Health and Disability Commissioner
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Women keeping patients safe: from Dame Sylvia Cartwright to HDC

Presentation to New Zealand Women in Medicine Conference
May 2022



Overview

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- Women and the establishment of HDC
- Trends in complaints about women's care
- Informed consent – the heart of the Code
- Case studies

The “unfortunate experiment”

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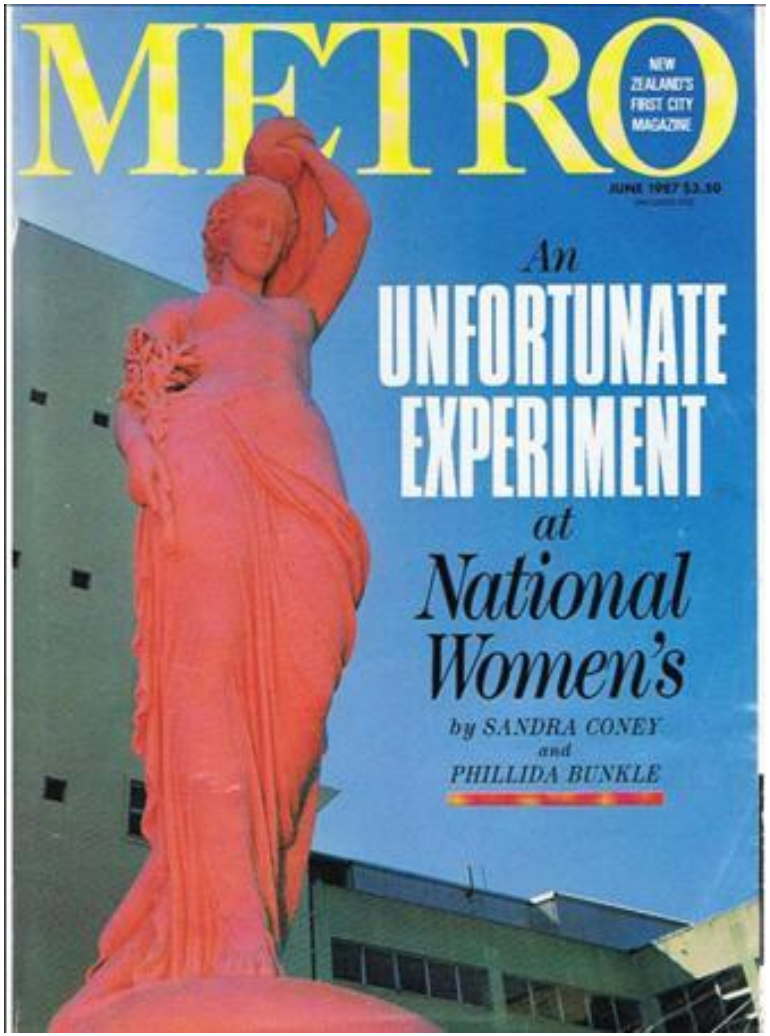
- Bunkle and Coney’s 1987 Metro magazine article made concerning allegations about National Women’s Hospital
- Some women with carcinoma-in-situ of cervix were withheld conventional treatment without their knowledge or consent
- 95% continued to have CIS. 22% developed invasive cancer of the cervix or vagina. Eight women died.



The Cartwright Report

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- *Cervical Cancer Inquiry* undertaken by Judge Silvia Cartwright.
- Her 1988 report concluded the study was unethical and marked a sea-change in public attitudes
- Recommended statutory recognition of patients' rights and led to establishment of HDC

What she said..

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"I have come to consider that the patient is entitled to all relevant information concerning her treatment, the options for treatment, and all information concerning her possible inclusion in a research trial. The focus should be centred on the patient, and not the doctor. It is a principle designed to protect and preserve the patients' rights, not to protect the doctor from liability…an informed patient is better equipped to participate in treatment".

