



Australian Government  
Department of Health and Aged Care



National Women's  
Health Advisory  
Council

# #EndGenderBias Survey Summary Report

March 2024



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# Introduction

In 2023 the National Women's Health Advisory Council conducted the #EndGenderBias survey to ask Australian women about their experiences of barriers and bias in the health system.

Women, girls and people assigned female at birth, as well as experts (academics, health care professionals and peak stakeholder groups) were invited to take part. The views of priority populations were specifically sought including First Nations women, lesbian, bisexual, transgender, intersex and queer people, those with culturally and linguistically diverse backgrounds, lower socioeconomic households, regional and remote communities and people with a lived experience of disability.

From across the country there were 2,570 responses about women's own experiences, 86 responses from caregivers about the experiences of women they cared for, and 497 responses from expert stakeholders.



# Main findings

Two thirds of women reported they experienced health care related gender bias or discrimination themselves, and almost 80% of caregivers reported that a person they cared for had similar experiences.

Caregivers within the report are those who completed the survey on behalf of a woman; this included those caring for and supporting someone with a disability, a child, parent, spouse, sibling or friend.

Gender bias in health care had far-reaching impact on women's lives. They reported:

- Feelings of abandonment, shame, blame and self-doubt
- Significant financial burden, lost educational and career opportunities
- Delayed diagnosis and treatment led to disease progression, fewer treatment options and worse health outcomes.

Conversely, women also recounted positive health care experiences that stemmed from strong interpersonal interactions and relationships.

## Women's experiences of gender bias

Among women reporting their own experiences, and those reporting the experiences of someone they cared for, gender bias was experienced most in relation to sexual and reproductive health and chronic pain (Figure 1).



Figure 1: Gender bias in care for specific conditions

Over 70% of women experienced bias in the diagnosis and treatment of health conditions (Figure 2).

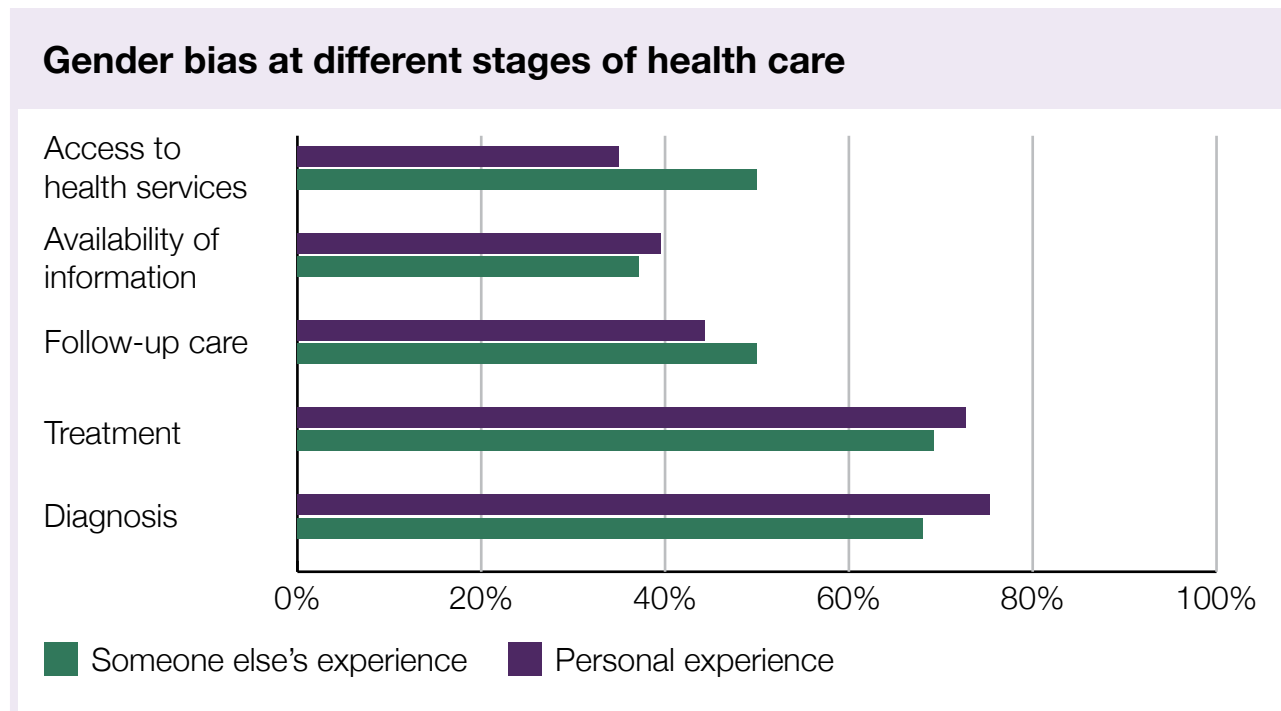


Figure 2: Gender bias at different stage of health care

Over 70% of women reported they experienced bias in GP visits, and almost half reported bias in hospital settings (Figure 3).

