Monthly Lunchtime Seminar

Health Law and Ethics Network
Melbourne Law School
21 April 2026

THE UNIVERSITY OF MELBOURNE

MITIGATING HARMS FROM EPISTEMIC INJUSTICES IN HEALTH CARE

A CLOSER LOOK AT PATIENT-REPORTED DATA

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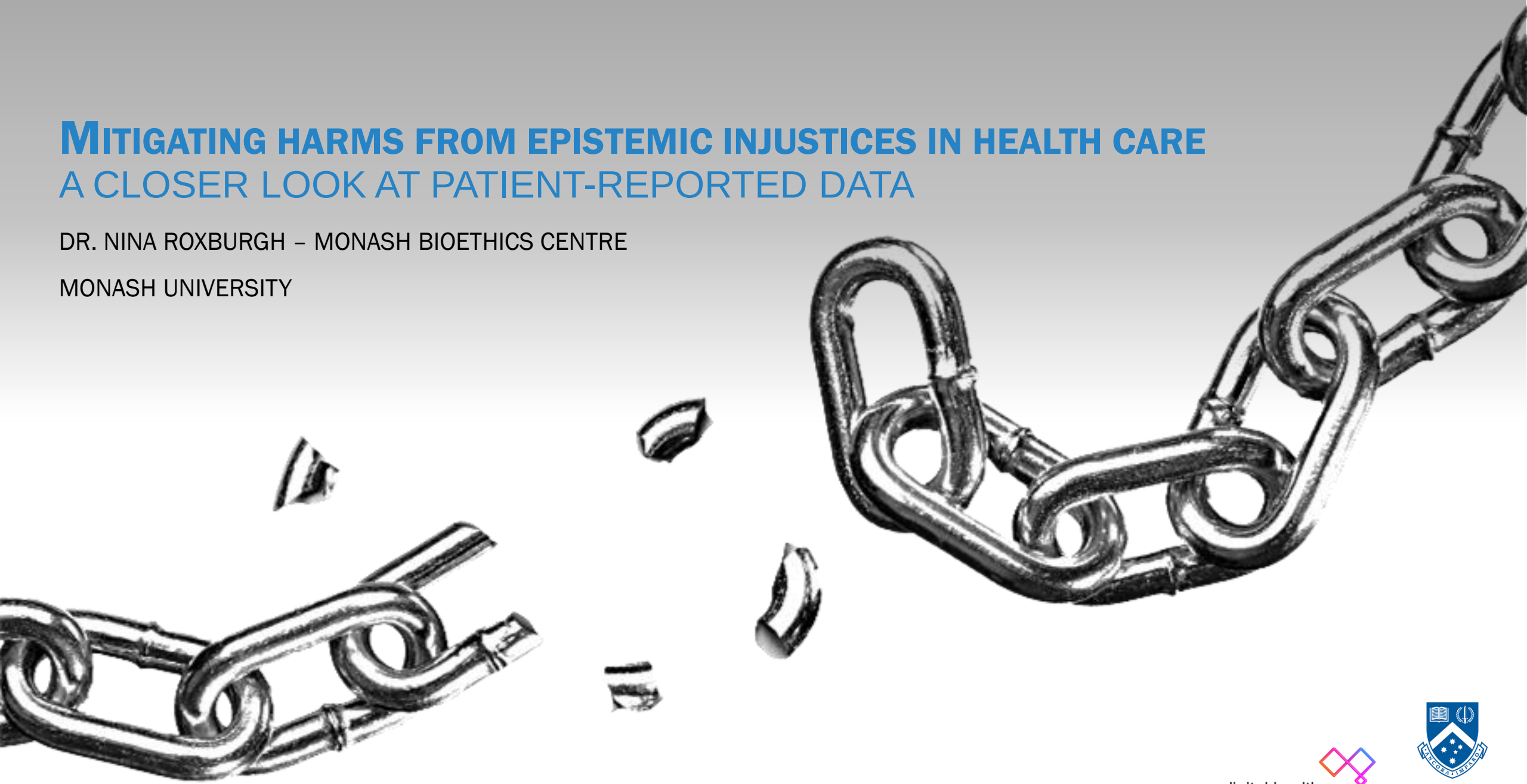
MONASH UNIVERSITY



