation with him, confirming his membership (as part of our obligations under the amended Charities legislation). He said that he was "flattered by the idea of being an Honorary member" and said that his great grandmother had been a New Zealand Suffragette; he seemed quite chuffed to belong to a feminist organisation.

Ron was a junior obstetrician and gynaecologist at National Women's Hospital in the 1970s, at a time when Herbert Green's unethical experiment into the natural history of cervical cancer had been underway since 1963. Ron had never been comfortable with what was going on at National Women's. He described himself (in his book *Doctors in Denial*) as initially a silent observer, later becoming "en-

meshed in the resulting controversy". Dr Bill McIndoe took Ron into his confidence "sharing his concern about the welfare of an increasing number of women initially presenting with CIS* who were later developing invasive cancer."

Together with Bill McIndoe, Jock McLean and Peter Mullins, Ron co-authored a landmark 1984 paper, published in the journal *Obstetrics and Gynecology*,¹ which discussed Herbert Green's work at National Women's Hospital on women with abnormal cervi-cal cytology. The paper suggested that some patients had been diagnosed with cervical cancer but had not been treated.

The paper ultimately led to Phillida Bunkle and Sandra Coney's *Metro* article in June 1987,² followed in quick succession by the establishment of a judicial inquiry led by [then] District Court Judge Silvia Cartwright.³

* carcinoma in situ

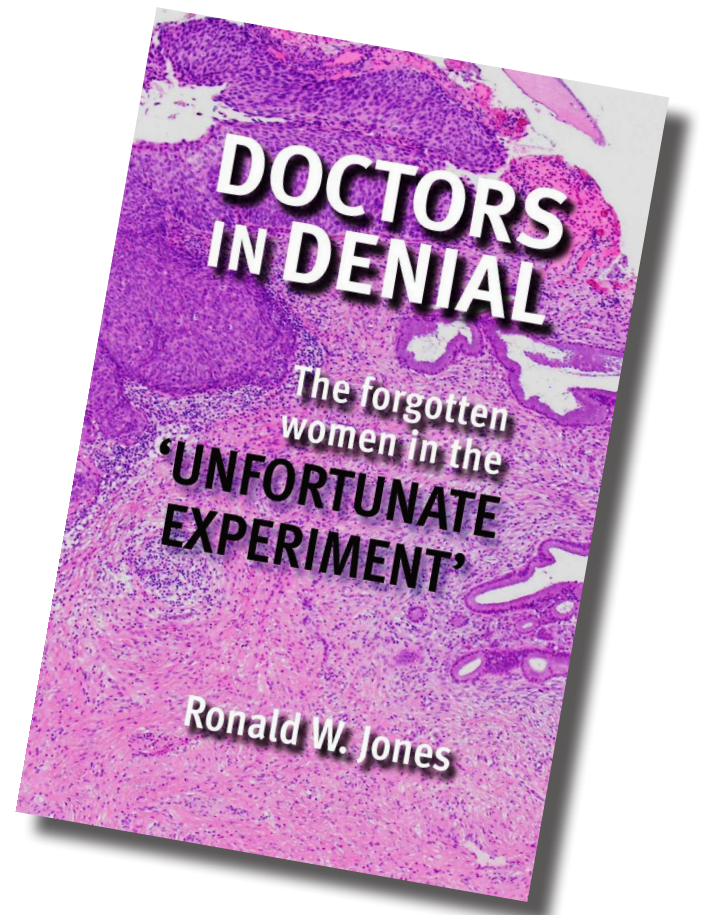
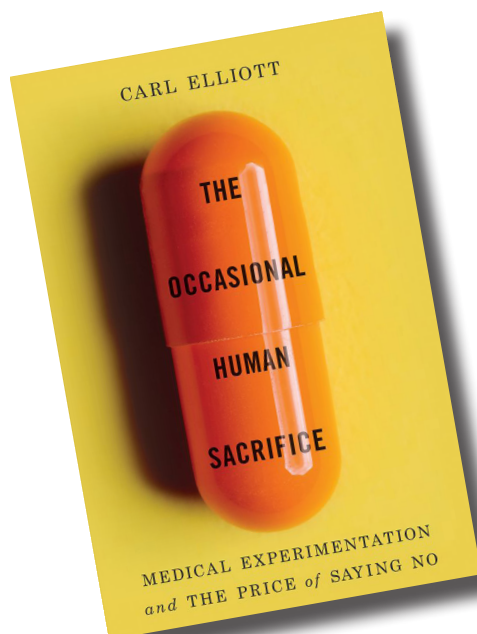
Thirty years later, Ron published his book *Doctors in Denial: The forgotten women in the 'unfortunate experiment'*⁴. All royalties he received from the sale of the book were donated to gynaecological cancer research and care.

In 2022, Ron was recognised for his work in exposing Herbert Green, and was awarded the 2022 Scientific Freedom and Responsibility Award from the American Association for the Advancement of Science (AAAS), the only New Zealander to ever receive the award.⁵

The AAAS said in their commendation that “Jones has spent much of his life confronting justifications for the scandal he considers revisionist and incorrect. Jones says he believes he had a moral duty to record his personal journey, extending over more than 40 years, and his role in exposing the ‘unfortunate experiment.’”⁵

The award honours engineers, scientists, or their organisations whose exemplary actions have served to foster scientific freedom and responsibility. The bravery of people like Ron Jones, and his colleagues Bill McIndoe and Jock McLean, whistleblowers who take on powerful people and institutions to expose wrongdoing, often go unrecognised. So, this international recognition was a wonderful tribute to Ron, whose efforts to uphold medical ethics came at some personal expense.

In 2024, Ron was the subject of a chapter in bio-ethicist Professor Carl Elliott’s book on whistleblowers, *The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No*.⁶ Carl spent some time with Ron in his research for the book, including staying in Ron’s home. Carl said that if there was an encyclopaedia entry for “Kiwi Gentleman” the accompanying photo would look something like Ron.



“At age eighty he is fit, tall, and brimming with good cheer. His manner is relaxed and unfailingly polite. When he’s not wearing a jacket, he favours Hawaiian shirts and a floppy hat. Like many New Zealanders, he jokes easily with strangers, and his humour is gently self-deprecating.”⁶

This is the Ron I knew, who invited me to lunch at his home a couple of years ago to discuss the ongoing issue of the smear campaign, undertaken by a minority of doctors who still seem to think Herbert Green was a saint.