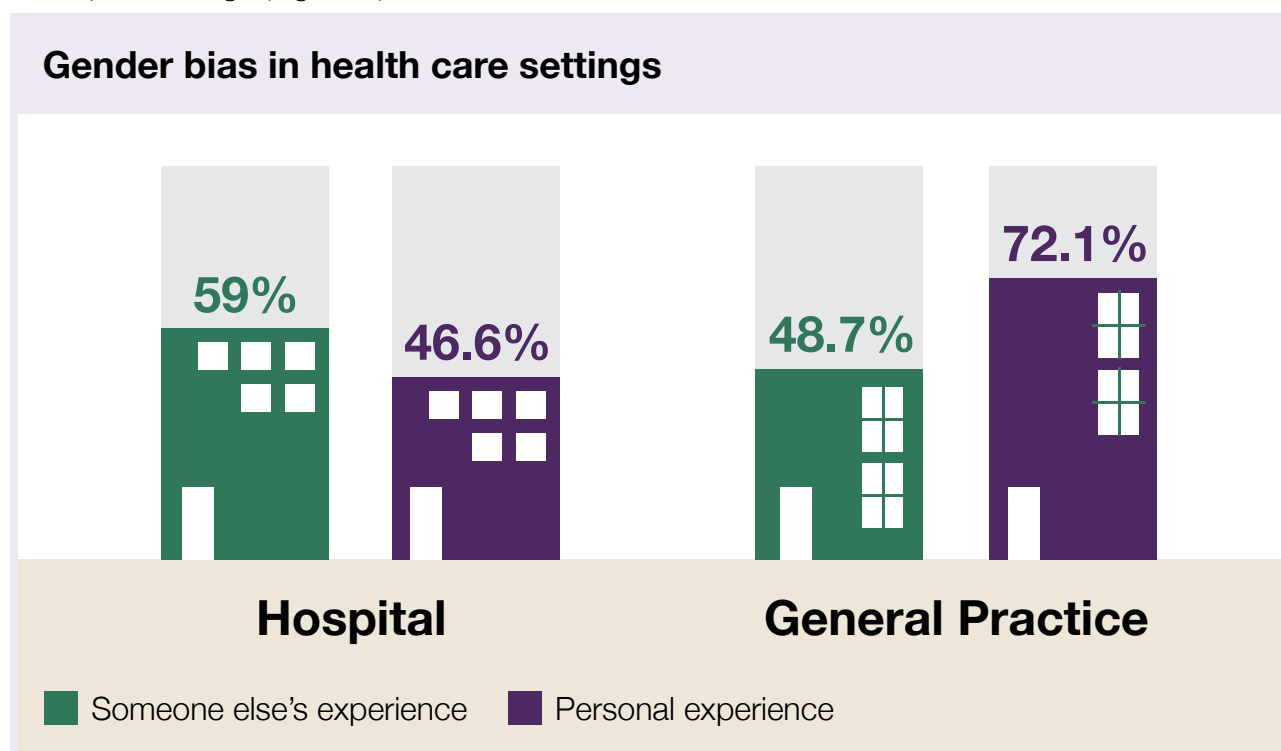


Figure 3: Gender bias in health care settings

Almost 500 responses were received from expert stakeholders (health professionals, researchers, consumer advocates) as either individuals or on behalf of national and state organisations.

Only 38% of the expert stakeholders felt women 'mostly or completely' have access to safe health care. In terms of women having choice in their health care, nearly half of the expert group (48%) felt this was 'only slightly or not at all' the case; and most experts (70%) felt women were 'only slightly or not at all' believed about a health issue.