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digital health crc

MONASH University

KEY CONTEXT

- The delivery of health care generates masses of health data **which can be leveraged to gain insights into performance, behaviour and culture.**
- There is **growing commitment** to prioritise the collection of patient-reported data using generic and disease specific measures (surveys, questionnaires, etc). This is health data ***as told by patients themselves.***
- This is evident in Australia:
  - Mental Health National Outcomes and Casemix Collection (NOCC) - 2002
  - NSW – HOPE (Health Outcomes Patient Experience) Platform - 2021
  - SA – Partnership announce with The Clinician to develop a PR Data Platform – 2023
  - National Cancer Plan - 2023

KEY DEFINITIONS

Patient-reported measures can be grouped into the following two categories:

Patient Reported Experience Measures

PREMs capture the patient's perception of their **experience with healthcare or services**

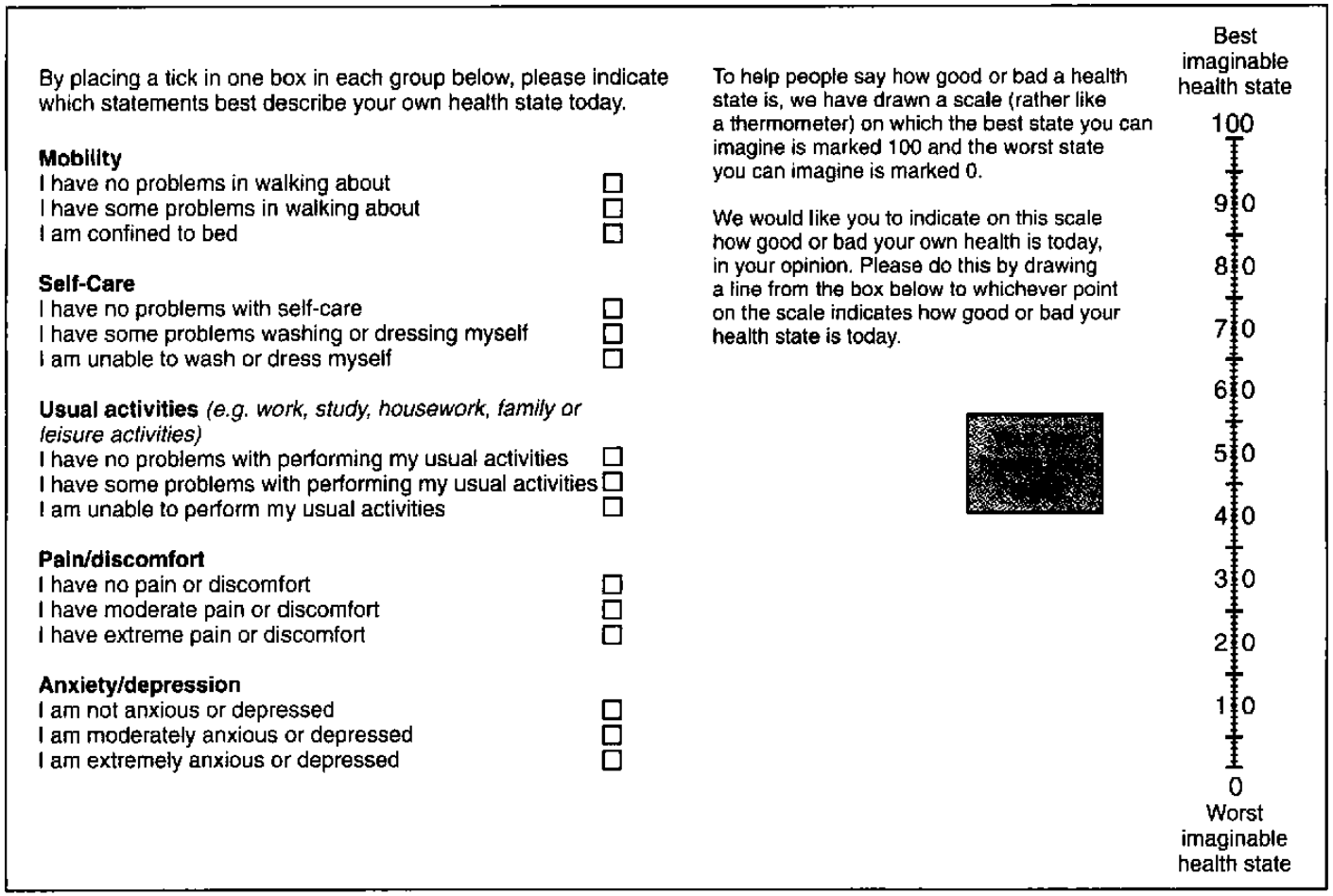
Patient Reported Outcomes Measures

PROMs capture the patient's perspectives about how illness or care impacts on their **health and wellbeing**

PATIENT-REPORTED OUTCOME MEASURES (PROMS)

EXAMPLE:

Patient-Reported Outcome Measures (e.g., Euroqol 5D)



By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility
I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

Self-Care
I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual activities *(e.g. work, study, housework, family or leisure activities)*
I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain/discomfort
I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety/depression
I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

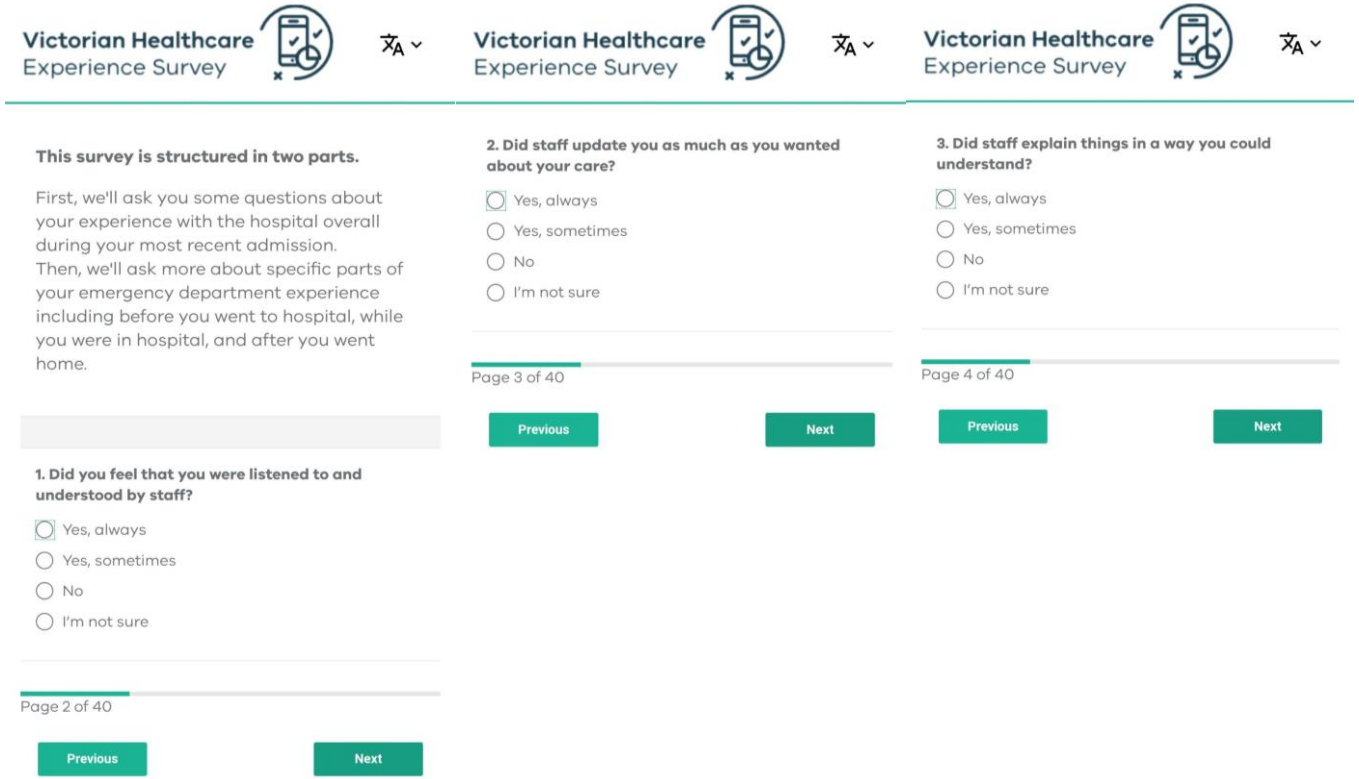
We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Best imaginable health state
100
90
80
70
60
50
40
30
20
10
0
Worst imaginable health state