But for all his good cheer, Ron still suffered the toll that being a whistle-blower takes on those who stand up for what is right, and fair, and just. As Carl writes, in the decades since Ron “helped expose the unfortunate experiment, he has become the primary guardian of its legacy, mainly out of his Presbyterian sense of duty.”⁶

“I wouldn’t have had a clear conscience had I run away from this,” Ron says.⁶

“It’s never out of my mind. There’s not an hour of the day when some aspect of it raises its head in my life. And this is forty years later. I cannot escape it.”⁶

It is a terrible thing that someone so upstanding, so loved by so many — evidenced by the many personal tributes to him under his [obituary in the New Zealand Herald](#), including from women whose children he delivered and other patients of his —

should have his life so tainted by the lack of ethics of colleague in medical practice.

The last time I saw Ron was on the 5th of August last year, at our annual 'pilgrimage' to the "Spirit of Peace" outside the old National Women's Hospital in Greenlane, to remember those harmed as a result of Herbert Green's unethical experiments on women. It was a very special event in 2024 with not only Ron in attendance, but also Sandra Coney and Phillida Bunkle, along with Jock McLean's widow, Ailsa, and Professor Carl Elliott and his wife, Ina.

In the evening, we were privileged to have Carl speak about his book *The Occasional Human Sacrifice* and the whistleblowers who exposed medical research scandals from the 1950s to 2016. Ron was in the audience and spoke about his experience at the end of the talk. It was clear that the awful events around the unfortunate experiment and the aftermath of its exposure, the impact of that on his life, were still vivid in his mind.

Ron never stopped fighting those who would re-write the truth of the unfortunate experiment; what happened, and his role in its exposure, never left him. He believed that it would be with him to the grave.

May he now rest in peace.

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3. See coverage of the [Cartwright Inquiry on the AWHC website](#).
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5. Jilani Z, 2022: [Ronald W. Jones Wins AAAS Scientific Freedom and Responsibility Award](#), American Association for the Advancement of Science, 15 February 2022.
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Sir David Skegg's tribute to Dr Ron Jones can be found on *Newsroom*:

[Dr Ron Jones: an unsung hero: Sir David Skegg honours the memory of a fine man, a gifted doctor, and an advocate for women's health and scientific integrity](#)

The [video livestream of Ron's funeral](#) is currently (30 April 2025) still online.



The gathering at the old National Women's Hospital on the 5th of August 2024.



What Healthcare is Teaching Our Little Girls

by Sue Claridge

In February this year, a six-year-old Auckland girl suffered a medical injury and had her pain and her patient rights ignored by nurses when she screamed that a plaster cast saw was cutting into her.

For the last eight years I have written regularly about how women's rights as patients are systematically ignored*. Since the birth of medicine — which arguably can be taken to have occurred at the time the Hippocratic Oath was originally sworn around 275 CE/AD — women's health and health concerns have been misunderstood, misdiagnosed, ignored or invisible.

It is almost 37 years since the founding of the Auckland Women's Health Council concomitant with the release of the Cartwright Inquiry Report into allegations of unethical medical experiments on women at National Women's Hospital in the 1960s and 70s. At the heart of the Inquiry and subsequent report was the abuse and denial of women's rights to informed consent in healthcare. Judge Silvia Cartwright's recommendations led directly to the establishment of the Code of Health and Disability Services Consumers' Rights, which include: the right to informed consent and to withdraw consent; the right to dignity and independence; the right to services of an appropriate standard; and the right to be free from discrimination, coercion, harassment.¹ Despite the Code of Rights being embedded in law, health consumers in Aotearoa New Zealand continue to find their most basic rights in healthcare are being ignored, including those of young children.

* For example, [AWHC March 2020 Newsletter](#).

Six-year-old Lola broke her ankle in December 2024, and in February 2025 was having her cast removed at the North West Medical Centre in Hobsonville.²

During the procedure, in which a special saw is used to cut through the plaster cast — a saw that is not supposed to cut the patient's skin — Lola complained that she was in pain and that the nurse had cut her.

Two nurses insisted she couldn't have been cut, that it was not possible, and they continued with the saw.

Lola became very upset; she was trying to get the cast off herself, was struggling to escape the pain and was screaming, 'I feel scared, take me home'. Lola's mother and the mother's partner had to hold Lola down.

Despite assurances from the nurses that she could not have been cut, when the cast was removed it was clear that was exactly what had happened; there were multiple lacerations on her foot that later became infected, requiring a 10-day course of antibiotics.

Saskia Corrigan, Lola's mother, made a formal complaint to the medical centre about Lola's treatment.² In responding to the complaint, the medical centre's general manager said she had "conducted a full investigation into the incident".

While she found several areas that needed to be addressed, including "staff manners, customer service, wound care and removing casts safely and correctly" and said that they had had the saw

serviced[†], in a statement to the *New Zealand Herald* she also attributed some of the “blame” for the incident to Lola. She said that the procedure was “challenging due to swelling in her limb — a secondary effect of the injury — as well as her heightened sensitivity related to her disability”. Lola is autistic, but clearly quite able to articulate her pain and fear and that she wanted the nurses to stop and let her go home.

Lola’s mother rejected suggestions that Lola had swelling in her foot at the time of the procedure. Ms Corrigan has laid a complaint with the Ministry of Health and Health and Disability Commissioner.

What happened to Lola may seem minor to some people, but it was horrendous on so many levels, and the trauma and lessons young Lola took from this incident may stay with her for life.

What Lola learnt is that when she tells nurses (and other health professionals) that what is being done to her hurts, she is not believed.

Lola learnt that saying no and asking them to stop is ignored. She learnt that her right to consent and to withdraw consent can be taken away from her.

Lola learnt that she can be gaslit, dismissed and fobbed off. When she repeatedly cried out in pain, she was repeatedly gaslit, told that the saw couldn’t hurt her. Her mother was forced to be complicit in the trauma by holding Lola down so the nurse could continue to cause her harm.

Lola’s mother learnt that, even when Lola complained that it hurt and she was being cut, and even when the health professionals admitted that what happened was wrong and that the health professionals were at fault, somehow Lola is still to blame.

Lola’s mother learnt that as far as the health professionals are concerned, Lola’s autism made her more sensitive, and that it was a problem with swelling in her foot, that somehow something about

her, over which she had no control (and which her mother disputes), was to blame.

