

‘WOMEN DESERVE BETTER’ AN EXPLORATION OF THE ‘SILENT’ HEALTH ISSUES AFFECTING WOMEN AND GIRLS IN AUSTRALIA

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**SISTERHOOD
FOUNDATION**

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ACKNOWLEDGMENTS

This research was commissioned by the Sisterhood Foundation and conducted by Monash University's Health and Social Care Unit. We recognise that the Sisterhood Foundation's registered office and Australian campuses of Monash University are located on the unceded lands of people of the Kulin Nations, and we pay our respects to their Elders past and present.

We are most grateful to the women, girls and experts who participated in the study and generously shared their perspectives and experiences.

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The terms 'women' and 'girls' have been used in this research and report to include people who self-identify as a woman or girl. We acknowledge that the findings may also be relevant for trans, intersex or non-binary people assigned female at birth.

Report prepared for the Sisterhood Foundation by Monash University's Health and Social Care Unit.

FOREWORD

The Sisterhood Foundation has a proud, 14-year history of supporting Australian women and their families. Today, as the corporate foundation for Wesfarmers Health, the Sisterhood Foundation is growing its impact with a new focus on health equality for Australian women and girls. Our purpose is: **to hear, acknowledge and address the unique health issues impacting Australian women and girls.** This includes tackling issues that are not well-understood, discussed or funded.

In 2024/2025 we commissioned Monash University's Health and Social Care Unit to identify and understand the 'silent' issues in the health of Australia's women and girls.

Over 2,200 women, girls and professional experts shared their thoughts and experiences about the health conditions and social issues they believe have not received the focus and support needed for women and girls to live healthy lives. As the participants stated, 'women deserve better' and the 'silence' around many of these health conditions and social issues has often resulted in discrepancies and adverse consequences for women's and girls' equitable access to health care, outcomes, and research participation.

These important findings will assist the Foundation to support capacity building in frontline charities that deliver programs designed to create positive health outcomes in the lives of women and girls in Australia.



Emily Amos

Chair

The Sisterhood Foundation

INTRODUCTION

In Australia, we hear a lot about certain issues that affect women's and girls' lives, but what about those we don't hear much about?

We know that women and girls are impacted by many health and social issues that don't make it into the media, aren't researched and/or remain quiet among communities. This often impacts their long-term health, wellbeing, safety and ability to live well. Women deserve better.

Funded by the [Sisterhood Foundation](#), this research aimed to learn, especially from women and girls themselves, what these issues are, the impact they are having, and what should be done about them. We will use the findings to help prioritise the issues we focus on and fund.

This research had three phases – each looked at the issues affecting women and girls in Australia from different angles:



We were interested in learning more about health and social issues which **only** affect women and girls (i.e. sex-specific conditions such as endometriosis and menopause) and those which affect them **differently** (i.e. those conditions where women and girls have different symptoms such as cardiovascular disease) or **disproportionately** (i.e. those conditions which are more common among women and girls such as fibromyalgia and depression) to men and boys.

In this report, we provide an overview of what we did and what we learned from each phase. We then bring this together to highlight the 'silent' issues that came up repeatedly and what could be done about them.

This research was conducted by Monash University's [Health and Social Care Unit](#) with approval from the Monash University Human Research Ethics Committee (Project ID: 45483; 19/12/2024).

PHASE 1

WHAT IS BEING FUNDED, AND WRITTEN ABOUT?

WHY?

In this phase, we wanted to understand which health and social issues are getting research funding and being talked about in the media - and importantly, which aren't.

HOW?

We looked for the most topical issues affecting women and girls in Australia by:

- Assessing how much funding is allocated to women and girls' health issues by key Australian research funders
- Looking at research and other resources published in the last 5 years (2020-2024), and
- Analysing media items that talk about women and girls' health issues (published in November 2024).

WHAT?

1. Of all the **research funding** allocated by the National Health and Medicare Research Council (NHMRC), Medical Research Future Fund (MRFF) and Australian Research Council in 2023-2024, only 3.3% was for women's health research projects. Most of this was for projects about pregnancy, breast cancer, gynaecological cancers, physical activity and ovarian cancer. Of the 3.3% of funding, the least amount was awarded to research into obesity, chronic kidney disease, social connection/support, depression (including antenatal and postnatal depression) and stillbirth.
2. Most of the **research** from the last five years has focused on pregnancy/maternal health (e.g. perinatal care). There was less about other health and social issues including ovarian cysts, motor neurone disease, egg freezing, vaginal/vulva cancer and pelvic organ prolapse (Table 1).
3. Overall, the five conditions which received the most media mentions were abortion, violence/abuse, breast cancer, endometriosis and alcohol. Some issues were not mentioned at all in the media items we looked at, and these are listed in Table 2.