PATIENT-REPORTED EXPERIENCE MEASURES (PREMS)

EXAMPLE:

Patient-Reported Experience Measures (e.g., VIC Healthcare Experience Survey)



WHAT DO THEY AIM AT?

- PRMs are used for:
- Research (Clinical Trials)
- Person-centred care - Patient voice and lived experience
- Benchmarking services
- Monitor safety/quality
- Clinician/Service feedback

IMPORTANTLY: While evidence is still indeterminate on how effective PRMs in all these spaces, **we do know that they improve communication, symptom detection**, between patient/clinicians.

MY FOCUS – WHAT ETHICAL POTENTIAL DO THESE TOOLS HAVE?

- Contribute to a sense of dignity for patients and could encourage the development of humility in clinicians by **recognising patients' as epistemic agents** with their unique ability to **produce, assess and evaluate knowledge** that contributes overall to the health information landscape.
- Creating **space within this landscape specifically for patients' voices** might deliver a sense of justice for those who are marginalised in health systems.

How Serena Williams Saved Her Own Life

Black women are nearly three times more likely to die after childbirth than white women. Serena Williams was almost one of them. Here, in her own words, she tells her story.

BY SERENA WILLIAMS PUBLISHED: APR 05, 2022 8:00 AM EDT

SERENA'S STORY

- Serena has a medical history where she is high-risk for blood clots.
- Post birth, Serena's body is not doing well – paralysed, numb legs, haze, passing out, excruciating pain.
- Given her medical history, she asks about treatment - 'heparin drip' to minimise risk of clotting.
- The response: "Well, we don't really know if that's what you need to be on right now." **No one was really listening to what I was saying.**

SERENA'S STORY

- The symptoms get worse. She has an embolism – a clot in one of her arteries.
- "I spoke to the nurse. I told her: "I need to have a CAT scan of my lungs bilaterally, and then I need to be on my heparin drip." She said, "I think all this medicine is making you talk crazy." I said, "No, I'm telling you what I need: I need the scan immediately. And I need it to be done with dye." **I guess I said the name of the dye wrong, and she told me I just needed to rest."**

SERENA'S STORY

- "In the U.S., Black women are nearly three times more likely to die during or after childbirth than their white counterparts. Many of these deaths are considered by experts to be preventable. **Being heard and appropriately treated was the difference between life or death for me**; I know those statistics would be different if the medical establishment listened to every Black woman's experience."

BREAKING

Lawsuits Against Yale Mount As More Patients Claim Nurse Stole Pain Medication During 'Torturous' Fertility Procedures

CASE 1: YALE IVF CLINIC

- In 2020, Yale IVF Clinic is conducting egg retrievals on hundreds of women
- Unbeknownst to them, one of their Nurses is stealing Fentanyl and replacing it with Saline
- The nurse is discovered by a colleague, and is charged and convicted of “Tampering with a Consumer Product”
- Yale settles with the Department of Justice for violating the Controlled Substances Act
- Case closed?

BUT WHAT ABOUT THE PATIENTS?

