

SENATE INQUIRY ON MENOPAUSE

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Submission to the Standing Committee on Community Affairs, Inquiry into issues related to menopause and perimenopause.

Dear Senate Inquiry Committee,

As a medical researcher in clinical trials & health data, perimenopause still absolutely floored me when it hit in 2021. My following submission is therefore strongly supported by my research expertise but absolutely driven by lived experience. The two together impassion me to power change across every facet related to the peri-/menopause journey. The below summarises my views on core issues but also where I know my VITAL registry can make the most immediate difference with your support. Even more will come from collaborative efforts with other advocates as we work towards better outcomes together.

The current problems with menopause in Australia:

1. Lack of knowledge – relevant to Inquiry points e), f), g) & h). You can't treat something if you don't know what's wrong, nor if you're not listened to, nor if you're scared to speak about it, nor if you can't afford being shunted around our medical system in a blind search because no-one has sufficient training or education, nor if our research/policy systems continue to reward siloing & academic record over innovation.
2. Immediate Individual Impact – Inquiry points b), c), d). Our medical system, like our research system, is very siloed, yet our body systems are not. Decreasing hormones can be detrimental to every part of our bodily function, & whether symptoms are physical, mental, emotional or a combination, we need advocates to consider the peri-/menopause experience as a whole. We have medical, research and political systems that reward competition, nepotism and exclusion, whether it be via non-competitive grants, promotions or positions via "expert" recommendation, or inter/national recognition and reputation (committees, track record etc). Our "best" should however be considered those that meet external KPIs for translational outcomes that actually improve community health, and this means collaboration should be central.
3. National long-term impact – Inquiry points a), h), j). All of the above are impenetrably intertwined, & so too their combined long-term impact on our society. Without broadly spread and accurate

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knowledge of menopause (point 1) we can't recognise its immediate individual impact (point 2) and therefore can't develop effective national nor local policies to improve the experience & outcomes for 13 million Australians.

One of my greatest concerns as relevant to the above, is the new & seemingly increasing trend to use the term "catastrophising" in relation to menopause. The traditional stigma applied to peri-/menopause and concept of the "hysterical woman" have led to the "put up and shut up" attitude that has prevailed for decades. As a society we wouldn't dream of applying that same attitude to similar conditions such as diabetes or thyroid deficiencies where hormones also stop naturally. Nor would we ever apply a word such as "catastrophising" to their rightful expectations and requirements for individual education, community understanding, clinical training, and appropriate, evidence-based treatment and care at the time of diagnosis and worsening symptoms. The provision of the above for these other conditions have and continue to enable people to get themselves sorted then get on with life, recognising they too may require lifelong medication to avoid or diminish their symptoms. *Exactly as with menopause.* By such skewed logic, it is similarly 'catastrophic' that we educate and treat our community for high blood pressure, cholesterol, and so many other bodily changes that are part of our natural lifespans. Insisting on minimum levels of care and education to improve both individual quality of life but also our societal and economic return at a national level is the least we should insist on as a first-world community and it is abhorrent to me that this terminology is being used. **The "catastrophe" in this situation is that we're not already providing the core tenets of care in this space.**

The solution to improving menopause in Australia:

#1 – DATA.

#2 – COLLABORATION.

#3 – SUPPORT (financial/policy).

How VITAL [<https://bespokeclinicalresearch.com.au/vitalimpact/>] addresses these:

My title for this section is chosen deliberately. As alluded to above, Australian research systems (funding and political) reward certainty. Grants, award recognition, and career progression are all dependent on your research-specific reputation and track record, both of which are built by your networking with others "ahead" of you. Even grant opportunities targeted as "Consumer-Led" score the experience of the team as *per their academic research track record and publications* irrespective of expertise in real world outcomes – eg. menopause-specific clinicians & actual community-based consumers aren't ideal. Observed experience shows that promising a singular "solution" is what gets researchers funding & the ear of policy-makers. BUT....

Research is all about what we don't know. Science is recognising the gaps, stipulating hypotheses, exploring truths and revising our understanding, our plans, & our policies. In the case of peri-/menopause and preparation for Peta Murphy's inaugural federal Parliamentary Roundtable on menopause (March 2023), feedback from moderators of a meno-specific private Australian social media group (>25,000 members then, >34K now) requested that reduced workforce participation be specifically mentioned as a big public concern. This was originally dismissed by certain experts in the group who refused to mention it as "there was no evidence" this was a problem, rather than considering that international evidence existed (not conducted by their own siloed network). The Australian perimenopausal community identified this as an important research and knowledge gap; we need to respect there are many gaps and (current) researchers in this space do not know what they don't know.