It is hard to imagine, looking at the photos of the cuts on Lola’s foot, that any six-year-old — with or without autism — would have not cried out in pain.

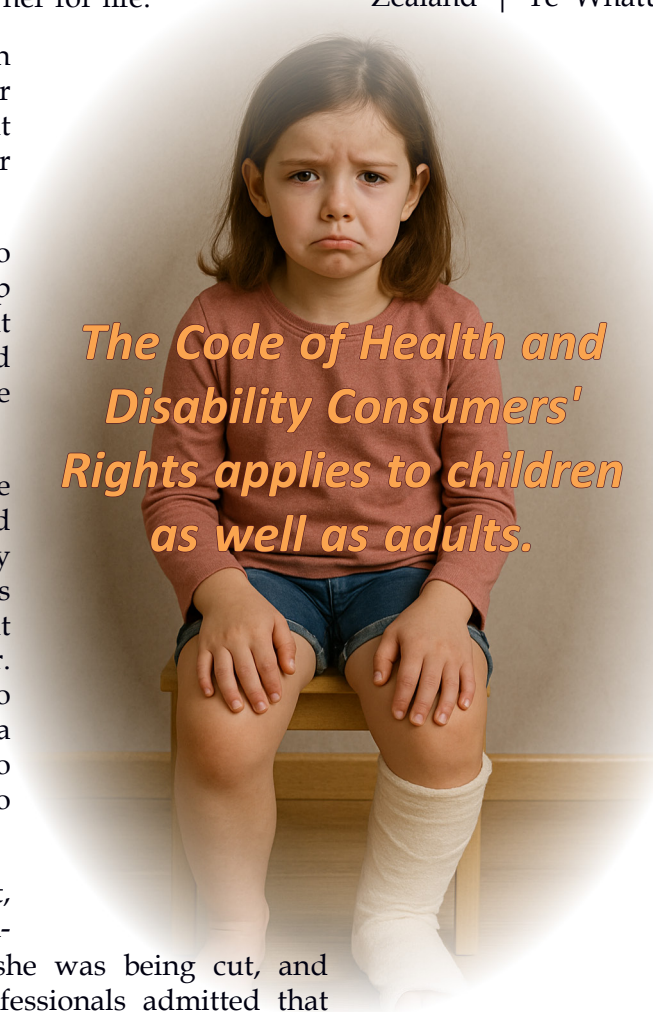
This little girl’s experience of healthcare may influence her interaction with health professionals for the rest of her life. It may make her anxious and frightened, and she may be labelled anxious and difficult in her medical notes, setting off a cascade of negative interactions. This may lead to her not being believed in the future when she describes her symptoms or pain.

There is much talk from within the health sector, including the Ministry of Health and Health New Zealand | Te Whatu Ora, about a patient-centred

health system. But these are just words — weasel words that are designed to placate consumers and lull them into a belief that patients and their needs and rights are at the centre of the health system.

However, when health professionals fail to listen to patients, fail to respond to complaints of pain and injury in health care, we know that they are just words. We have yet to see any real evidence of a change in culture that genuinely puts patients at the centre of health care.

Listening to health consumers, really listening to them, is the very first step towards patient-centred health care... and it still isn’t happening, centuries after the Hippocratic Oath bound doctors to ‘first do no harm’.



The Code of Health and Disability Consumers' Rights applies to children as well as adults.

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1. [Code of Health and Disability Services Consumers' Rights.](#)
2. Leask A, 2025: [Mother horrified as 6yo cut by nurse using saw to remove cast.](#) *New Zealand Herald*, 20 February 2025.

[†] However, the general manager also said that the saw was not faulty, but said that too much pressure had been applied and the nurses were cutting in the wrong place.

Professor Bev Lawton ONZM

New Zealander of the Year 2025

Kiwibank
New Zealander of the Year
Te Pou Whakarae o Aotearoa



Champion of Women's Health Honoured

Professor Bev Lawton ONZM, a champion of women's health, was named as the Kiwibank New Zealander of the Year in March.

Dr Lawton (Ngāti Porou) trained as a GP, working in general practice in Wellington for 17 years, during which time she co-founded the Wellington Menopause Clinic, and she has specialised in women's health for many years. She is particularly known for her work in maternal health and the prevention of cervical cancer.

Dr Lawton has made significant contributions to women's health in Aotearoa New Zealand and has especially worked to address the inequities and disparities faced by wāhine Māori. She is the founder/director of Te Tātai Hauora o Hine (the National Centre for Women's Health Research Aotearoa) and has driven critical advancements in cervical cancer screening. In particular, she has been a strong advocate for a change in the cervical screening programme to ensure it is safe and equitable for wāhine Māori, and has been a driving force in research into HPV self-testing aiming to increase cervical screening uptake for wāhine Māori, especially in rural communities.

Another major area of Dr Lawton's research is the Severe Acute Maternal Morbidity (SAMM) project, which identified opportunities to improve maternal health outcomes and avoidable morbidity. This research highlighted that two-thirds of cases of severe maternal morbidity were preventable or needed improvement in care, and most of the preventability was due to clinician factors such as delay in diagnosis and delayed or inappropriate treatment. One outcome of this research was Ministry of Health funding of the Health Quality and Safety Commission (HQSC) to establish SAMM reviews.

In 2005, Dr Lawton was appointed an Officer of the New Zealand Order of Merit for services to women's health, and was made a Distinguished Fellow of the Royal College of General Practitioners in 2017. She was awarded the Royal Australia and New Zealand College of Obstetricians and Gynaecologists' Māori Women's Health Award in 2020; the 2021 Women of Influence Award (Innovation, Science and Health); The Beaven Medal by the Health Research Council in 2023; and The Maarire Goodall Award by Te Ohu Rata o Aotearoa in 2024.

Dr Lawton is an appointed member of the Maternity Commissioning Framework Technical Advisory Group (Te Whatu Ora), the National Cervical Screening Programme Advisory Action and Equity Group, and the Royal Australian and New Zealand College of Obstetrics and Gynaecology Māori Health Committee — He Hono Wahine. In addition, she is the co-chair of two international indigenous alliances: The International Indigenous HPV Alliance and The Alliance for Perinatal and Reproductive Justice.

It is notable that all three finalists in this year's Kiwibank New Zealander of the Year awards were wāhine Māori; the other two finalists were world champion kayaker Dame Lisa Carrington (Te Aitanga-a-Māhaki, Ngāti Porou), and Sarah Hirini ONZM (Ngati Kahungunu ki te Wairoa), champion rugby player for the Black Ferns and Black Ferns Sevens.