The Role of HDC

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- Health and disability sector watchdog
- HDC promotes and protects the rights of health and disability services consumers through:
  - resolution of complaints;
  - promoting the Code through publicity and education;
  - contributing to health quality and safety;
  - where appropriate holding providers to account

What the Code Says

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1. The right to be treated with respect.
2. The right to freedom from discrimination, coercion, harassment, and exploitation.
3. The right to dignity and independence.
4. The right to services of an appropriate standard.
5. The right to effective communication.
6. The right to be fully informed.
7. The right to make an informed choice and give informed consent.
8. The right to support.
9. Rights in respect of teaching or research.
10. The right to complain.

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Trends in complaints: Women in complaints to HDC

Complaints per year

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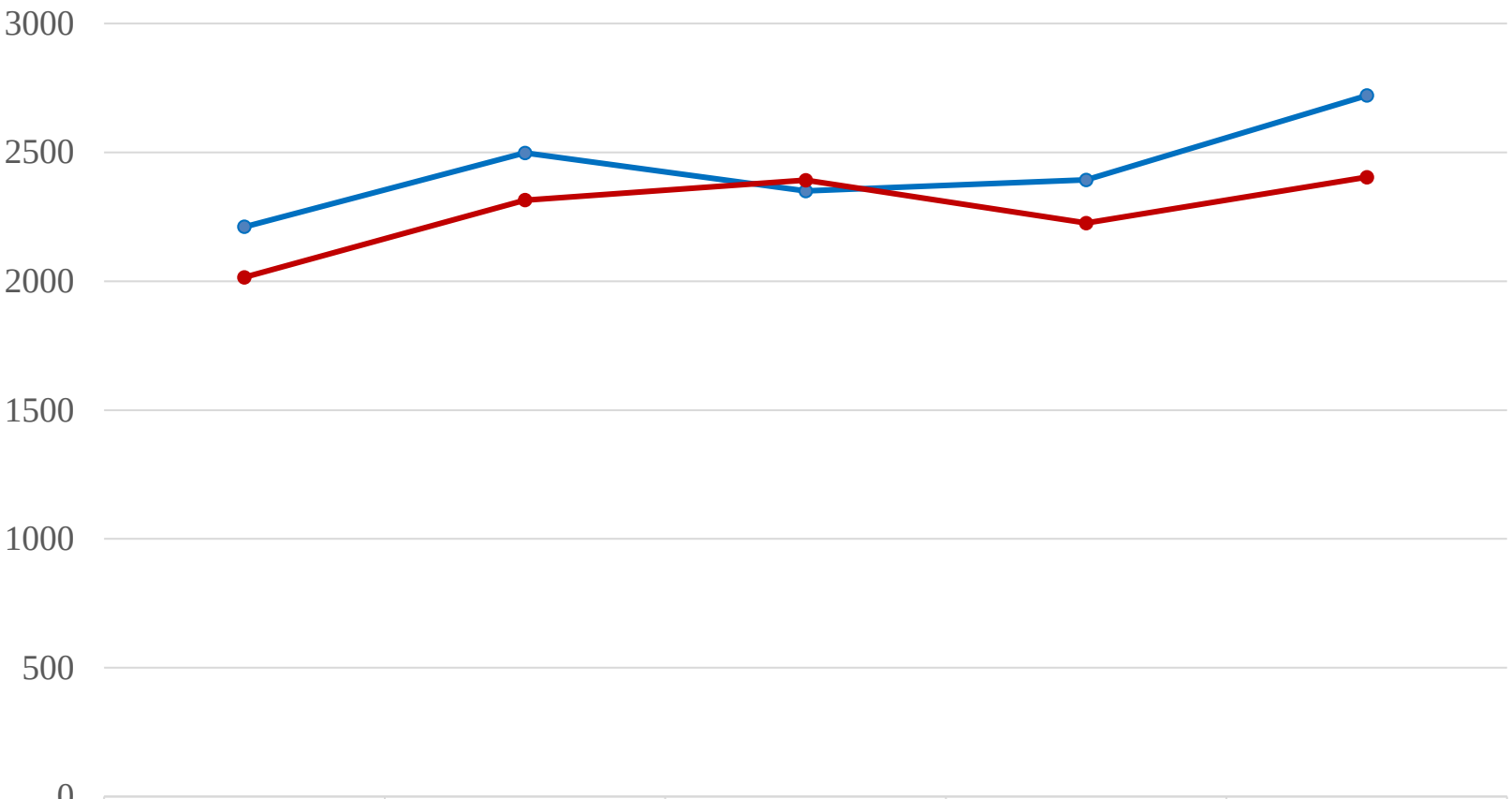