- 95+ women
- Physical suffering (pain during and after procedure)
- Psychological suffering (questioning their sanity and ability to assess their own experiences)
- Family suffering (loved ones enduring unimaginable experiences, also affecting caring roles/responsibilities)


Podcast 'The Retrievals' reveals painful experiences of female patients are often ignored

Aug 29, 2023 6:25 PM EDT

BUT WHAT ABOUT THE PATIENTS?

- Laura: "*I remember like thrusting my hips up, actually thrusting my hips up saying, I feel everything. Like, and like,* ***nobody believed me****…"*

- Post-surgery, on confronting her clinician about the poor experience of care, Julia says her doctor was not concerned: "*He said he was* ***not alarmed, but perplexed and surprised at my experience.*** *Those words I guess, ring pretty hollow now, right, knowing that there was a pattern of many women who had extreme, inexplicable pain after the egg retrieval."*

- *[Burton, 2023]*

BUT WHAT ABOUT THE PATIENTS?

- “…I mean, I guess I felt crazy … I mean, by this point, I’m asking myself like, am I being difficult? … you just question your sense of self, like your ability to assess your situation rationally…”
- *[Burton, 2023]*

BUT WHAT ABOUT THE PATIENTS?

- "Our clients walked into this clinic during the most vulnerable time of their lives expecting their medical providers to **listen to and believe them**… Instead, their complaints of agonizing pain were **repeatedly dismissed**, and they were **gaslit.**"
  - *[Pierson. 2024]*

WHY COULDN'T STAFF SEE IT?

- If patients were reporting (verbally) either during or after their retrievals that they could *feel everything*, that *something wasn't right*, and that *the fentanyl wasn't working*, why didn't staff recognise a pattern?

- There could be several explanations:
  - Staffing combinations change – not the same surgical team in every case
  - A belief that there will be pain, and that is an acceptable trade off for the benefit of IVF
  - A lack of time or capacity to reflect on outcome and experience trends
  - A disbelief or discrediting of the testimonies of women

Women's and Children's Hospital cochlear implant bungle left Aspasia and Amelia to 'suffer in silence'

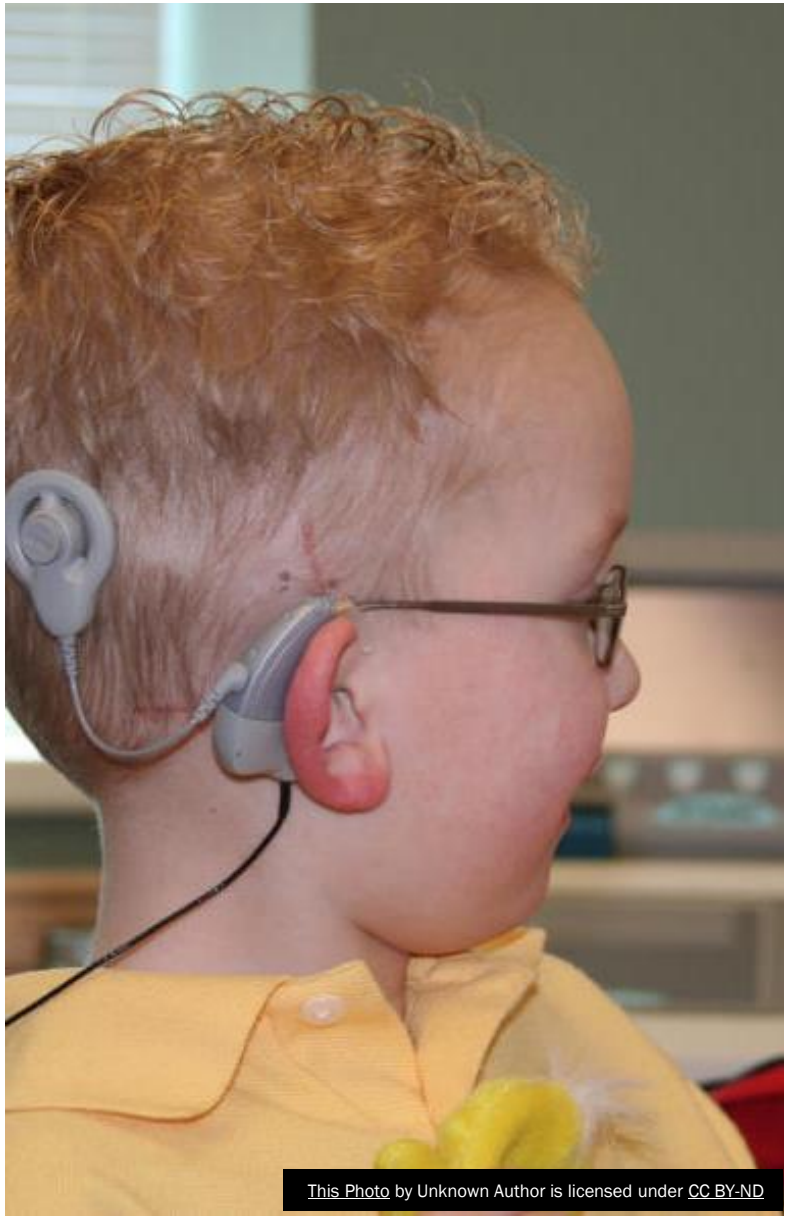
By Claire Campbell | Doctors and Medical Professionals