TABLE 1: LEAST PUBLISHED RESEARCH TOPICS

Overall	Affect women/girls only	Affect women/girls disproportionately	Affect women/girls differently	
			Health	Social Issues
Ovarian cyst	Ovarian cyst	Gender pay gap	Motor neurone disease	Financial literacy
Motor neurone disease	Egg freezing	Irritable bowel syndrome	<u>Muscular dystrophy</u>	Child marriage
Egg freezing	Vaginal/vulva cancer	<u>Fibromyalgia</u>	Hip fracture	Road accidents
Vaginal/vulva cancer	<u>Adenomyosis</u>	Health disparities*	Cystic fibrosis	Pornography
Pelvic organ prolapse	Pelvic organ prolapse	Gut health	Assisted reproductive treatment	Disability - physical

*Health disparities are differences or inequities in health outcomes and access between different population groups (e.g. due to gender, race, sexual orientation, socioeconomic status, geographic location etc).

TABLE 2: TOPICS WITH NO MEDIA MENTIONS

Affect women/girls only	Affect women/girls disproportionately	Affect women/girls differently
Vaginal cancer, vulva cancer, uterine cancer, womb cancer	Multiple sclerosis (MS), irritable bowel syndrome (IBS)	Chronic obstructive pulmonary disease (COPD)

PHASE 2

WHAT DO WOMEN AND GIRLS THINK IS BEING OVERLOOKED?

WHY?

In this phase, we wanted to hear what women and girls themselves feel are the health and social issues that are most overlooked. That is, the ones they think often have a significant impact but do not get the funding or attention they need.

HOW?

We invited women and girls over 16 years living in Australia to complete a short, voluntary, anonymous online survey. We used various channels such as social media, email and our networks to ensure that women and girls from all backgrounds had the opportunity to take part. We also translated the survey into commonly spoken languages: Arabic, Mandarin, Punjabi and Vietnamese.

WHAT?

The women and girls who completed the survey generally reflected the Australian female population. They were aged between 16 – 93 years (average 50 years) and most were born in Australia (74%), partnered (69%), heterosexual (90%), living in a metropolitan area (71%) and had a post-secondary school qualification (76%).

We gave them a list of issues and asked them to choose and rank the five they were most **concerned** about, followed by the five they thought were most commonly **funded**, and finally the top five they felt got the most **attention**. We then looked to see which issues were ranked one to five for each of these (i.e. the top five ranked issues) (Table 3).