	2016/2017	2017/2018	2018/2019	2019/2020	2020/2021
Received	2211	2498	2350	2393	2721
Closed	2015	2315	2392	2226	2404

Providers complained about

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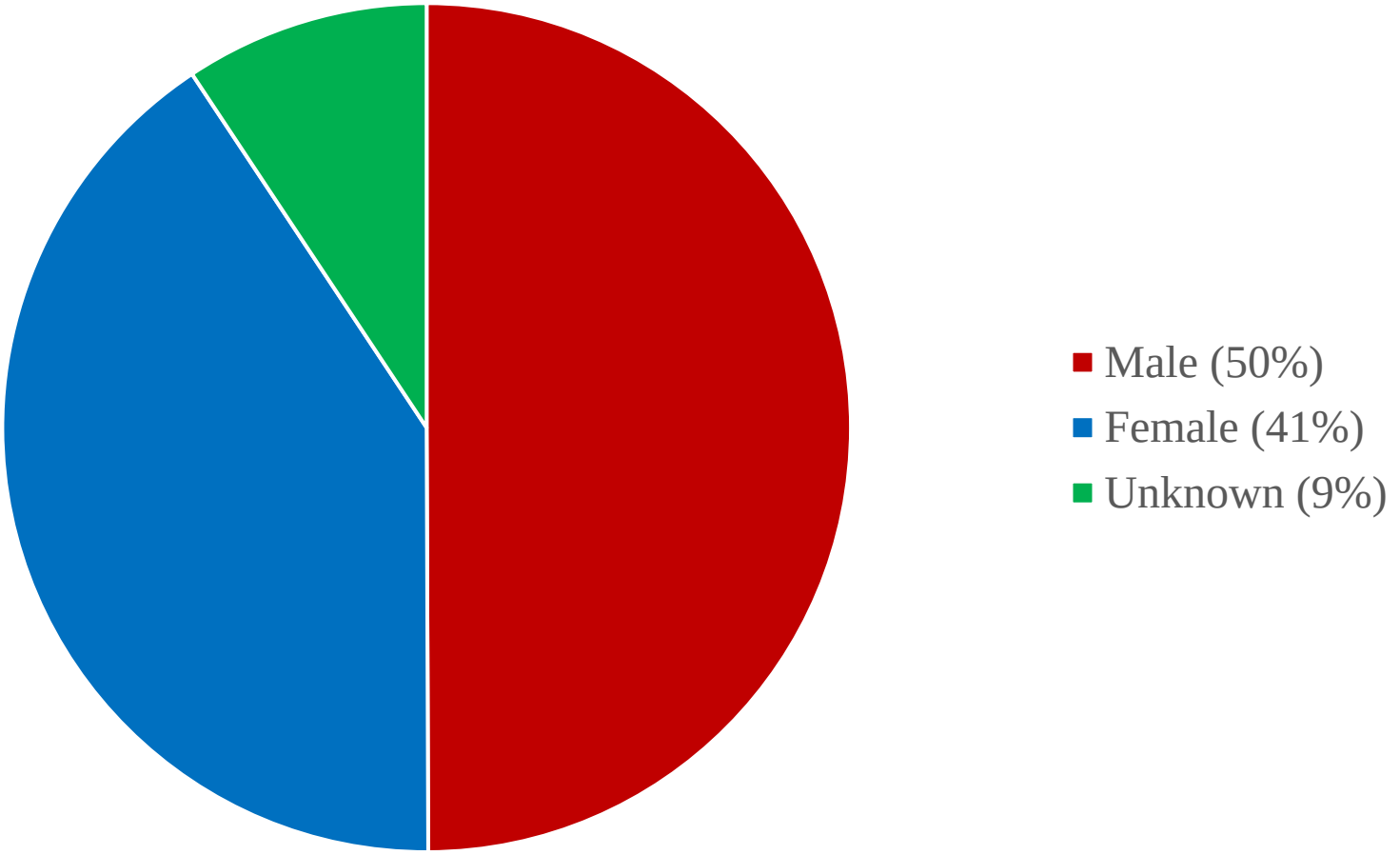