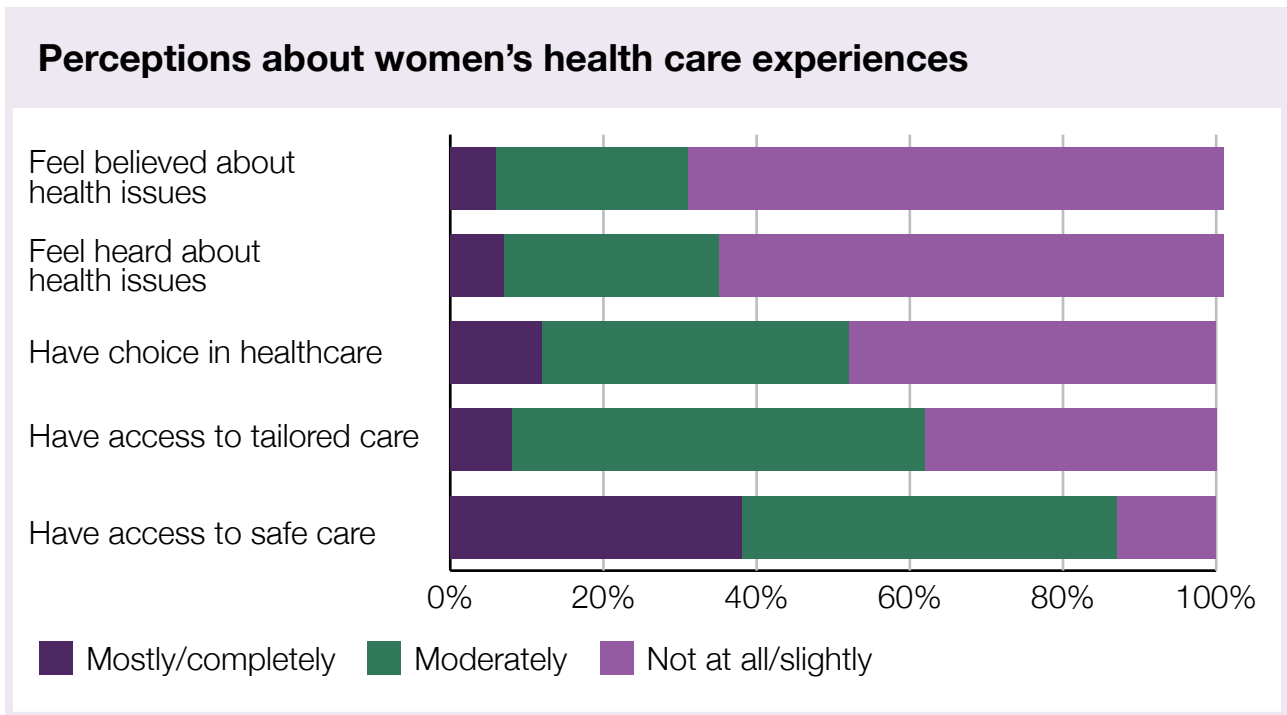


Figure 4: Perceptions about women's health care experiences

# What women and stakeholders told us

Women and stakeholders described experiences of gender bias in health care that were layered and overlapping. Five domains were identified to describe gender bias in health care (Figure 5):