Auckland Women's Health Council congratulate all three finalists and are particularly thrilled that Professor Lawton, as a champion of women's health, was named as New Zealander of the Year, honouring her for her dedication to, and improvements in, the health of the women/wāhine of Aotearoa New Zealand.



Where is our Health System Heading?

Is it about money or about people?

by Sue Claridge

Since the Covid-19 pandemic and former Minister of Health, Andrew Little's insistence on going ahead with massive health system reforms in the middle of the very costly pandemic response, many New Zealanders have had good reason to question where our health system is heading.

Almost 100% of the health professionals and the people working in or on the periphery of our health system, (including NGOs and non-profits such as the Auckland Women's Health Council) I have spoken to over the last few years have said they have never seen such a deep crisis in health.

There is so much truth and rationale in the maxims that "The greatest wealth is health,"¹ and "If you don't have your health, you don't have anything,"² that few would argue that health and well-being is one of, if not our most, precious possessions.

Many New Zealanders are in despair over the state of our health system and the lack of action of successive governments to address the needs of both the health system and our citizens. It has long been a political football, with promises made at each election to give a desired health benefit to particular lobby groups, in particular, as yet unfunded medicines, for example, specific drugs for specific cancers. Each successive government blames the previous one for the state of health in Aotearoa New Zealand. Yet the reality is no government for the last three decades has really invested in health at a level that realises any genuine improvement in the health of our people.

The current Government's cost-cutting across the public sector may be seen as fiscally prudent by some. However, the gross underinvestment in a

health system already on its knees is extremely shortsighted, and in the long term economically imprudent.

Simeon Brown was appointed the Minister of Health on the 19th of January, replacing Dr Shane Reti. He has no health background, having graduated with conjoint Bachelor's degrees in Law and Commerce, after which he worked for the Bank of New Zealand as a senior associate. He's a money man!

That Simeon Brown holds the health portfolio as someone with no health background is not particularly unusual. Over the last 25 years, only 45% of our Ministers of Health had a health background* (if you include Pete Hodgson who was a veterinarian). However, now we have yet another non-health professional appointed to a critical position in our health system.

The Director-General of Health (DGoH) is the second highest ranking health role in Aotearoa New Zealand and the DGoH is responsible to the Minister of Health for the stewardship of the Ministry of Health. The role of Director General of Health was established in 1900. Until April this year, there have been 19 appointed to the role (excluding two who were only acting DGs for one year or less). Of the 19, only two had no health/medical degree or substantial experience in health prior to appointment.

It may come as a surprise to many New Zealanders that, at a time when our health system has never been in deeper crisis, the newly appointed Director

* David Clarke commenced a degree in medicine but abandoned that for degrees in theology and philosophy.



Hon. Simeon Brown, Minister of Health



Audrey Sonerson, Director of
General of Health

General of Health, Audrey Sonerson, has no health education or training.

Rather, she has a MCA (Hons), Economics, BA/ BSc, Economics, Politics, Statistics. She worked as an assistant analyst/analyst at the Ministry of Health for three years seven months, straight out of university. Since then she has worked in a number of different ministries, including Justice, MFAT, Education and Treasury, and most recently was the Chief Executive of the Ministry of Transport.

Ms Sonerson was “hand-picked” for the role of DGoH. There was no open and contestable recruitment process and it appears that process was handled by Deputy Public Service Commissioner Heather Baggot, with whom Ms Sonerson had a “short interview” as part of the hiring process.³

She joins the Minister of Health, Simeon Brown, who also has no health background and has degrees in law and commerce, and whose previous portfolio was Minister of Transport.

We’re seeing a bit of a theme here!

How are New Zealanders supposed to have confidence in two people, who seem have no

background in health, to know anything about what is wrong with our health system and what health consumers and the health workforce desperately need from our health system.

It seems pretty clear that the focus is on reducing health costs for the current Government.

We have to hope that at least one of those with the power to make changes and address the current crisis in health services, knows something

about the downstream costs of a grossly inadequate and overwhelmed health system.

In a civilised society the health and well-being of people should be paramount. We all realise that Aotearoa New Zealand cannot live beyond its means and that there must be cuts and savings. However, our Government must not be wringing every last cent out of the health system; it is a blatantly false economy to do so.

Many, if not most, of the people who work in the health system and its periphery do so for altruistic reasons to do with helping and caring for people; the drivers are not predominantly economic.

However, if we were to view things through an entirely economic lens – the lens through which our current Government seems to view things – we can clearly see that, purely on an economic basis, people do not get the health care and medical treatment they need it will cost us far more in the long term. It is much cheaper to maintain health and well-being than to try to claw it back after years/decades of under-investment.

If people are too sick to work, there is a decline in productivity and a loss of tax revenue.

“So many people spend their health gaining wealth, and then have to spend their wealth to regain their health.”

— A. J. Reb Materi⁴

“To get rich never you risk your health. For it is the truth that health is the wealth of wealth.”

— Richard Baker⁵

When people's health deteriorates to the point of disability, either through inadequate healthcare or outright unsafe healthcare, disability increases; sick and disabled people can't work or their ability to work at capacity is compromised, there is a decline in productivity and a loss of tax revenue, and many people must be supported by disability and sickness benefits.

When people are diagnosed late with diseases, such as cancer, the costs of care are higher, mortality is higher, disability and loss of productivity is higher and tax revenue drops.

When money is not invested in our health system the financial demands of caring for and supporting an increasingly disabled and sick population will increase exponentially.

Our new Director General of Health, Andrea Sorenson, has two degrees in economics. Hopefully she will look at the big picture — the long term — and see that investment in all areas of health reaps significant rewards: a healthy, productive tax-paying workforce, and reduced downstream costs for health care and medical treatment that could have been avoided had we had a robust, functioning and best practice public health system.

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3. Howell A, 2025: [Why Director-General of Health Audrey Sonerson was hand-picked, not traditionally hired](#), New Zealand Herald, 18 April 2025.
4. Canadian clergyman
5. British composer.
6. Stuff, 2025: [Paddy Gower's TFN: Sir Ashley Bloomfield reflects on lockdown lessons](#), 27 March 2025.

Ashley Bloomfield on the Health System Crisis

We need a plan; a long-term, bi-partisan plan.