Consumers in complaints to HDC

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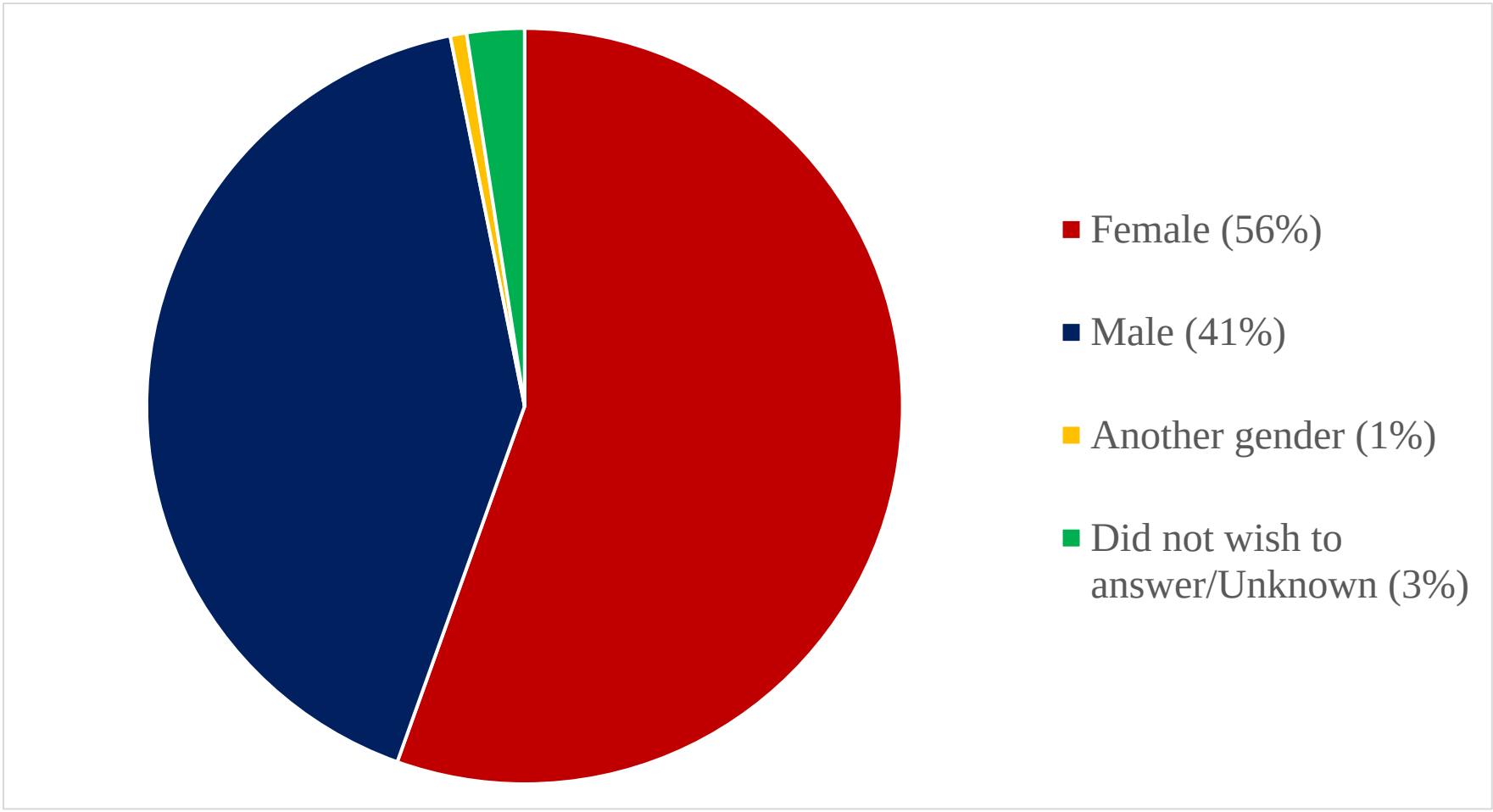