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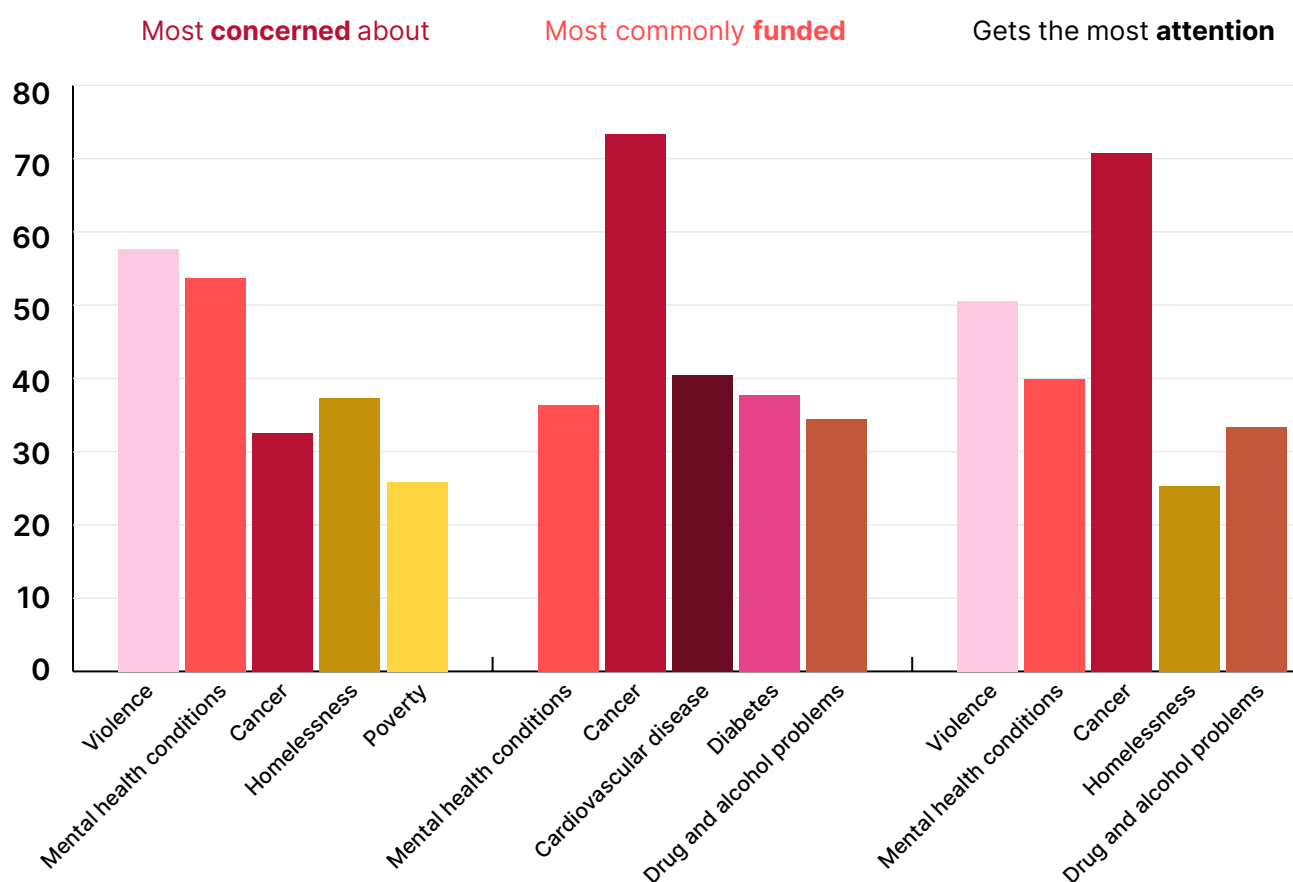
women and girls completed the survey.



TABLE 3: TOP 5 RANKED ISSUES



Figure 1: Comparison of health and social issues respondents are most concerned about, perceive as most funded, and most discussed.



PHASE 2: WHAT DO WOMEN AND GIRLS THINK IS BEING OVERLOOKED?

From there, we asked women and girls to think about what 'better' might look like – that is which conditions and issues should get more **funding**, or women and girls need **more information** about.

- The top five ranked issues women and girls felt needed **more funding/support** were homelessness, endometriosis, ovarian cancer, depression and Alzheimer's Disease.
- The top five ranked issues where women and girls felt **more information** was needed were mental health conditions, violence, menopause/perimenopause, gynaecological cancers and endometriosis.

As well as answering these ranking questions, the women and girls who took the survey also wrote comments about the issues they think are overlooked and need more attention and support. Many highlighted issues of **access** to, and **affordability** of care, especially gender responsive healthcare and care for First Nations women and girls and those living in regional and rural areas.

Endometriosis needs significantly more funding and Medicare support. Despite the new "endo" clinics, patients still have to pay out of pocket for the recommended treatments, example, pelvic floor physio / massage etc., so many women face chronic pain from this condition, it should be studied more, and have Medicare and government funded support. (Survey respondent free-text comment)

Please consider girls and women with low socio-economic status, of Aboriginal and Torres Strait Islander descent and those living in rural areas when allocating resources and how to make it easier for them to access information about various health conditions and social issues. (Survey respondent free-text comment)

Women and girls also highlighted how there was often a **lack of awareness** among both healthcare providers and women themselves about certain issues such as chronic health conditions, hardship and violence, which often means that these issues have a greater impact on their lives and wellbeing.

Perimenopause has a big gap. Women receive education at puberty and through natal periods but menopause seems to be forgotten and has a huge impact on women contributing to the workforce, caring for children and aging parents. (Survey respondent free-text comment)

It would be useful if the funding and support went towards making information more easily accessible. When I was experiencing these conditions, I found that going to my doctor wasn't enough to answer my questions and concerns, but often information online was contradictory or hard to find. (Survey respondent free-text comment)

Homelessness in the over 50's + women population really needs addressing now, not forgotten and pushed aside. (Survey respondent free-text comment)

Autoimmune diseases are silent and don't receive much media attention even though they cause so much pain and stress to those who suffer from them. (Survey respondent free-text comment)

Lastly women and girls called for more research about women's health, adding that this research should include (more) female participants.