Resolution of both current & future problems in menopause will result from gathering data, collaborating on its use, financially supporting foundational platforms, & driving improved outcomes via policy change. This is our VITAL purpose.

VITAL - In 2021, I first realised what was actually happening to me in experiencing perimenopause, how little was known about it in the community, how scarce the healthcare professional training provided, how dismissed and stigmatised it was in terms of cultural, clinical, workplace and policy considerations, and simply how this wasn't good enough by any measure. In 2022, after managing to get my own symptoms under control, I started using my uniquely-formed research expertise to do something about it.

In any clinical or research space there are hundreds if not thousands of questions we could ask, *which is why consumer engagement has been an ever-increasing requirement* over the last decade or so. In peri-/menopause this is even more so given the number of life factors (physical and beyond) that are affected, the consistent stigma and prior lack of focus and funding for this area, and the constant in clinical research everywhere that those who are studied are those that can be accessed for study. Menopause research has to date has thus been limited to the academic or clinical focus areas of high track record, with such research conducted within limited subpopulations unfortunately not representative of the entire Australian population.

VITAL is the Virtual registry of Peri-/Menopause in Australia. I designed VITAL, a global first, as a researcher with lived experience, to be community-driven as to the real needs and impact of the Australian peri-/menopause experience, and to encompass collaboration with and for all. Over 2022 and 2023 I reached out to stakeholders across the country – plus key internationals – to draw on the expertise of others, not just the typical clinicians and researchers, but community organisations and individuals as well. My only condition is that those involved in VITAL be **COLLABORATIVE** (AKA SOLUTION PART #2), so that over time we can save the constantly wasted time and health dollars in reinventing the wheel and/or not asking the right questions. The VITAL registry is effectively an ongoing **DATA** (AKA #1) survey where:

1. We ask everyone questions - whether personally in peri-/meno, or a friend, family-member, colleague, clinician, policy-maker or other.
2. We ask everyone for feedback – what have we not asked, what should we be clearer on, what conditions need to be met (e.g. optional anonymity) for certain answers, how should we use this information, how can we do better
3. We ask everyone if they want to get involved – whether on a VITAL working group, sharing their own story, as a future research participant, or many other methods
4. We provide a safe and unbiased data platform towards better menopause care across the country and the world, so that the key questions can be asked, answered without starting from scratch, and enhanced by collaborative specialist expertise.

To date, VITAL is yet to receive a cent in financial support. Despite this, through passionate advocacy, word-of-mouth, and volunteered time alone, VITAL has amassed >1300 participants, **almost 600,000 data points**, and >300 stakeholders across the country. **Incredibly, VITAL has also gathered >5750 comments of lived experience feedback in only 7 months of conduct.*** VITAL is listed with the World Health Organisation registries clinicaltrials.gov and ANZCTR; has been reviewed & approved by an NHMRC-accredited Human Research Ethics Committee; complies with the national recommendations for Clinical Quality Registries by the Australian Commission on Safety and Quality in HealthCare; has enhanced education via international, multidisciplinary conference dissemination; and is the only known project in the world in which community participants are **explicitly credited for every output via a VITAL-specific “doi”**. A “doi” is a unique “digital object identifier” that provides a persistent Internet link more permanent and reliable than a URL, **enabling participants to freely (and anonymously) access a current list of activities supported by their participation**. Meanwhile an established - and self-pronounced “leading” – Australian Women's Health group have received >\$20million in non-competitive public-taxpayer funding in just the last 5 years, with no apparent KPIs, no measurement nor clear public reporting of outcomes, and still conclude “if the effort going into monetising menopause went into tackling the misogyny and ageism that make the transition so unwelcome,

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we might actually get somewhere”. Imagine what breakthroughs VITAL could unlock across the country with priority funding allocation, transparent & accountable reporting, & the political **SUPPORT** (AKA #3) to help us help ourselves.