Common issues complained about re: women's care

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- Inadequate/inappropriate treatment
- Missed/incorrect/delayed diagnosis
- Failure to communicate effectively with woman
- Disrespectful manner/attitude
- Inadequate/inappropriate examination/assessment
- Lack of access to services
- Delay in treatment
- Unexpected treatment outcome

Issues identified in complaints about women's health services

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- Informed consent
- Access to care, in particular access to care for pelvic pain conditions
- Geographical variation in care
- Delayed diagnosis
- Cultural safety/equity issues
- Maternity complaint profile
- Access to maternal mental health services

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Informed consent – the heart of the Code

Informed Consent

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Informed Consent accounts for 15% of complaints to the HDC

A process with three components:

1. Right to effective communication (r5)
2. Right to sufficient information (r6)
3. Right to make an informed choice and give informed consent (r7)

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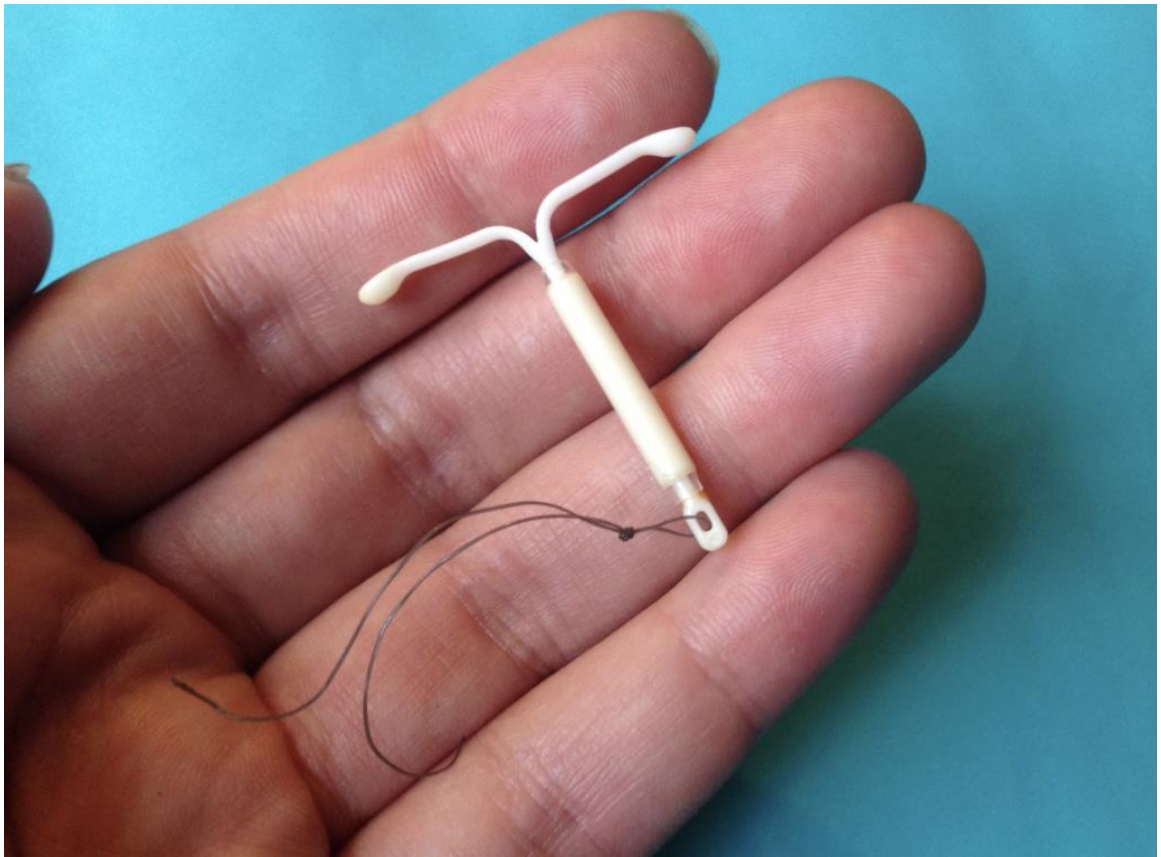
Case Study 1

