

22nd August 2024

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Senators,

Re: Senate Standing Committee on Community Affairs: Issues related to menopause and perimenopause

Thank you for hearing our evidence highlighting the urgent need to understand intersectional¹ experiences of the menopause transition in Australian society, through inclusive and culturally appropriate methods.

During the hearing, Senator Pratt requested that we review the methodology and findings of the 2023 National Women's Health Survey (NWHS)², commissioned by Jean Hailes for Women's Health (JHWH), to understand the extent to which that study represents the experiences of priority populations (Social Research Centre, 2023). Senator Pratt also requested we provide details of different research methods we suggest for engaging with priority populations.

The Australian Government defines priority populations³ as Aboriginal and/or Torres Strait Islander people, culturally and linguistically diverse people, people with disability or mental health concerns, lesbian, gay, bisexual, trans/transgender, intersex, queer, and/or other sexuality (including asexual), gender and bodily diverse people, people living in rural, regional and remote areas, and low socioeconomic groups. With regards the menopause transition, we suggest that people experiencing homelessness, family and domestic violence and/or the effects of climate change, as well as people who are incarcerated, and all other peoples impacted by poverty, be considered as priority populations. Emerging research also identifies that those experiencing the menopause transition whilst working in non-office and male-dominated employment spaces, as well as in casual positions or the gig economy may also be particularly impacted by symptoms themselves and the interaction of these symptoms with the socio-cultural-economic environment (Barrington et al., 2024; Hobson & Dennis, 2024; Yoeli et al., 2021). Many individuals identify with several of these priority groups, and these identities intersect in ways which are often unique to their circumstances and can contribute to negative experiences of the menopause transition.

We have reviewed the NWHS Technical Report (Social Research Centre, 2023) and taken the time to discuss the study with the CEO of Jean Hailes, Dr Sarah White, as well as considered the many potential research methods we recommend for understanding and improving the experiences of priority populations experiencing the menopause transition.

¹ 'Intersectionality' recognises the interconnected nature of many social categorisations and identities that individuals and communities live with, and which influence their experiences (see Crenshaw, 2017)

² <https://www.jeanhailes.org.au/research/womens-health-survey>

³ <https://www.health.gov.au/resources/publications/national-preventive-health-strategy-2021-2030>

Sampling and recruitment of priority populations

2023 National Women's Health Survey: Who was reached?

The NWHS is conducted annually, although the topics included vary each year. In 2023 the survey included a module on menopause. The survey itself was conducted by the Social Research Centre⁴ (SRC), who randomly recruited participants via their Life in Australia™ panel, with invites extended to 1953 panel members who had previously indicated that they were assigned female at birth (1553 surveys completed). To increase the number of responses and allow stratification of certain sub-groups, the Online Research Unit⁵ (ORU) was engaged. Via non-random sampling, ORU invited 8075 panel members, and filtered by those who had been assigned female at birth (2017 surveys completed).

The survey included a module on demographics, where respondents were asked questions regarding topics such as their sexual orientation and marital status, living and housing situation, and employment. However, when discussed with JHWH⁶, Dr White indicated that SRC did not use data from the demographic module (other than an attempt to use the languages other than English data, and identification as Aboriginal or Torres Strait Islander, discussed in the next section) in statistical tests regarding the menopause transition. Results concerning socioeconomic status, etc., were based on Socio-Economic Indexes for Areas (SEIFA), i.e., postcodes of respondents, not self-identified livelihood variables.

Who else do we need to hear from?

As noted by the authors of the NWHS report and JHWH⁷, analysis of sub-populations other than age brackets and a binary measure of economic (dis)advantage based on SEIFA was not possible. Although SRC and JHWH designed stratified sampling to enable the sub-analysis of women speaking a language other than English at home, on further analysis this sub-group of respondents was skewed young and did not represent this segment of the Australian population. The authors also stated that there is a need to investigate impacts of the menopause transition at work across more sectors, and that the number of participants who identify as Aboriginal and/or Torres Strait Islander was inadequate to run sub-analysis:

Further studies – recruited by random sampling and stratifying data by verified menopause symptoms – across different sectors and levels of management are needed to differentiate the true impact of perimenopause and menopause on women in the workplace from other causes of midlife stressors... Greater action is urgently needed to work with priority populations... women from multicultural communities; women with disability; lesbian, bisexual or queer women; people assigned or presumed female at birth, and; Aboriginal and Torres Strait Islander women ... to understand their knowledge and information needs and co-design culturally intelligent health promotion approaches to better manage menopause symptoms and seek care when required. (pg. 33, Social Research Centre, 2023)