Tue 21 Mar 2023

Aspasia Paspaliaris, pictured with daughter Amelia, says she no longer has "full faith" in the Women's and Children's Hospital. *(ABC News: Claire Campbell)*

CASE 2: ADELAIDE WCHN

- Adelaide's Women and Children's Health Network (WCHN) Cochlear Implant Program
- 2022 – Concerns were raised by an external provider regarding the mapping of CIs
- An External Review is conducted
  - Recognises that incidents such as these 'often stem from **system related issues and team culture** rather than individuals' [page. 12]
  - Number of organisational issues caused conditions for failure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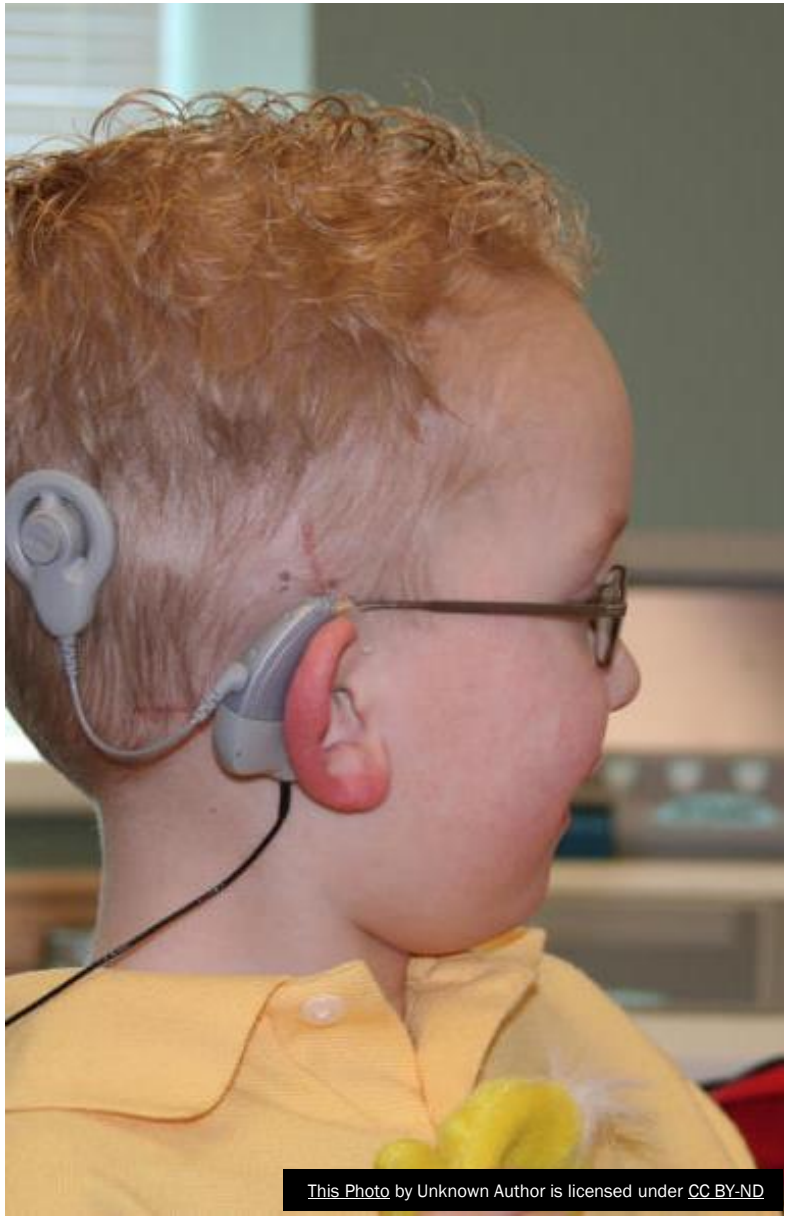
BUT WHAT ABOUT THE PATIENTS AND THEIR FAMILIES?