In an interview with Paddy Gower⁶, Sir Ashley Bloomfield denied that our health system is broken, saying “every day there are great people working in the system delivering fantastic care despite the challenges.”

There is no doubt that we have, for the most part, amazing and dedicated healthcare professionals; but, inherently, that we have great people delivering fantastic care is not enough. We have plenty of evidence, and often directly from members of the health workforce, that there are too few health professionals working long hours in unsafe conditions, unable to ensure that their patients are safe and properly cared for. We don't offer best practice care on many levels, from staffing, to delays in diagnoses, surgeries and other treatment, and the lack of funding for drugs that are standard of care in other countries.

Sir Ashley says that “just calling out the crises and the failures and saying things are broken is not enough.”

He says we need a plan.

He says what is required to fix the health system is to take a longer term view, and we couldn't agree more. Health has been a political football for far too long. Without getting into a debate about political ideology, the reality is that no sooner has one government put something in place, the next government repeals or disestablishes it. We saw this with Te Aka Whai Ora | The Māori Health Authority. Irrespective of those who thought it gave Māori something the rest of us weren't getting (it didn't!) it simply wasn't in place long enough to find out if delivering health to Māori by Māori and through a Māori lens would address the long standing and undeniable inequities and disparities in Māori health and health outcomes.

“Let's take a ten-year view of the system, where do we really want to be in ten years' time, and let's come up with a plan and work our way towards that,” Sir Ashley told Paddy Gower in the interview.

Ten years covers three electoral cycles, putting it beyond the immediate potential changes in government, and the partisanship that plays out around elections. Ten years would make a difference in training the workforce; make a difference in investment in buildings and data systems; and, importantly, allow real investment in primary care. A non-partisan approach to agreeing on the plan would be vital, to avoid kicking the “health football” around but achieving very little. Sir Ashley made clear he was not talking about a vision or a strategy but a clear plan.

He says we need to convene all the interested parties and get agreement on what needs to be done.

We don't agree with all that he says; he needs to spend more time with the people whom the health system has failed in the last 15 to 20 years. However, there is a lot of merit in a non-partisan, long term plan, that the major political parties would agree to and back, and then just get on with, rather than the ongoing waste of time and money as we go back to the drawing board with health in as little as three years. Critically, his plan must include the input of health consumers, those with vital lived experience of the health system – no matter what else, we need a truly patient-centred plan.



Bowel Cancer: Reflecting our Health System Crisis

A Bowel Cancer and Bowel Screening Update By Sue Claridge

In March this year, the coalition Government announced that it would lower the bowel screening age from 60 to 58 years for all New Zealanders, going against expert health advice that lowering the screening age to 50 for Māori was critical to address the significant inequities and disparities in bowel cancer for Māori.

In many ways the crisis in, and approach to, bowel/colorectal* cancer incidence, diagnosis and treatment in Aotearoa New Zealand reflects the greater, whole health system crisis and the downstream cost of an ill-conceived and inadequate response to the situation. We have worsening colorectal cancer statistics, especially for younger New Zealanders, Māori and Pasifika, and decisions at a governmental level that ignore expert advice that will lead to more people dying because of late or delayed diagnosis.

Colorectal cancer has the second highest incidence for cancer in Aotearoa New Zealand for both men (behind prostate cancer) and women (behind breast cancer), with 1849 and 1696 new colorectal cancer registrations respectively in 2022.¹ It is the third highest cause of cancer death in women behind lung and breast cancer, and the third highest cause of death in men behind lung and prostate cancer. In 2022, 625 women and 640 men died from colorectal cancer.¹

Between 2018 and 2022, the incidence rates for

wāhine Māori and non-Māori are similar at 33 and 36[†] per 100,000 of population respectively.¹ The rates are higher for men, at 43 per 100,000 for tāne Māori and 45 for non-Māori men.¹ Mortality shows similar patterns, with the death rate for wāhine Māori at 11[†] per 100,000, and 12 for non-Māori women for the same period. For men the death rate was 15 for Māori and non-Māori.

However, the age-standardised rates for Māori for all age groups combined have been consistently increasing since 1996, while non-Māori rates have been consistently decreasing. If these trends continue, it is very likely that in the next few years Māori will have a higher incidence of colorectal cancer.²

The major inequities appear in the age and stage at diagnosis. Between 2000 and 2020 the incidence of early onset colorectal cancer (EOCRC) — that is, colorectal cancer diagnosed before the age of 50 — rose significantly and the rise in EOCRC among Māori is particularly concerning.

“Māori patients are disproportionately affected by early-onset disease, with 30% of diagnoses in Māori women and 25% in Māori men occurring prior to the age of 50 years.”³

* Colorectal cancer is used in this article rather than bowel cancer as most research and cancer statistics refer to colorectal cancer.

† Rates are rounded up to the next whole number.

“Just over half of bowel cancers in Māori present before the age of 60 years (58% in females and 52% in males), whereas just under a third of bowel cancers in non-Māori are diagnosed before the same age (27% in females and 29% in males).”²

Dr Oliver Wadell, and his colleagues at the University of Otago, write that the “incidence of EOCRC increased by 26 per cent per decade on average [between 2000 and 2020] (with 44 per cent of all EOCRC occurring in the 45 to 49-year age group), compared with an 18 per cent decrease per decade in those aged 50-79.”⁴

They predict that if the trend in EOCRC continues there will be 361 cases per year of EOCRC diagnosed in Aotearoa New Zealand by 2030, and 524 cases per year by 2040.³

Māori are more likely than non-Māori to be diagnosed with bowel cancer following presentation to an emergency department (ED) and to undergo emergency surgery,⁵ indicative of late diagnosis. Additionally, those younger than 50 years or older than 74 years, women, Pasifika, and those living in areas of high social deprivation were more likely to be diagnosed after presenting at an ED.⁵

Previous research has found that as many as 34% of people diagnosed with colorectal cancer in this country first present to an emergency department.⁶

The 2022 *Bowel Cancer Quality Improvement Monitoring Report Update*⁵, using data from 2017 to 2019, confirmed the findings of the earlier *Bowel Cancer Quality Improvement Report*⁷ that 26% of people diagnosed with bowel cancer were diagnosed following an emergency presentation. Nineteen per cent of bowel cancer diagnoses result in emergency surgery.³

Essentially, the symptoms experienced by these people were so severe that they had to have an emergency major surgical resection of their bowel.