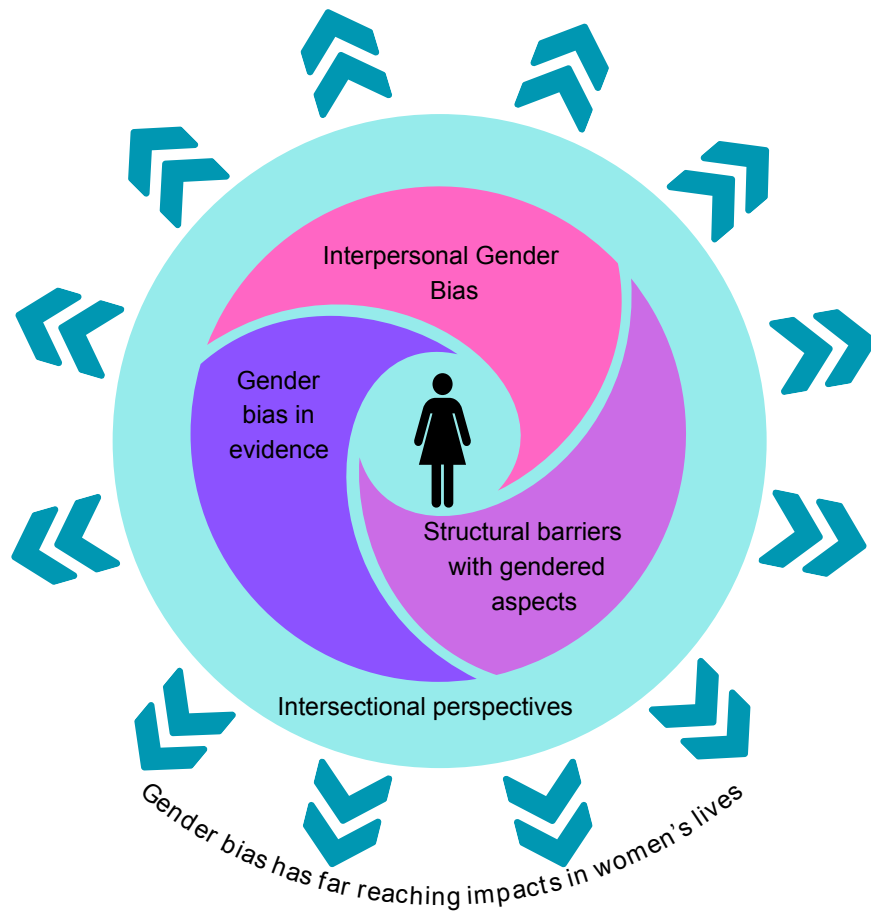


Figure 5: Thematic map of gender bias in health care

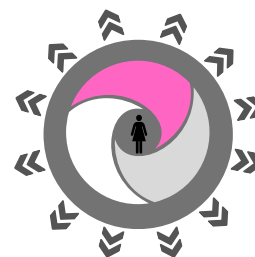
- **Interpersonal experiences** - consultations between individuals and their health care providers.
- **Structural barriers**, affecting the accessibility and affordability of health care.
- **Evidence base** underpinning health care and medical innovation.
- **Intersectional** experiences of gender bias - related to other aspects such as age and rurality.
- As a result of each layer of gender bias, gender bias in health care has **far reaching impacts** on women's lives.

It is riven through with gender discrimination – in the actions and judgements of doctors, the costs of all the repeated scans, the lack of expertise to see endometriosis on ultrasound scans or read pain diaries, in the historical and ongoing lack of research funding to advance our knowledge of pelvic pain, in the underlying belief that it is normal for women to experience pain.

**[35-44 years, woman, metropolitan]**

## Interpersonal Gender Bias

Four themes emerged in women's descriptions of their experiences of gender bias in health care. On one hand being 'dismissed and disbelieved' and 'dehumanising interactions'; on the other hand, women recounted positive experiences that stemmed from strong interpersonal interactions and relationships.



### **Dismissed and Disbelieved and Listened to and believed**

#### **Dismissed and Disbelieved**

- Women felt they were stereotyped as 'hysterical', a 'drama queen'.
- Concerns were often inadequately investigated; women's symptoms were readily attributed to other causes, such as normal menstruation, lifestyle factors or even 'faking it'.
- This was particularly evident where women's symptoms related to pain.

Within the first few moments of meeting me, [the doctor] had decided I was a "waste of time", a hysterical woman with a non-urgent problem who was being dramatic

**[25-34 years, woman with a disability, metropolitan, LGBTQI+]**

#### **Listened to and believed**

- Finding a doctor who listened and took their concerns seriously was often a turning point in women's health care.
- Women felt listened to when health care professionals had an openness to learn and treated the patient as an expert about their own experience.
- It often took a long time to find such a doctor.

When you find a good doctor who listens and is willing to help, it makes so much difference. It brought so much optimism back into my life

**[25-34 years, woman with a lived experience of violence]**



## Dehumanising interactions and Building positive relationship-based, person-centred care

### Dehumanising interactions

Women experienced disrespectful and demeaning interactions with health care professionals. Many of these experiences occurred in situations where women were most vulnerable, such as intimate examinations and childbirth. The cumulative effect of these interactions was dehumanising.

I think it [healthcare] would be improved if doctors approached me from a perspective that I'm a person. Often, I feel dehumanised, as if they're just checking a box speaking to me or that I'm nothing but a burden.

**[25-34 years, woman with disability, metropolitan]**

These dehumanising interactions existed on a continuum, which caused women increasing distress:

### Insufficient information to make informed choices

Without preamble or discussing risks/benefits [doctor] presented two choices...like it was a McDonalds drive through option. How can you decide without context, facts, risks, long term impacts?

**[55-64 years, woman, regional]**

### Denied access to preferred treatment

The gynaecologist refused to explain the [sterilisation] procedure to me and noted that 'I would need to meet your mother and partner'

**[18-24 years, woman, LBGTQI+, metropolitan]**

### Coercion to accept treatment

I was bullied into accepting another IUD during this surgery [for endometriosis] I was told that the surgery would not be scheduled if I do not consent to an IUD.

**[18-24 years, First Nations woman with disability and lived experience of homelessness]**

### Demeaning treatment

[The doctor] was very rough with his internal examination and when I told him he was hurting me, he replied with a comment along the lines of 'well, you got yourself into this mess, you'll just have to deal with it'.

**[55-64 years, woman from migrant background, experienced violence, metropolitan]**

## Treatment without consent

The anaesthesiologist refused my request for gas [instead of needle to induce anaesthesia for a surgical procedure], even as I started getting very distressed...the anaesthesiologist inserted a needle into my arm without any warning while I was crying and hyperventilating.

**[18-24 years, woman with needle phobia, metropolitan]**

## Building positive relationship-based, person-centred care

- Women wanted and reported positive experiences where health care professionals invested time in discussing options, explaining procedures carefully and asking questions to elicit the woman's experiences.
- Women wanted health care professionals to be honest about what they didn't know and explicitly address power imbalances.
- These things were seen as foundational to culturally safe care and trauma informed care. But they were difficult to achieve in context of short consultations, fragmented care, rushed health care professionals.