Although we agree that priority populations have not been heard in the NWHS, we disagree that random, stratified sampling is the only way to recruit these important voices. To be recruited by the methods used for the NWHS, participants needed to be comfortable sharing their personal data to a research panel database and/or answering a phone/SMS message from an unknown entity. In addition, even though SRC and ORU have strict procedures in place to protect participants' data, many members of the public distrust such systems, and may thus have chosen not to be involved on this basis. It is likely that purposeful sampling of priority populations, through relationship development with relevant leaders, will be necessary to recruit individuals and ensure a deeper understanding of their experiences.

⁴ <https://srcentre.com.au/>

⁵ <https://www.theoru.com/>

⁶ Dr Sarah White, Jean Hailes for Women's Health CEO, *pers comm*. 19th August 2024

⁷ *Ibid.*

Research methods and priority populations

2023 National Women's Health Survey: How and what were respondents asked?

Respondents recruited via the Life in Australia™ panel could complete the questionnaire over the telephone or online; those recruited via ORU were required to complete the questionnaire over the phone. It is possible this impacted on the participation of some potential participants, e.g., people who are incarcerated, people who are uncomfortable speaking about sensitive topics over the phone.

The authors of the NWSH and JHWH⁸ are clear that the items within the questionnaire do not refer to verified perimenopause and menopause symptoms, but those which respondents considered linked to menopause. Specifically, respondents were asked “D4. In the last five years, have you been bothered by menopause-type symptoms, such as hot flushes, night sweats or difficulty concentrating?” Possible responses to this were “Yes,” “No,” “Not sure,” or “Prefer not to say.” If a participant selected “Yes”, they continued the menopause module of the survey. However, if they gave a different response, the skip logic suggests they were not asked further questions about the menopause transition (including questions about whether they had consulted a doctor).

“Yes” respondents

Respondents who answered “Yes” to the question were asked briefly about the impact of the symptoms they attribute to (peri)menopause on work, study, exercise and other daily activities, mental wellbeing and relationships. Responses to these questions about everyday life were largely predefined, so it is possible that there were impacts felt by respondents but not captured by the survey. The predefined answers also did not allow respondents to indicate the severity of their symptoms or their impacts.

“No,” “Not sure,” or “Prefer not to say” respondents

Hot flushes, night sweats and difficulty concentrating can be symptoms of the menopause transition, but there are many other (peri)menopause symptoms⁹ which respondents may have experienced, but which did not compel them to answer “Yes” to question D4, due to, e.g., the inclusion of only those three symptoms in the text, or because education on the menopause transition is known to be inadequate, with many people experiencing symptoms without knowing they can be attributed to (peri)menopause. Emerging research suggests that for more educated women, particularly those with job flexibility, vasomotor symptoms (i.e., hot flushes and night sweats) are their greatest concern at work, but for those in lower status jobs or with limited flexibility, musculoskeletal pain is more problematic (Yoeli et al., 2021). Such pain may not have been captured in the NWSH.

In addition, by not answering “Yes” to D4, respondents were then not asked the questions about how (peri)menopause symptoms impact their lives, e.g., if a person experienced anxiety due to (peri)menopause, but answered “No” to question D4, the impacts of their anxiety on everyday life would not have been captured. Similarly, this person would not have been asked whether they had consulted a doctor about their experience of anxiety as a symptom of the menopause transition.

We note that there are only so many questions/options that can be included in a quantitative survey, due to, e.g., participant fatigue and cost. The NWSH does give an indication of the occurrence of some impacts of (peri)menopause-attributed symptoms on everyday life. However, it may underestimate occurrence and severity of these symptoms and their impacts due to the wording and skip-logic of question D4, as well as the predefined responses of other questions. Thus, the NWSH may not expose many of the ways that people experience (peri)menopausal impacts.

⁸ Dr Sarah White, Jean Hailes for Women's Health CEO, *pers comm*. 19th August 2024

⁹ <https://www.menopause.org.au/health-info/fact-sheets/menopause-what-are-the-symptoms>

How and what should we be asking priority populations?