The highest rates of emergency presentation were for Pasifika people at over 44%, and Māori at almost 37% of total colorectal cancer diagnoses for those populations in the period 2017 to 2019. Emergency presentations were also substantially higher in the highest deprivation quintile** at over 34% of diagnoses in quintile 5 (compared to 22% in quintile 1, 24% in quintile 2, 25% in quintile 3, and 26% in quintile 4). By age, the highest rates for emergency presentation were for those under 50 years (33%) and 75 and over (30%) compared with total diagnoses in those age groups.

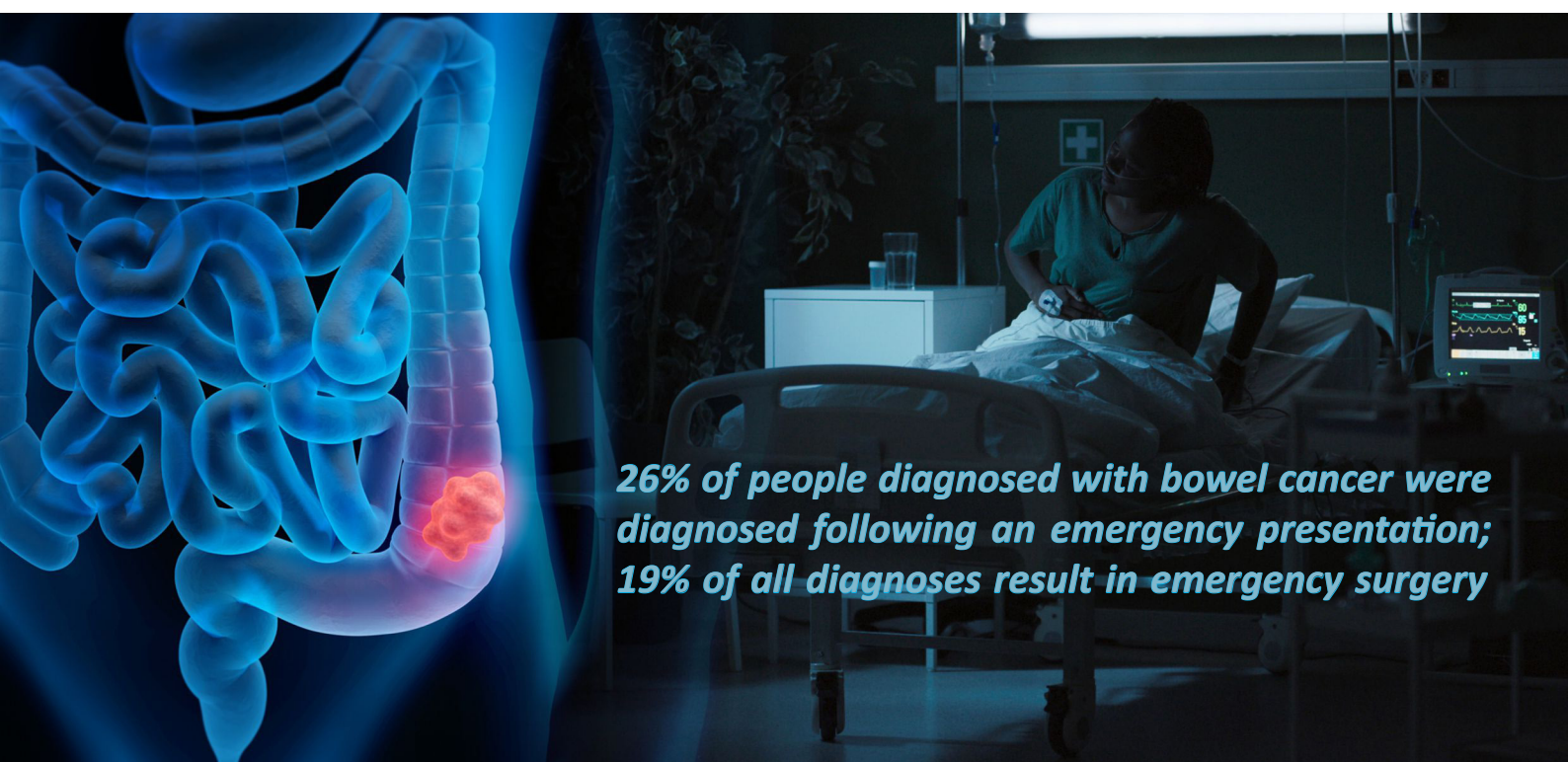
The proportion of emergency surgeries for bowel cancer is higher in Aotearoa New Zealand than comparable countries.⁵ Emergency surgery correlates with a more advanced cancer at diagnosis and poorer outcomes; there is also a significant increase in mortality associated with emergency surgery.^{5,7}

Windner *et al.*, wrote in 2018, that:

“Late-stage diagnoses are overrepresented in New Zealand; 24% of colon cancers in New Zealand are metastatic, compared with 19% and 17% in Australia and the UK respectively, despite the countries having comparable healthcare systems. New Zealand’s later staging at [colorectal cancer] diagnosis predicts poor outcomes, particularly for Māori.”⁶

Windner *et al.*, also found that those under the screening age for bowel cancer (<60 years) were

** Quintile 1 relates to children who live in areas scoring the lowest on the deprivation index (1 or 2), all the way up to Quintile 5 that relates to children who live in areas with the greatest deprivation scores (9 or 10).



26% of people diagnosed with bowel cancer were diagnosed following an emergency presentation; 19% of all diagnoses result in emergency surgery

significantly more likely to experience a delay in diagnosis despite presenting to a health care professional with concerns, including symptoms typical of colorectal cancer.⁶

On the one hand, we have a national bowel screening programme on the basis that early detection saves lives, yet on the other hand, we have New Zealanders dying from bowel cancer because their cancer is not being diagnosed despite them presenting with symptoms to a health professional.⁸ Bowel Cancer New Zealand say that 36% of younger patients see three or more doctors before a referral is made for further investigations. They continue to hear of young people who, “despite seeking help for their bowel cancer symptoms, were turned down for diagnostic bowel screening because they were considered too young.”⁹

Given these statistics, it is beyond comprehension that the coalition Government has decided to lower the bowel screening age from 60 to 58 for all New Zealanders, rather than follow the expert health advice to lower the screening age to 50 for Māori, in order to address the inequities that see Māori being diagnosed younger and with more advanced cancer.