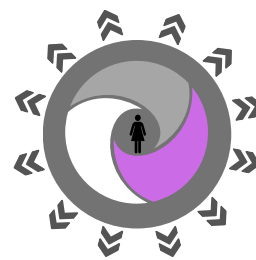
I feel safer when doctors explain procedures and options first and discuss what they will do physically. I feel safer when we discuss ways to make that process be as comfortable as it can and what cues they should look for that I am overwhelmed and need to stop. I feel safer when they ask for feedback afterwards and we can adjust or refine our plan for next time. I feel safer when they listen to me and give me time to talk

**[45-55 years, woman, survivor of childhood sexual abuse]**

## Structural barriers with gendered aspects

Structural barriers to accessing health care restrict women's choices. Often these structural barriers have gendered aspects. For example, health workforce shortages in rural areas may disproportionately affect women.

Two themes were identified: availability and affordability. Well over half (62%) of women found health care unaffordable, and 45% found it inaccessible.



### Availability

- Long waiting times to consult with health care professionals at every level, from primary care to medical specialists to treatment, including surgery.

There are very extensive waiting times for specialist appointments ... There is very little after hours medical care. There is no private Emergency service and wait times at [hospital] are very long.

**[55-64 years, metropolitan, woman]**

I have no choice if I want to see a [medical specialist] locally. She is only available every 6 months and one of those appointments will be by telehealth, which is pointless, except for a prescription renewal that the local Dr can't do.

**[65-74 years, rural, woman]**

- Exacerbated by health workforce shortages, especially in rural areas.

GP funding for services related to intrauterine device implantation is poorly funded, resulting in many doctors declining to provide this service. ... In rural and remote locations ... fewer or no ... GPs providing contraceptive services.

**[Health Professional Society submission]**

Approximately 30% of women reside in regions with no access to abortion care through their GP ... 50% for women living in rural and remote [areas] ... Abortion care largely illudes routine healthcare in public hospitals, further discouraging GPs from providing medical abortion, fearing that they will not have hospital back up.

**[Health Professional Society submission]**

- More expeditious access to care was dependent on the capacity to pay for private care.

It was a massive stretch for us to be able to afford this as a private patient, [but we] still had yet to hear that the public system would even talk to me about an appointment... It's been a week since my surgery, and I cannot remember feeling this good in years.

**[25-34 years woman, metropolitan]**

## Affordability

- Women had poor access to bulk-billed primary health care.

Women's out-of-pocket medical costs are disproportionately higher than men's for every single age grouping from 19 to 64, even when excluding pregnancy-related services.

### [Health Professional Society submission]

In 9 months, I spent over \$1500 in GP appointments, over \$600 in 2 specialist appointments, surgery costs and diagnostic testing. All as a part time worker, full time student under the age of 21.

### [18-24 years, CALD background, metropolitan]

- Aspects of women's health care may be less likely to attract bulk billing.

There is a significant discrepancy in [bulk billing] rates, between scans overwhelmingly required by women, and other ultrasound scans.

### [Health Professional Society submission]

- Women's health conditions were expensive to manage, with much of the management not funded by public health care.

I'm paying out of pocket for pelvic floor physio and dietitian appointments to see if I can help myself deal with pain while waiting for surgery [for endometriosis].

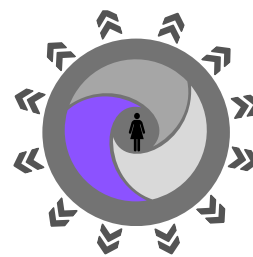
### [35-44 years, woman, regional]

- Delays in diagnosis sometimes put women outside eligibility criteria for subsidised treatment options.

Without medical support (via prescriptions or diagnosis) many of self-management options are not eligible for subsidies through the Pharmaceutical Benefits Scheme, Medicare Benefits Scheme or National Disability Insurance Scheme. Funding self-management care options is expensive and can place additional financial burdens on women experiencing hardship

### [Stakeholder]

## Gender bias in evidence



Women's opportunity to access timely and appropriate health care was also perceived to be constrained by the evidence-base which underpins clinical practice. Two themes were generated to summarise participants' views and experiences in this domain: 'Women missing from the evidence base' and 'Limited translation of evidence into practice.'

**Women missing from the evidence base:** Participants perceived that a lack of diversity in all aspects of research led to gender bias in the evidence available to inform health care and medical innovation. Calls for greater diversity related to the 'who', the 'what' and the 'how' of research.

**Who is taking part in research:** Historically health and medical research has often excluded women from taking part in studies, leading to gaps in knowledge about differences between women's and men's physiology, responses to treatment and experiences of care. For these reasons, survey respondents called for:

- Increasing the participation of women in research, including diverse participants
- Effort to address barriers to participation such as caring responsibilities, need for interpreters.
- Reconsider exclusion criteria related to pregnancy, medication use.