The bare basics are that as a supported, ongoing, community-driven, responsive and collaborative registry, VITAL can provide the facts needed to improve menopause education, care, & policy in Australia on a continual basis. **My initial Recommendations to the Senate Inquiry Committee** are listed below, but we’re limited only by what we think to ask. E.g. data-driven broad improvements in:

- Education: Improved recognition of symptoms by both community and healthcare professionals, less stigma, better understanding of cultural differences in approach, development of better workplace and healthcare policies, less economic and knowledge loss via early resignations or decreases in workplace participation (productivity, FTE, sick leave, seniority level, specialist outputs).
- Research: Improved understanding of the menopause experience that actually is representative of our population, enabling determination of a more accurate Australian incidence and relevance, better direction of research efforts to more meaningful health outcomes for community, improved and collaborative co-design with those with lived experience.
- Policy: Optimisation of overarching healthcare delivery and surrounding policies via: improved knowledge of menopausal healthcare needs e.g. GP vs specialists, methodology e.g. telehealth vs F2F vs combination, accessibility e.g. timing vs location vs financial, impact e.g. symptoms vs responsibilities, support and communication e.g. cultural, societal and community

More specifically, short-term changes that Australia needs to improve menopause include:

- Communication – determining what are the preferred methods of communication of our a) perimenopausal population, b) clinical workforce, c) workforce policy-makers, and adapting the different types of necessary education appropriately to e.g. podcasts, online workshops and “white paper” reports.
- Support – determining the support preferred by our perimenopausal population directly from they themselves for:
 - a) healthcare, e.g. 1st meeting face-to-face, all virtual, anything that gets you seen sooner,
 - b) workplace, e.g. flexible hours/location, role and appointment adaptivity per pregnancy, protection from bias-derived career penalties, and
 - c) societal respect including financial & political support of the activities needed to successfully implement the above, e.g.
 - i. financial and/or political support only given subject to externally-decided clear & measurable KPIs specific to improved and relevant community health outcomes,
 - ii. stronger and broader research support and national committee positions, not automatically given to the “usual suspects”, with opportunities broadcast in such a way so as not to advantage only large/specialist institutes that can devote FTE to searching ‘the small print’ and bearing the administrative burden for such,
 - iii. menopause not subsumed under broad “women’s health” banners meant to cover everything with very little, enabling better development of evidence-based menopause-specific care to counteract the growing “menopause market” where entrepreneurs are making money filling the gaps that evidence-based care is not, with no or little evidence of improved outcomes,

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- iv. clinical care enhanced via longer Medicare-supported health appointments, methodologies per community-requested need, and increased multidisciplinary undergraduate and post-graduate training for healthcare roles, including pharmacy,
- v. prioritisation of women's health and economic success via a National Menopause Action Plan and enforced, informative reporting of gender workplace levels for any organisation receiving governmental financial or political support e.g. not just 56% of all staff are women, but also split down to: 80% of female staff are on the lowest 3 role levels with only 20% in the senior 2 levels.
- vi. Proper health economic evaluations of introducing menopause-related changes. These include but are not limited to: implementation of a menopause-specific safety net (all related treatments, scripts, appointments under specific DRG or other code, with costs decreasing once an individual reaches the annual limit); full MBS/PBS approval system revamp; and the workforce and clinical changes suggested above, versus the clearly phenomenal health economic savings of maintaining long-term workplace and societal involvement and consequent financial impact on individual & society. E.g. superannuation, increased quality of life, decreased adverse events from modern medications, significantly diminished lifetime disease risk (proactive hormone supplementation decreasing cardiac, mental ill health, diabetic, and dementia development) and thus optimised healthcare utilisation & minimised costs including length of stay, QALY's, DALY's etc.

VITAL provides the cost-efficient and collaborative platform for foundational data collection to address the above goals and subsequent activities,** whether you might be a clinician in Sydney, researcher in Adelaide, workplace specialist in Perth, PhD student in Brisbane, member of the International Menopause Society, or a policy-maker in Canberra.

I sincerely thank you for your time and consideration and welcome any questions or further discussion you may wish.

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Bespoke Clinical Research

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<https://bespokeclinicalresearch.com.au/vitalimpact/>

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*Confidential and anonymised VITAL data available upon request, e.g. a 2-month grouping of VITAL perimeno entries reported **19.4% with suicidal ideation**; raw data shows hot flushes were not even in the top 5 of reported symptoms despite common perception; aggregated feedback targets lack of community, societal, and clinical understanding; etcetera.

**A range of additional questions of early interest to myself and collaborators are listed in a confidential appendix available upon request. The confidential status is required since these concepts and collaborations are what will drive any future funding of VITAL and thus further progression of its goals and subsequent activities on behalf of the Australian perimeno community.