The Government claims that by lowering the screening age for all New Zealanders to 58, it will prevent 218 additional diagnoses and 176 additional deaths over 25 years¹⁰ – amounting to preventing nine diagnoses per year and seven deaths.

Minister for Health, Simeon Brown, says “This also aligns with the Government’s policy of ensuring that healthcare is delivered on the basis of need.”¹⁰

Peter Huskinson, Chief Executive of Bowel Cancer New Zealand, says that nationwide bowel cancer screening for 50 to 60-year-old Māori and Pasifika is expected to save 44 lives each year,¹¹ which is more than six times the projected lives saved by lowering the screening age to 58 for all New Zealanders.

Auckland Women’s Health Council questions the rationale of the coalition Government’s decision, when those with the greatest need for early screening are clearly Māori and Pasifika, and those living with the highest level of deprivation, again disproportionately Māori and Pasifika. If “need” was the driver for changes to the bowel screening age, then earlier screening would be available to those groups that need it most; clearly not the case with the changes announced in March.

Once again “equality” wins out over “equity”. AUT Māori health professor Jacquie Kidd (Ngāpuhi) says that the Government decision on the bowel

screening age will save more Pākehā lives; it won’t save [more Māori] lives, and as a result inequity will get worse.¹²

Dr Kidd points out that “The Government only seem[s] to worry about equality when applied to ethnicity. Otherwise, it would call for free vaccinations for all, not just babies and oldies or offer everyone free breast cancer screenings, not just women.”¹²

It seems entirely implausible that our elected decision makers don’t understand the difference between equity and equality, so one can only draw the conclusion that this decision is blatant institutional racism.

As Drs Sue Crengle, Nina Scott and David Tipene-Leach said in 2020, “it is unconscionable that the New Zealand Ministry of Health should be rolling out a programme that produces new inequities when evidence exists to direct us otherwise.”¹³

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Recommendations from the HDC's Review of the Act and Code of Rights

No Right to Appeal!

By Sue Claridge



The Health and Disability Commissioner, Morag McDowell, has submitted to Parliament her Recommendations Report that is the outcome of her 2024 review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights.¹

Her recommendations were delivered to the Minister of Health on the 20th of December 2024 and the Review document was made publicly available in early April 2025. The [report is available online along with the submissions received](#).

To progress some of the recommendations would require the development of a Health and Disability Commissioner Amendment Bill, which would be undertaken by the Ministry of Health.

In a generalised statement the HDC said "Overall, we found the Act and Code are generally working well but have recommended small changes to both the Act and the Code to align with modern expectations, help shift practice in the sector, and improve the way HDC operates."

The HDC's recommendations report¹ is 92 pages long and beyond the scope of this Newsletter to review in its entirety, so this article will consider the two issues that were of greatest concern to the AWHC:

- research on incompetent or incapacitated patients who are unable to provide consent to participate in clinical trials, about which we have been lobbying the HDC since 2014, to protect the rights of patients incapable of providing consent;* and



Morag McDowell, Health and Disability Commissioner.

* AWHC lobbied the HDC between 2014 and early 2017 on this issue until the release of a consultation document by then HDC Anthony Hill in March 2017, on which we made [a written submission](#).

- the right to appeal HDC decisions, an issue on which we have made submissions in the past.[†]

Research on Patients Unable to Consent

In May 2014, then AWHC co-ordinator, Lynda Williams, wrote to Commissioner Anthony Hill, saying:

“We have become increasingly alarmed and are now extremely concerned at what has happened to patient rights in the current clinical trials environment. There are many clinical trials being undertaken which involve vulnerable patients, including infants, children, young adults with Down Syndrome, as well as unconscious patients.”

Consultation, discussion and review of this issue has been ongoing (in a rather *ad hoc* way) since early 2017 — eight years — and we are not practically any closer to any greater protection against exploitation of vulnerable New Zealanders in medical research.

In our submission on the review of the HDC Act and Code of Rights we stated:

“The AWHC believes that absolutely no incapacitated or incompetent adults should be enrolled for medical experiments, clinical trials or any sort of research, until there are sufficient protections and safeguards established in law that first and foremost protect their rights and interests, health and well-being. This would include an adequate ethical and legal framework, including specific definitions of terms such as “minimal risk/burden”, “benefits”, “best interests”, and who constitutes an authorised legal representative.”²

The HDC’s recommendations are broadly aligned in principle. The report acknowledges the concerns of submitters and recommends clearer guidance and oversight for research involving patients, especially where consent is unclear or absent. Ms McDowell recommends updates to legislation to better align with ethical standards and the Code of Rights.

The HDC report takes a more procedural and policy-focused approach, recommending improved frameworks and guidance rather than the outright bans that our submission sought. AWHC’s views reflect a stronger advocacy perspective, rooted in historical trauma, particularly the events that led to the Cartwright Inquiry, and concern that any permission

[†] See the AWHC [written](#) and [oral](#) submissions on Renate Schutte’s Parliamentary petition requesting that the “House of Representatives amend the Health and Disability Commissioner Act 1994 to give complainants, and those that are the subject of complaints, the right to appeal decisions made by the Health and Disability Commissioner.”

Key info about the HDC ACT & Code review:



- The HDC received a record number of submissions — 259 — including three in te reo Māori. Of these, 149 were from individuals and 110 from organisations, including AWHC. Almost a quarter of submitters were Māori, and just over a quarter identified as having a disability.
- The HDC sought feedback from 45 organisations and five individuals in the “scoping” phase of the review in February 2023 and received 30 responses (including from AWHC).
- The HDC held more than 60 face-to-face and virtual engagements across the country, including a work-shop in which AWHC participated.
- A range of recommendations were made in five different areas:
 - Better and Equitable Complaints Resolution.
 - Making the Act and the Code effective for, and responsive to, the needs of Māori.
 - Making the Act and the Code work better for tāngata whaikaha | disabled people.
 - Considering options for a right of appeal of HDC decisions.
 - Considering options for a right of appeal of HDC decisions.

[The Recommendations Summary can be found online.](#)

- The Recommendations Report was tabled in Parliament on the 3rd of March 2025 and it is now up to the Minister of Health and Government to decide whether to progress the HDC’s recommendations.

to involve patients unable to provide consent is a slippery slope towards a situation where patients are exploited and harmed for the benefit of research that, in itself, may offer no benefit to the patients involved.