**Who is doing research:** Women are also underrepresented in the health and medical research workforce, particularly in leadership roles. Survey respondents therefore recommended:

- Prioritisation of funding for research conducted by and led by women researchers
- Prioritisation of funding for multidisciplinary research teams
- Increasing diversity of those involved in research policy making, including consumer and community representatives.

Those passionate about this work are often in small satellite research groups with little to no funding. Research funding should allow for encouraging smaller, female led research groups to encourage and sustain those who are doing work in female dominated conditions.

### [Researcher, Nurse/Midwife]

**How is research being done:** As further steps to ameliorate gender bias in health and medical research, survey respondents called for methodological changes:

- Value qualitative and mixed methods research
- Involve consumers and community members in all phases of the research cycle, including research priority setting
- Ensure sex- or gender-disaggregation in data analysis.

As ... interventions around endometriosis become more advanced over time it is essential that we understand why these interventions are important in the first place. Without insight into how endometriosis affects those diagnosed, the continuation and development of strategies aiming to solve the problems are null and void.

### [Researcher, Advocate]

Include women and consumers in co-design and co-production of research... consultation of female consumers regarding priority areas of research, including women previously not consulted such as culturally and linguistically diverse minority populations, women living with disability... Establish models that promote consumer and community involvement in research... Develop a Lived Experienced/Consumer Research workforce

### **[Researcher, Medical doctor]**

**What research areas are being overlooked?:** Participants (both stakeholders and those with lived experience) identified numerous research gaps that impacted on women's health experiences and outcomes. Under researched areas included:

- Evaluations of grassroots programs or approaches that originate in practice

There is rarely funding available in community-led programs for proper evaluation, which hinders the development of an evidence-base.

### **[Nurse/Midwife]**

- Health experiences which are exclusively or more commonly experienced by women
  - Gynaecological health: female sexual dysfunction, menstruation, menopause, chronic pelvic pain, endometriosis, polycystic ovary syndrome (PCOS), dysmenorrhea, dyspareunia.
  - Pregnancy and childbirth: medication safety during pregnancy, pregnancy loss, abortion, birth trauma, intrapartum care, labour analgesia, perinatal mental health.
  - Autoimmune conditions
  - Chronic complex syndromes: chronic migraine, chronic pain, fibromyalgia, chronic fatigue, chronic urinary tract infection (UTI), postural orthostatic tachycardia syndrome (POTS).
  - Lipoedema
  - Ehlers-Danlos Syndrome

Migraine is the second leading cause of disability globally, second only to low back pain. It is the leading cause of disability in women under 50. Despite the magnitude of the problem, we have no robust epidemiological studies of migraine prevalence in Australia.

### **[Advocacy Organisation Submission]**

- Situations where women present differently or have different experiences/outcomes to men
  - Attention deficit hyperactivity disorder (ADHD), Autism and other neurodiverse conditions
  - Heart disease, stroke
  - Narcolepsy
  - Emergency department presentations
  - Pulmonary embolism

The diagnostic criteria [for autism] does not adequately recognise the ways in which females express their autism.

**[25-34 years, individual with disability, LGBTQI+, metropolitan]**

- Conditions which are more common in men, but still experienced by women
  - Haemophilia

Gaps in research and barriers to appropriate care for women and girls with bleeding disorders have occurred due ... a commonly held but mistaken belief ... that only males have haemophilia and that females carry the gene change without symptoms. However ... 20-30% of female haemophilia carriers have reduced factor levels and bleeding symptoms, and may be diagnosed with haemophilia.

**[Advocacy Organisation submission]**

**Limited translation of evidence into practice:** Even where research evidence exists, over half of the health professionals, researchers and consumer advocates who responded to the survey did not consider research was incorporated into guidelines, implemented into clinical practice, or implemented into policy (Figure 6)