Definitely more research is needed to the issues specific related to female bodies. Female symptoms to a variety of conditions that affect man and women are very different, yet the data available is from research conducted in men. There are far more health issues affecting women and girls which are overlooked and passed by as 'normal' whilst causing a lot of suffering to those affected. (Survey respondent free-text comment).

PHASE 3

WHAT DO EXPERTS THINK IS BEING OVERLOOKED?

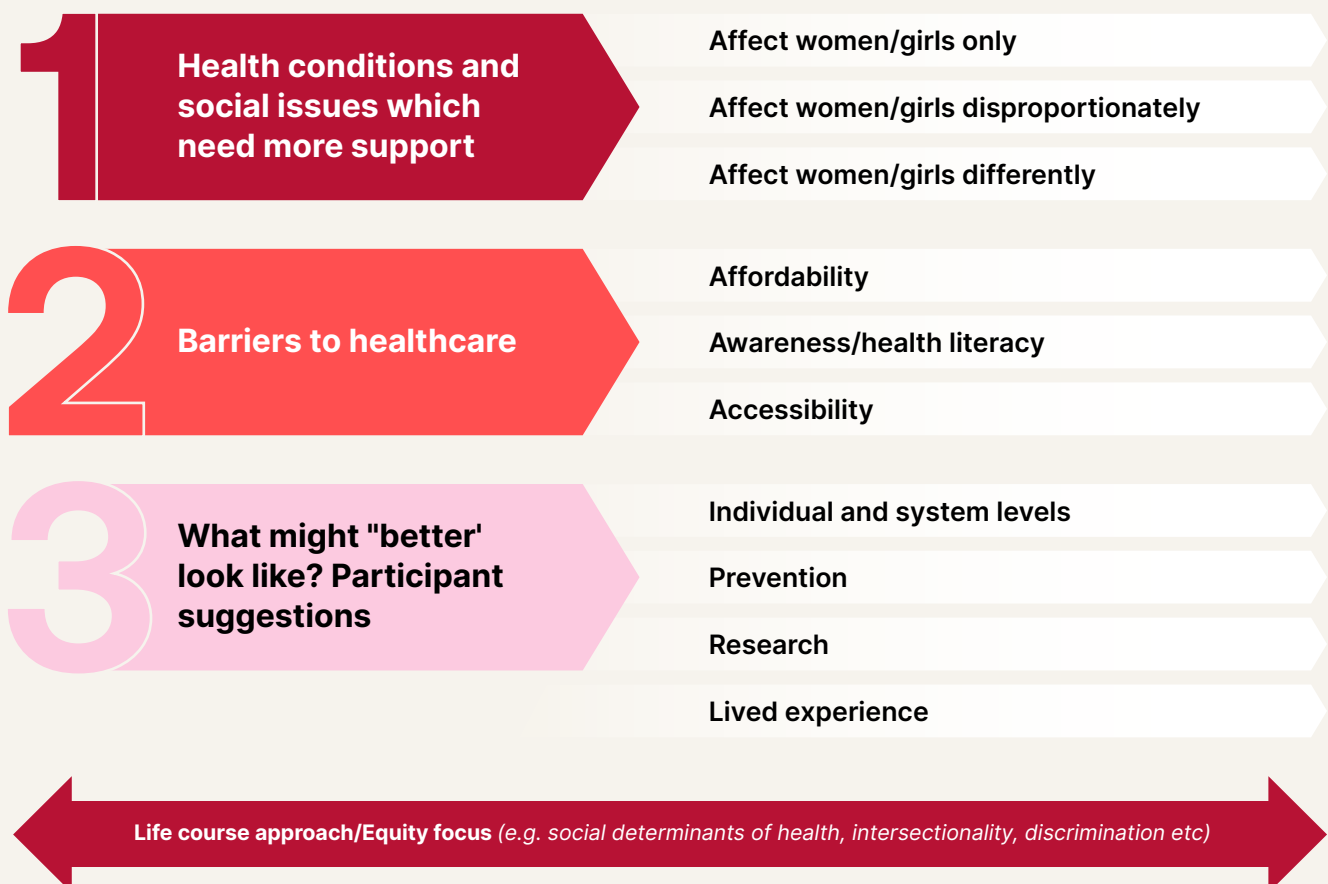
WHY?