Whilst quantitative work such as the NWHS is important and useful, possible responses were pre-defined and did not allow for qualitative responses of the diversity of lived/ing experiences. Although quantitative studies allow for larger numbers of respondents, they lack the depth of qualitative work, which we argue is necessary for understanding the lived/ing experiences of priority populations regarding the menopause transition.

There is a need for qualitative (or mixed method) research tools that allow participants to 'write in' symptoms which they associate with the menopause transition (or which at least provide a full list of the symptoms clinicians currently agree on), and to speak about the impact and severity of these symptoms on parts of their lives beyond those which have been predefined. Research into experiences of the menopause transition that consider not just physical and mental symptoms, but their interaction with the socio-cultural-economic environment, and the intersecting identities of individuals, is in its infancy, and studies which predefine possible responses may thus be 'missing' part of the puzzle.

We argue that there is a need to use a range of participatory research methods (these tend to be largely qualitative, but often with quantitative components) so that people with intersecting vulnerabilities and identities can share their lived/ing experiences. It is important to reach these sub-populations, but more importantly to obtain valuable lived/ing experience data which is often unattainable in large quantitative studies. Participatory research engages sub-populations through various methods, is often relational in nature while maintaining rigorous design, and is tailored to specific groups and localities, taking into account that:

- People from diverse and minority backgrounds, including those with intersecting identities (race, sexuality, disability, etc.), often experience (peri)menopause differently due to cultural, socioeconomic, and health access issues. Current large-scale quantitative studies do not adequately represent these populations, leading to a lack of understanding of their specific needs.
- A class focus is important in data collection processes, as Senate Inquiries and research often centre on middle to high-income populations (including data collection methods favouring these groups, e.g., written submissions and verbal evidence in formal proceedings), overlooking the significant impacts of menopause on low-income individuals. This focus results in a gap in the data, missing critical insights from those most affected by socioeconomic circumstances.
- Quantitative studies fall short in capturing the depth of emotional, psychological, and cultural dimensions of menopause. Qualitative research is essential for exploring these areas with people themselves, to provide a richer and more comprehensive understanding of the menopause transition.
- Understanding individual experiences over time needs longitudinal research to capture the longer-term implications of menopause, something qualitative methods are well designed to address.
- Qualitative research employs a range of methods tailored to diverse populations. Some individuals prefer to talk, rather than type, while others may benefit from photoshopping or storying to share their unique experiences. Participatory research methods ensure the voices of those who are otherwise overlooked are included in developing better interventions, including education and workplace practices.

Mixed-method participatory studies, combining quantitative and qualitative research, provide comprehensive insights, enhance validity, present rich data, allow for triangulation and more. For example, a study by Sydora *et al.* (2021) provides an illustration of a mixed-methods approach where First Nations women in Canada actively participate in research studies, including devising research tools specific and applicable to their experiences. An important outcome in this research was it providing a

method for capturing the voices of women and starting a dialogue for raising awareness and understandings of (peri)menopause in communities where often such topics are considered private or taboo. Quantitative research methods complemented this study by providing demographic information for further exploration.

Other participatory research approaches include, e.g., Community-based Participatory Research (CBPR), Action Research (AR), Photovoice, Narrative Inquiry, Co-design and Co-Creation, Open Dialogue, World Cafe, and Emancipatory Research (Duea et al., 2022 provide a good overview of participatory methods and their applicability). Participatory research approaches aim to engage with community members as equal partners in the research process and are democratic in nature, with outcomes representative of the targeted population group, with participants invested in developing the outcomes and implementing changes that are directly applicable to them (Vaughn & Jacquez, 2020). Central to such approaches are their emancipatory potential for participants, increased relevance and applicability to the participants. Buy-in and sustainability are often significant outcomes, alongside contextual knowledge and capacity building.

Research into experiences of the menopause transition is desperately needed throughout a variety of contexts and across Australia. We call for the allocation of a dedicated funding source for research into the menopause transition that is competitive and independently assessed. It must fund both qualitative and quantitative research, with resources specifically targeting understanding and improving the experiences of Australia's priority populations.

We trust that the evidence we have provided here, and during our verbal evidence, will contribute to recommendations by the Committee which will assist in improving the lives of all people experiencing adverse impacts of the menopause transition in Australia.

Sincerely,

Dr Dani Barrington and Dr Antonia Hendrick

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