- In interviews with parents, the ERT learnt that parents had frequently raised concerns, but that these were **often dismissed** by the CI audiologists.
- The review found: “A lack of…**listening to parents’ concerns about their child’s progress” led to delays in identifying concerns**, correcting mapping and access to sound potentially leading to long-term impacts for some of these children.” [page. 40]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EXPLANATIONS OFFERED:

- "… your child needs to **wear the processor more**"
- "[your child is] **'just a bit slow**"
- "just give him **more time** [with the implant]"
- "[as a parent] **you need to do more**"
- "I remember constantly leaving those appointments **not feeling heard**"
- "… are you doing the homework I gave you to use at home … I felt so judged, like I wasn't doing enough, **like I was the reason my child was so behind**"
- [page. 63]

THE INFLUENCE OF PROFESSIONALS' ATTITUDES ON OUTCOMES

- "The WCHN Clinical Governance Framework - "Effective consumer partnerships are essential for improving healthcare outcomes and driving continuous improvement. **Listening and responding to the consumer voice** is at the origin of good clinical governance". [page. 64]
- Disconnect between Policy and Professionals on the ground.

People with invisible disabilities like me are routinely disbelieved — and it can have long-lasting effects

By the Specialist Reporting Team's Evan Young

Posted Wed 30 Nov 2022 at 5:00am, updated Wed 30 Nov 2022 at 8:26am

Melbourne hospital 'ignored' pleas for help before eight-year-old Amrita Lanka's death

By William Ton • AAP | 3:03pm Aug 26, 2024

Elderly patients and carers say age discrimination in NSW hospitals is real and heartbreaking

By Jessie Davies for ABC Regional Investigations

ABC Western Plains | Health

Sun 16 Aug 2020

Australian-first inquiry into women's pain launched as Victoria seeks to tackle 'shame and stigma'

Premier Jacinta Allan says 'there is a gendered pain gap', as survey of women finds two in five suffer from chronic pain

Aboriginal and Torres Strait Islanders face racism amid testing and treatment of COVID-19

The Australian Indigenous Doctors Association (AIDA) says an Aboriginal patient in NSW was denied testing, with the health practitioner claiming priority treatment was only given to "real Aborigines".

Endometriosis sufferer says years of pain were only ended by chance encounter with a gynaecologist

ABC South West WA / By Amelia Searson

Posted Thu 4 Apr 2024 at 8:50am

"I went to him with graphs of my pain, everything I'd consumed food-wise, what my toilet experiences were like, and I asked numerous times to go to a gynaecologist but was pushed aside," she said.

"He told me ... 'It's all in your head, you just don't cope with pain very well'.