In this phase, we wanted to hear what experts working in and researching women and girls' health think needs more attention and support.

HOW?

We interviewed 23 professionals from a range of backgrounds, including healthcare providers, academics, policy makers and leaders from non-government organisations and health services. The interview participants spoke about three main topics (Figure 4).

Figure 2: Interview themes and subthemes.



WHAT?

1 Health conditions and social issues which need more support

Many of the experts we spoke to emphasised that women's and girls' health is more than just sexual and reproductive health and breast cancer, with one expert highlighting that we 'need to go beyond the bikini line'.

They called for greater attention, funding and support for issues that affect women **only**, as well as those that **disproportionately** affect women and girls, or affect them **differently**.

1. Affect **only** women and girls

The experts talked about a number of issues such as endometriosis, peri/menopause and abortion where, although awareness levels are growing, more is needed to help the growing number of women and girls impacted.

Endometriosis is still not understood. And, you know, we barely use the name, you know, except for the last few years. So I think that's one [health condition which is having an impact on women and girls, and means that they can't live healthy lives]. (Interview participant #5)

Domestic violence is an interesting one, because it's, obviously, it's, you know, it's a priority area. There's a huge, there's a lot of investment in it, it has huge impacts, but I would almost say there's not enough investment at the same time, because the stats aren't changing. (Interview participant #3)

2. Affect women and girls **disproportionately**

The experts called for more acknowledgement of, and support for issues that affect a greater proportion of women and girls than men and boys, such as body image, eating disorders, body literacy (especially for young women and girls); mental health conditions; and chronic health conditions such as fibromyalgia.

So I think if you talk to most women about women's health, they'll go, 'oh yeah, it's menopause and it's endometriosis and it's

having babies and it's breast cancer' yeah, you know. And they might rattle off a couple of other different things, but, but actually it's women have more back pain. 70% of migraine sufferers are women, about 80% of fibromyalgia sufferers are women. Autoimmune diseases affect more women. So I think we've actually got to really get past this very narrow understanding of women's health as sexual and reproductive health. (Interview participant #15)

3. Affect women and girls **differently**

Lastly, the experts felt that a range of conditions that affect women and girls differently to men and boys and have been overlooked for too long. These included violence against women and girls (especially where this leads to head injuries), mental health conditions, cancer screening (especially for lesbian, gay or bisexual (LGB) women) and bowel screening (for young women), cardiovascular disease and dementia.

A specific health impact of domestic violence is head injuries, repeated head injuries. ... Now, if a football player gets a head injury, life stops until they're well, and they don't go home to nothing. They have repeated visits to neurologists. They have all this stuff. We have a brain bank of rugby players, and no one is looking at the head injury impact [of the large number of women who have experienced domestic violence]. And if women are keeping the rest of the community well, and a 30 year old woman has a brain injury profile that means she is not functional and now she's drinking or now she's God knows what ... Because it is repetitive, it is invisible, because no one outside the community knows that. Yeah, no one's collecting the data. ... But to me, it's head injury, violence, yeah. The domestic violence you've got all the, you know, all the other injuries that happen, but I think head injuries are having the most impact. ... we're not looking at this long term injury [head injuries]. ... Yeah I mean a rugby player at 45 with a brain disorder is a tragedy, but a woman at 30 with a brain injury is invisible. (Interview participant #4)

2

Barriers to healthcare

Although many women face challenges accessing the care they need, the experts we spoke to thought that some groups of women and girls face greater barriers, and these barriers need addressing. These groups include First Nations women and girls, those who live in regional and rural areas, migrant or refugee women, younger women and teenage girls, and women with different sexual orientations.

I really do think that young girls and young women who have mental health issues or intellectual disabilities, physical disabilities. I think for those women and girls, accessing health can be very, very daunting. Women who come from a non-English speaking background, Aboriginal Torres Strait Islander women, I think, you know, there's sort of those specific groups that, you know, we always tend to recognise that, you know, healthcare is not equitable, and their ability to navigate the healthcare system is significantly reduced compared with a, you know, a white, middle aged or a white privileged woman who can sort of work out more easily what services are available and what she can access. And is able to advocate for herself. (Interview participant #10)

Racism and sexism, and the way those intersect in terms of being able to get care, like, regardless of what kind of issue you're facing that will basically always affect the way you're able to like respond, whether that's whether you're able to feel empowered to go and seek help, or whether you're treated with the kind of respect that you think you deserve. And it's different depending on different communities for people like they're all going to have different experiences. (Interview participant #8)

- Increasing **awareness** of and **education** about the issues experienced by women and girls.