Ms McDowell supports the suggestion to implement changes through the Act rather than the Code, saying “We consider that research should continue to be covered by the Code, but that incorporating exceptional circumstances for research where consent is not possible has the potential to overwhelm and complicate Right 7.”¹

AWHC agrees that changes should be made at a legislative level, as we believe this would have greater powers of enforcement.

Ultimately, the HDC recommends “that the Ministry of Health progress the HDC’s 2019 report recommendations ‘Health and Disability Research with Adult Participants who are Unable to Consent’,* and ensure lived experience representation, as part of the development of a Health and Disability Commissioner Amendment bill.”¹

Our major disappointment concerning the issue of patients unable to consent to participating in research is the sheer length of time it has taken to gain any traction in our advocacy for vulnerable patients. It is now 11 years since Lynda Williams raised concerns about this, and now we will have to wait for the MoH to develop an Amendment Bill, assuming the Report’s recommendations are approved and acted upon. This will be followed by the lengthy (albeit necessary) process of Parliamentary readings and debate of the Bill, plus further public consultation and further refinement of the Bill before it can be passed. Only then might we finally have legislation that properly protects incapacitated New Zealanders from exploitation and harm in medical research.

The Right to Appeal HDC Decisions

AWHC’s involvement in lobbying for a right to appeal HDC decisions began in 2020 when we supported Renate Schütte’s Parliamentary petition³ requesting the right to appeal decisions made by the Health and Disability Commissioner.

The right to appeal is at the heart of concerns around fairness and accountability in the Health

and Disability Commissioner (HDC) complaints process. We strongly advocated for a right of appeal against HDC decisions, particularly for complainants who feel their cases are not adequately investigated or resolved. Current avenues for review of decisions (e.g. a judicial review or a complaint to the Ombudsman) are costly, often inaccessible, and not effective substitutes for a genuine appeals process. We highlighted power imbalances between complainants and providers and a lack of transparency on the part of the HDC, especially when serious complaints are dismissed with little explanation, for example, when a ‘no further action’ decision is given and a complaint is not formally investigated. We advocated for and provided a model for an independent appeal process.

Thus, it is very disappointing that in her recommendations¹ the HDC says:

“A statutory right of appeal is not recommended, given the unique nature of the Commissioner’s process and the existing mechanisms to challenge or review decisions.”

This recommendation ignores the limitations of the existing mechanisms for challenging decisions, especially if the decision is a ‘no further action’ decision. The report suggests that giving complainants or providers a right to appeal might undermine the efficiency and finality of the HDC process, which is designed to be inquisitorial, not adversarial.

This decision sacrifices natural justice and fairness in order to protect the “efficiency” of the HDC and holds the HDC up as a paragon of infallibility.

The report does suggest improved communication and explanation of decisions, but refutes the need for an independent appeal mechanism. We believe the lack of an appeals process is a major barrier to justice, especially for complainants harmed by health system failures and who are denied an HDC investigation. Essentially the HDC is prioritising procedural efficiency and system function (and, we believe, avoiding a scenario where there could be criticism of decisions that are clearly unfair) to the detriment of health consumers.

However, there is some improvement over the *status quo*, with these recommendations:

- to incorporate a statutory requirement for HDC to review decisions in the Act, with a time-limit and criteria to limit the scope and circumstances of a review in the interests of finality;
- to consider opportunities to make HDC’s existing review processes, as well as external options

* The [report of the former HDC Anthony Hill](#) as a result of the 2017 consultation on Health and disability research involving adult participants who are unable to provide informed consent.

to challenge HDC's decisions, more transparent;

- to consider opportunities to improve HDC's complaints processes and communication of decisions to address reasons why parties may request a review.

It will be interesting to see how soon any of these recommendations are implemented and what impact they have on complainants' satisfaction with the decisions made by the HDC.

We are committed to maintaining a watching brief on the HDC and the decisions made. Only recently we have expressed considerable disappointment over a 'no breach' decision made by the HDC in a case of serious breaches of informed consent rights,⁴ so it remains to be seen whether or not these recommendations improve outcomes for health consumers who deserve accountability, fairness and justice when they suffer harm in our health system.

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The HDC's Odd Lack of a Complaints Process

It has been drawn to our attention by a health consumer that, unlike most if not all other public service agencies, the Health and Disability Commissioner does not have complaints handling process or policy; that is, a policy that sets out how parties to complaints who are receiving services from the Health and Disability Commissioner, can complain about the procedure by which their complaints are being handled.

The HDC has no internal complaints policy whereby people (complainants) can complain about the services and processes of the HDC, as opposed to complaining about the outcome of/decision on their health and disability services complaint.

Despite years of making submissions on issues concerning the function and role of the Health and Disability Commissioner and writing articles on the HDC, it had never really occurred to this author to question whether or not the HDC had a complaints policy for people wishing to complain about the HDC. In fact, it is quite a significant oversight, given that last year we had an opportunity to contribute to the review of the HDC Act and Code of Health Consumer Rights; an ideal opportunity to raise this issue had we been aware of it. Unfortunately, we have been so focussed on lobbying for a right to appeal HDC decisions and advocating for the rights of incapacitated patients who are involved in medical research (and unable to consent to their involvement) that such a basic right — to be able to complain about the services and processes of the HDC itself — was entirely absent.

In stark contrast to the HDC's lack of any complaint

handling process, let alone an effective one, they apparently do have an Unreasonable Complainant Conduct policy, which enables them to deal with so-called unreasonable complainants, although this policy does not seem to be published on their website. It appears that consumers only find out that there is such a policy when they have become the subject of it.

It is ironic that the Code of Rights has a right to complain (Right 10), which is applicable to health and disability services providers, but HDC does not hold itself to the same standard as it holds health or disability services providers.

It seems particularly unfair to prioritise the development of an Unreasonable Complainant Conduct policy while choosing not to establish a complaints policy for complainants dissatisfied with HDC's service, especially in light of the Ombudsman's 2012 document on *Effective Complaint Handling*.⁵

In this document the Ombudsman sets out why public service agencies should have a complaints process, saying that "people have a right to make comments or raise concerns and expect them to be heard by the agency they have been dealing with." He writes that "effective complaint handling is fundamental to the provision of a quality service."⁵

In the interests of providing a quality service it behoves the HDC to develop and implement an effective complaints policy. If they had an effective complaints policy and processes for resolving complaints, they may have less need for their Unreasonable Complainant Conduct policy.