Epistemic injustice in healthcare

Not new — but persistent despite decades of ethics scholarship

FRICKER (2007)

Testimonial injustice

Your report is discredited because of who you are — your gender, race, age, health status — and this shapes the credibility you are assigned.

Hermeneutical injustice

Your experience cannot be adequately expressed or received — no shared interpretive resource exists to make sense of it.

The Distinction: "who says something (for example, a patient)" and "how something is said (for example, in lay terms)." (Pot, 2022: 682)

Healthcare as a high-stakes epistemic landscape

- Power asymmetries between clinicians and patients are structural and historical
- Credibility assigned on identity, not content of testimony
- Embedded in professional culture, curricula, institutional practice – e.g canon of medical knowledge built on researching the male experience
- Consequences: delayed diagnosis, disengagement, erosion of therapeutic trust
- **Despite extensive ethics literature — this persists. Why?**

THE MISSING LINK? EPISTEMIC HUMILITY SUPPORTED BY PRMS DATA

- Medicine privileges “certain types of knowing over others”, such as the results from a blood test over the testimony of their patient. (Fricker, 2007)
- Testimonies of patients need to be “recognised, sought out… judged to be relevant and articulate (where they are) and, at least in certain aspects, judged as epistemically authoritative.” (Carel and Kidd, 2014)
- Clinicians need to practice reflexivity and self-correct when they receive patient testimonies (whether verbal or as patient-reported data).

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THE MISSING LINK? EPISTEMIC HUMILITY SUPPORTED BY PRMS

Epistemic Humility

- Not just self-awareness — a relational virtue (Muyskens et al. 2025)
- Requires extending knower status to patients, not just recognising one's own limits
- PRMs create structure for humility to be practised, not merely held

Respect and Solidarity

- Respect for persons — not only respect for autonomous decisions (Beach 2024; Barclay 2016)
- Dignity: being heard, seen as having unconditional value, responded to appropriately
- Epistemic solidarity: humility expressed through action, not just attitude (Pot 2022)

IN PRACTICE:
ATTITUDES/PERSPECTIVES FROM HEALTH CARE PROFESSIONALS

- "… there's a large focus on technical solutions rather than focusing on, um, you know **who's actually gonna do the work, look at the results, act on the results**, in my experience."
  - Doctor, Oncology, Public Hospital (Inner City)

- On asking whether patient-reported data can be an accurate reflection of events

  "**…hence why we always document ourselves**… we quotation marks what the patients have said, we only put in the factual information… **So a patient can say whatever they like, but we'll put the facts in,"**
  - Nurse, Emergency/Surgery, Public Hospital (Regional)

IN PRACTICE: ATTITUDES/PERSPECTIVES FROM HEALTH CARE PROFESSIONALS

- "...I've done some, some research **but I don't have a huge experience** in regards to having**, knowing how to properly analyse data and have it available as well.**"
  - Nurse, Oncology, Public Hospital (Inner City)

- "I don't feel that any of that would be helpful or necessary to be honest... **I'm not particularly stats driven, and, and I just feel as though, you know, having that rapport with a client I'm getting all that**, anyway but in a more therapeutic way rather than in a clinical way."
  - Psychologist, Mental Health, Private Clinic (Inner City)

KEY TAKEAWAY POINTS FOR DISCUSSION

- While not all cases of poor health experiences/outcomes are a result of epistemic injustices, we do know that a proportion relate to patients' testimonies being overlook, dismissed or undervalued in relation to other clinical health information and professional judgement
- There is a role for patient-reported data in enhancing patients' epistemic authority and visibility in this crowded information landscape
- Forming epistemic partnerships in solidarity with patients is necessary for genuine respect (i.e. dignity, recognition, equality) to occur
- PRMs data are an aid, but the work still lies with clinicians and organisations to cultivate epistemic humility

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THANK YOU

- Contact: nina.roxburgh2@monash.edu
- Ideas and collaborations welcome! Scan the QR code to connect

Cartoon source: Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr AJ. The routine use of patient reported outcome measures in healthcare settings. BMJ. 2010 Jan 18;340:c186.