I think providing good education is the thing that I would, I would focus on, and then actually using that as a platform, you know, to then sort of talk about disease specific conditions or that kind of stuff. But I think even just giving young girls and young women a better understanding of their bodies and what their reproductive system is actually about. I think sometimes we just assume that people know what we're talking about. But yeah, I don't think they do. (Interview participant #10)

- **Including** women and girls in designing and implementing any research, program or initiative that aims to benefit them.

In order to change [healthcare] guidelines and change the understanding of health provision, we need evidence and evidence base and, and in order to have an evidence base, we need to actually include women in trials. Yeah, so women are vastly underrepresented in all cardiovascular trials and, and that, that's been a long-standing issue. (Interview participant #12)

I'm going to be really honest and say, for the Aboriginal communities in remote areas, it's probably better asking Aboriginal communities ... And maybe actually Aboriginal Health Workers and practitioners. (Interview participant #4)

3

What would 'better' look like?

Agreeing that 'women deserve better' the experts we spoke to offered suggestions about what this might look like. They included suggestions about:

- Striving for **equity**, where all women and girls are able to access high quality, timely, affordable, gender responsive healthcare; and be healthy and well. This included the need to recognise that different things impact women and girls at different times – some are outside of their control (i.e. cultural background, sexual orientation) and some have a cumulative effect throughout women's lives.

BRINGING IT ALL TOGETHER



Overwhelmingly the women, girls and experts we spoke to said that women and girls' health is more than just their sexual and reproductive health. They agreed that all issues affecting them are important, and that 'women deserve better' so they can thrive.

However, by bringing our learnings from all three phases of this research together (Table 4), we can see that some issues came up as particularly 'silent' or overlooked in all phases, and have negative impacts on many women and girls.

We can also start to see what may help ensure women and girls can live healthy, happy and safe lives. We see what the areas needing greater focus and action are. This includes increasing awareness and education for women and healthcare providers; improving access to high quality, affordable, gender responsive healthcare; co-designing research, programs and interventions with women and girls themselves; and further research to increase our understanding of sex and gender differences in health conditions and care.

Health condition/social issue	Desktop review	Survey	Interviews	Prevalence (Australian women)
Affect women/girls only				
Endometriosis		✓	✓	14% ^a
Menstruation		✓		
Peri/menopause		✓	✓	
Abortion		✓	✓	25% ^b
Affect women/girls differently and/or disproportionately				
Violence (especially health effects of intimate partner violence)		✓	✓	27% ^c
Mental health (including depression)		✓	✓	45% ^d
Fibromyalgia	✓	✓	✓	5% ^e
Cardiovascular disease	✓	✓	✓	5.8% ^f
Body image/literacy and eating disorders		✓	✓	
Healthcare provider awareness and dismissal of symptoms		✓	✓	
Healthcare costs/access		✓	✓	

^a [AIHW](#) (2023); ^b [Children by Choice](#) (2025); ^c [AIHW](#) (2023); ^d [AIHW](#) (2023); ^e [Better Health Channel](#) (2024); ^f [AIHW](#) (2024)

CONCLUSION

This research has helped us better understand the inequities women and girls living in Australia experience when it comes to their health and wellbeing. In doing so, it has shone a light on the health conditions and social issues that need (more) recognition and support.

Working together with our partners and collaborators, as well as women and girls themselves, we will take these women's voices and use them to help us with our Foundation's decision-making and priority-setting. With our goal of **hearing, acknowledging and addressing**, we will share these learnings broadly, so that all Australians can be involved in addressing the "silent" issues impacting women and girls' health. They deserve better.

**CONNECT WITH US TO FIND OUT MORE ABOUT
THIS PROJECT, OR OUR WORK GENERALLY.**

Katie McLeish

Executive Officer, Sisterhood Foundation
katie.mcleish@wesfarmershealth.com.au

priceline.com.au/sisterhoodfoundation

**REPORT PREPARED FOR THE SISTERHOOD
FOUNDATION BY MONASH UNIVERSITY'S
HEALTH AND SOCIAL CARE UNIT.**

**Dr Sara Holton
Haimanot Hailu
Mitchell Bowden
Professor Helen Skouteris**