**Perception about women’s health research**

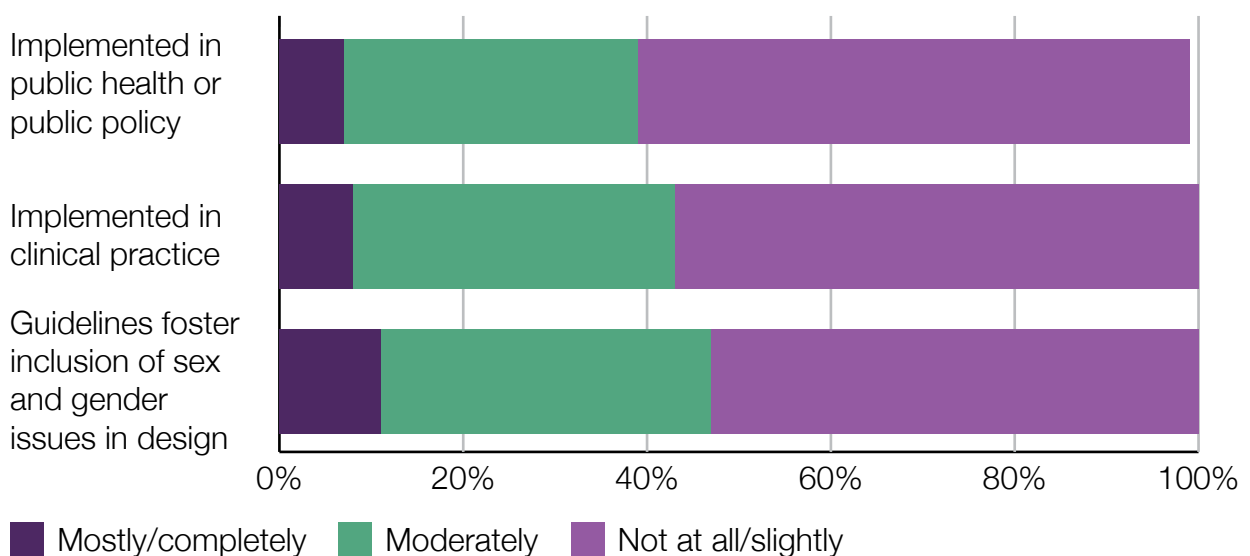


Figure 6: Perceptions about women’s health research

## **The lack of translation into practice was attributed to limited:**

- researcher capacity to communicate findings in accessible ways to key audiences
- access to latest evidence
- health workforce opportunity to conduct research, and equitable access to professional development leave (including in female dominated professions, such as general practice, nursing and midwifery)

Science communication should be encouraged, as should continuous professional development for health care practitioners. Too many are not across the latest research, which contributes to archaic ideas being perpetuated.

### **[Researcher]**

- Engagement with consumers and other marginalised voices

Consumer groups lobby health, but hit walls constantly, only to see ... waltz in being favoured and responded to.

### **[Nurse/midwife]**

- Vested interests and lack of political will to implement changes

Deeply embedded paternalistic and discriminatory attitudes towards women and female-dominated health professions ... acts as a barrier to the translation of research evidence into clinical practice. For example ... continuity of midwifery carer services”

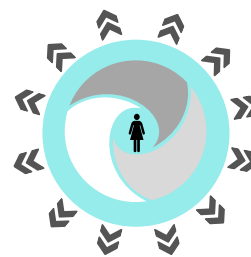
### **[Health Professional Society submission]**

- funding to implement evidence-based practice change, scale up and sustainability
- funding precarity for community-led health and wellbeing programs.



## Intersectional perspectives

Gender bias in health care – interpersonal, structural and in the evidence-base – intersects with other aspects of women’s identities to amplify impact on their experiences and health outcomes. Nine themes were generated to describe how participants experienced gender bias interacting with other aspects of women’s identities:



### Age

Older women are really invisible. Older people in general are so dismissed.

**[Advocacy Stakeholder submission]**

### Disability

[I’m] unable to access adequate women’s health care such as pap smear, breast scan and gynaecologist due to my disability and access issues.

**[35-44 years, woman with a disability, metropolitan]**

### Rurality

Women living in rural and remote locations experience geographic inequality ... For example ... difficulties accessing emergency contraception.

**[Industry Stakeholder submission]**

### Sexuality

I was to have a melanoma removed from my face ... The surgeon ... said to me in a sarcastic tone, “Why would it matter anyway you aren’t trying to get a guy?” He believed that since I am a lesbian my face can be mutilated with no consequence.

**[55-64 years, woman with a disability, LGBTQI+, regional]**

### Gender

Contamination of records based on ‘assigned sex at birth’ - this permeates referrals, prescriptions, the title ‘Mr’ being added to my name, and is often difficult to remove/correct... it is usually easier to just seek new providers.

**[25-34 years, Trans woman, Metropolitan]**

### Culturally and Linguistically Diverse

Immigrant and refugee women ... are less likely ... to take health related action when ill and have amongst the lowest rates of participation in breast and cervical cancer screening

**[Industry Stakeholder submission]**

## **Socio-economic status**

Women are more likely to experience bias due to social determinants that arise specifically due to gender [including] poverty restricting access and choice, [and] older and women being poorer.

**[Advocacy Stakeholder submission]**

## **Body weight**

[I'm] always seen as a fat woman ... I was told that I was just fat for my whole life by GPs and told over and over to lose weight WHATEVER medical issue I was seeking treatment for.