Insertion of intrauterine device without consent



Insertion of intrauterine device without consent

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- Woman consulted gynaecologist for assessment and management of heavy menstural bleeding
- She consented to several procedures, including endometrial ablation, under general anaesthetic
- Gynaecologist experienced equipment difficulties and so could not undertake ablation
- Gynaecologist considered alternative options, and decided to insert Mirena
- Had not obtained consent for this procedure

Insertion of intrauterine device without consent

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- Woman told HDC:

"I feel very angry about this abuse of my wishes while I was under anaesthetic. … I actively, firmly and clearly stated numerous times that I did not want a Mirena. At no point did my position alter … … I firmly believe he was aware I did not want a Mirena and that he used the circumstances to do what he felt I needed, not what I had wanted. He acted against my express wishes. He may well have had good intent however he knew I had not consented and that I did not want a Mirena."

Insertion on intrauterine device without consent

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- **Issues raised:**

- Gynaecologist inserted Mirena without women's consent
- Gynaecologist was fully aware that the woman had not provided consent, and commented that although she might not like the idea, it was the only valid option.
- In the absence of an emergency, the gynaecologist's clinical preference was not relevant – best interests did not apply
- The theatre nurse did not advocate for the patient

- **Findings:**

The gynaecologist was found in breach of right 7(1) and referred to the Director of Proceedings

Adverse comment was made about the theatre nurse as she did not query the absence of written consent when the gynaecologist began considering alternative treatment options.

Case Study 2

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Use of saline as placebo pain relief

Use of saline as placebo pain relief

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- Woman presented to hospital in labour – she was attended by her LMC midwife
- Use of pethidine was in the woman's birth plan
- Woman was assessed by an obstetrician who recorded that she was requesting analgesia and suggested fentanyl or pethidine be used
- The woman chose pethidine
- The LMC instead drew up a syringe of saline, and told two other midwives in attendance that she would give the woman saline and tell her it was pethidine

Use of saline as placebo pain relief

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- Midwife told HDC:

"The way [Ms B] was presenting led me to believe that she was transitional. Knowing this, I felt it was in the best interests of the baby not to give Pethidine. However, in the best interests of [Ms B], I was to give her a sense of support and help in a difficult time, therefore I administered normal saline, leading her to believe it was Pethidine. I knew it would do no harm, and that Pethidine could still be administered at any stage going forward, if required."

Use of saline as placebo pain relief

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Issues raised:

- Midwife told woman she was being administered pethidine when in fact she was being administered saline – this was dishonest and showed a concerning degree of paternalism
- By not providing the woman with the medication she had requested and agreed to receive, the midwife ignored the fundamental importance of consent

Findings:

The midwife was found in breach of right 7(1) and referred to the Director of Proceedings

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- Valuing the voice of consumers
  - Complaints are an opportunity to learn
  - Can effect quality and safety improvement at a systemic and individual level
  - Can set standards for the profession
- Ethical clinical leadership and behaviour
- “Speak up” culture

HDC's role – lessons learned

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- Delay
- Barriers of access
- Monitoring the sector

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www.hdc.org.nz