**[55-64 years, woman, metropolitan, participant's emphasis]**

## **Caring responsibilities**

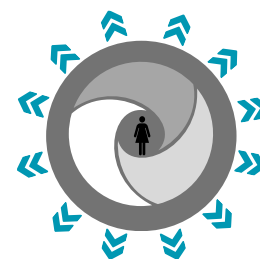
The health of primary carers is significantly impacted by their caring role. Women are 2.5 times more likely than men to be a primary carer.

**[Advocacy Stakeholder submission]**

## Gender bias has far reaching impacts

The combined impact of encountering gender bias in health care was far reaching in women's lives.

- Feelings of abandonment, shame, blame and self-doubt.
- Significant financial burden, lost educational and career opportunities.
- Delayed diagnosis and treatment leading to disease progression, fewer treatment options and worse health outcomes.
- 'Near misses' where dismissed health concerns turned out to be immediately life threatening.
- Giving up



Delayed diagnosis of endometriosis can negatively impact a woman's quality of life, including reduced participation in school, work and social activities and reduced fertility.

### **[Advocacy Organisation submission]**

In the 20 years [it took to get diagnosis and treatment] I lost so much ... I had a [full time] job in attending medical appointments... I lost confidence in my body, I lost enjoyment in sex due to pain and discomfort, and this impacted by romantic relationships. I felt a lot of shame.

### **[45-54 years, woman with a disability, metropolitan]**

Now it's over \$100 to get a prescription for my pain, antidepressants and oral contraceptives that help me live day-to-day with crippling pain. I might as well just die. I can't afford to live and be pain free at the same time.

### **[34-44 years, non-binary person, metropolitan]**

**Reclaiming agency:** Women also responded to the challenges they encountered in formal health care by accessing support online, seeking support of a trusted advocate or becoming their own advocate. Although women found this extremely helpful, it often led to further dismissal from health care professionals.

However most doctors are appalled when I said I was on the [online] forums for my support ... They are all amazing resources with ACTUAL CURRENT information ... They have in fact saved my life. All my questions were answered, and I knew I was not alone.

### **[45-54 years, woman, metropolitan]**

My boyfriend explained to the GP that I had chest pain. The GP actually believed my boyfriend ... Had I not taken a man [with me], it is unlikely I would have made it this far.

### **[25-34 years, woman, metropolitan]**

# How the #EndGenderBias Survey was conducted

The National Women's Health Advisory Council (Council) members, stakeholder organisations, consumer groups and professional bodies were asked to share information about the survey and encourage survey participation through social media, newsletters, posters, etc. An **information kit** in 17 languages was available to support promotion activities.

The online survey was developed by the Department of Health and Aged Care in conjunction with the Council, with results analysed by the Australian Women and Girls' Health Research Centre at the University of Queensland. The survey was structured in three parts:

- Women, girls and people assigned female at birth were invited to report their own experiences (Section A; 2,570 completions)
- Caregivers of women, girls and people assigned female at birth were invited to report the experiences of the person they cared for (Section B; 86 completions)
- Stakeholder experts were invited to report their perspectives (Section C; 497 completions)

Each section included closed response items on socio-demographic characteristics, health conditions and experiences of the health system. There were also 23 open ended questions that provided a wealth of insights into experience of gender bias. Many people responded in more than one section, reflecting their multiple roles.

For people reporting their own experiences, a quarter had experienced violence and/or abuse, a quarter had a disability, 22% identified as LGBTQI+, almost 8% cared for a person with a disability and 2% were First Nations Australians. Amongst responses describing someone else's experiences, a third were for someone with a disability, a quarter for someone who identified as LGBTQI+, 12% were for someone who had experienced violence, 6% were on behalf of women who were themselves caring for a person with a disability, and 6% were for First Nations Australians.

Expert stakeholders could respond either individually or on behalf their organisation. Nurses (28%) were the largest group in the individual responses, followed by researchers (23%), allied health professionals (20%), doctors (19%), health advocates (13%), policy makers (11%) and health administrators (8%). Amongst organisational responses, disability groups (27%), pregnancy organisations (25%) and groups representing low socio-economic people (25%) were all well represented, followed by LGBTQI+ groups, culturally and linguistically diverse groups, and organisations representing rural and remote areas and First Nations Australians.

To protect the privacy of respondents, only the major categories have been reported here and some response options have been aggregated.

All open-ended responses and stakeholder submissions were analysed thematically. In Part A (own experience) and Part B (someone else's experience) responses to at least one open ended question were received from 1,989 and 67 participants respectively. In Section C, 418 responses were recorded to at least one open-ended question. Participant responses to later questions often referred back to their earlier responses, and participants often referred to their own and other people's experiences in responding to questions in both Section A and B. Therefore, data from all open-ended questions in Section A and B was analysed together. Also, responses to open ended questions in Section C that related to stakeholders' perceptions of women's experiences were analysed with the relevant Section A and B data. Questions about research (from Section C) were analysed separately.

