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Department of the Senate
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MONASH CENTRE FOR HEALTH RESEARCH AND IMPLEMENTATION (MCHRI)
Submission:
Issues related to menopause and perimenopause to the Senate Community Affairs References Committee for inquiry and report

Thank you for the opportunity to make a submission for this inquiry.

Introduction

Menopause, defined as the final menstrual period, is a pivotal point in a person's life and can be accompanied by significant psychological, physical and social impacts. The average age of natural menopause in Australian women is 51 years[1] (range 45-55 years) and is preceded by the menopause transition (or perimenopause), usually commencing in your 40's. However, menopause can occur at a younger age with even greater impacts; early menopause occurring before age 45 and premature menopause or premature ovarian insufficiency (POI), occurring before age 40 years[2,3]. Early menopause affects approximately 12% of women[4], translating to potentially 270,206 Australian women aged 15-44 years in 2021 (www.abs .gov.au). Although early menopause can happen spontaneously, for many women this is as a result of medical treatments. Increasing cancer survivorship and risk reducing or endometriosis surgery, means more individuals are living with early menopause. Societal silence, gender or age-related bias or ignorance regarding menopause, especially in younger individuals, has resulted in significant awareness and care gaps in relation to consumers, healthcare providers, society and policy makers, potentially translating to sub-optimal health related behaviours, outcomes, decreased quality of life and increased expenditure.

Need for empowerment and equity, education, and evidence-based solutions

A/Professor Amanda Vincent and Professor Helena Teede are clinician researchers and world leaders in early menopause research. They lead an extensive community engagement, research, translation and the largest clinical menopause health services in the public system nationally across Monash University and Monash Health – the Monash Centre for Health Research and Implementation (MCHRI Academic website & Consumer website). They lead an NHMRC Centre for Research Excellence and Translation in this field and are leading the update of the 2024 International POI guideline heavily focused on patient experience and improving quality of life. They have developing MRFF funded co-designed digital health tools and resources with and for women and health professionals including ASK Early Menopause App and Oxford Healthtalk resources. A/Professor Amanda Vincent also attended the Parliamentary Round Table on March 7th 2023 (Appendix 1) and they have both had significant policy input and professional society leadership roles.

Issues related to menopause and perimenopause, with particular reference to:

a. the economic consequences of menopause and perimenopause, including but not limited to, reduced workforce participation, productivity and retirement planning;

Experience narratives:

Executive manager Vera (medically-induced premature ovarian insufficiency - POI), from a minority ethnocultural background, recalled returning to work after uterine cancer treatment at the medium-sized business where she had worked for 17 years: *"… the memory lapses, my energy levels, my diet, the exercise, the hot flushes. I was in a role where weakness, general management, female, [being] of culture (…) all of these things combined to the perfect storm really and so I was removed from the role – I was in a role with a lot of pressure and a lot of responsibility and (…) I had been really open and honest with the company (…) about the impacts [of the surgery and after-effects]. There wasn't a lot of support. The CEO was male. Everyone else but me were males in all the leadership roles, the senior roles. (…) I had taken a month off to recover from the hysterectomy [and in that time] they made some aggressive moves to (…) push me into a part-time role. (…) I worked hard to really get my communication up, my energy levels up, (…) to support this team, to be everything that they expected me to be. (…) They put me on to 12 months performance management and at the end of that they terminated me."*

Lucia (spontaneous POI age 25) former graphic designer, migrated to Australia and now working in hospitality: *"But I am sure that I want to maintain the quality of life I'm having here because I don't need crazy bosses telling me stupid things. I can have more simple work, but so much better quality of life. (…) Now my priority is good quality of life because this influences everything in my health, my mental health…"*

Issue:

(i) There is no high quality, empirical evidence on the effects of menopause and perimenopause, solely and specifically, on workforce participation, productivity and retirement planning in Australia. Although figures are cited in the media, their origin and the quality of the evidence is unclear. Peri/menopause symptoms are unquestionably an issue for some women but we need accurate data to understand the extent of the effect on the population. The International 2021 European Menopause and Andropause global consensus recommendations have highlighted that there is a "diversity of experience of menopause in the workplace" influenced by menopause symptoms and context as well as the workplace environment with potential multiple impacts.

Monash Centre for Health Research and Implementation (MCHRI) researchers recently published our NHMRC funded patient experience study in 30 Australian women with early menopause, including those from CALD backgrounds. It highlighted the multifaceted relationship between work and menopause identifying both (i) short term impacts related to work performance, physical manifestations of symptoms such as hot flushes and feelings regarding disclosure of early menopause; and (ii) career trajectories which ranged from unaffected to altered to arrested. Factors impacting this interaction between work and early menopause included: career (type of work, environment, working conditions), personal (age, socio-economic background, family arrangements, migration history) and menopause experience (spontaneous versus iatrogenic, treatment complexity). Support and a culture of open disclosure in the workplace was noted as important. It is notable also that symptoms extended for many years.

Experience narrative: Zoe (spontaneous POI at age 31, Educational Professional)

"All my colleagues know that I have menopause, because … that means that I can make requests of my working environment and not have to justify it every time. They know that I just need to cool down, and they're really supportive of that."

(ii) There is no high quality, empirical evidence to differentiate between the impact of peri/menopause and the impact of other midlife stressors that have economic consequences for women, e.g., caring responsibilities and gendered ageism in the workplace. This is problematic as there is a risk that bundling all issues affecting women under the label of 'peri/menopause' will mean the root cause(s) of all stressors that have economic consequences for women are not identified and addressed; for example, lower pay, 'motherhood' penalty (loss of pay and superannuation), fewer career progression opportunities, reduced participation in the paid workforce, productivity and retirement planning for women, and lower pay for feminized workforces.

(iii) Women have a range of highly impactful medical reproductive conditions. For example PCOS affects 140M or 12% of women, has profound reproductive, metabolic, physical and psychological impacts (8 fold risks of suicide) and endometriosis has major health effects as does pregnancy and pelvic pain. These all have workplace and financial implications, and have been shown to have highly significant impacts on quality of life. POI and menopause are important, but need to be contextualised in women's lives, family and work and supported through a range of measures that do not provide isolated, differential recognition and support whilst neglecting those with severe reproductive health impacts.

RECOMMENDATIONS:

- There is a need for high quality empirical data on the effects of menopause and perimenopause, solely and specifically, on workforce participation, productivity and retirement planning in Australia.

- It is important to ask women what they want with respect to improving their workplace environment specifically tailored to peri/menopause and also to engage employers and industry, policy makers and all key stakeholders to ensure needs can be met appropriately and according to the workplace constraints/opportunities. This combined with effective implementation approaches are key to implementing meaningful and effective strategies at a systems level.

- The MCHRI Monash University team is already leading research into understanding the experience, preferences, economic consequences and workforce participation for women with menopause or early menopause. We are federally funded via NHMRC to lead the International POI Guideline under our Centre of Research Excellence in Women's Health in Reproductive Life (CRE-WHiRL) with extensive clinical and researcher expertise in understanding the health impacts and symptoms of early menopause. Our Ask Early Menopause App - www.askearlymenopause.org- codesigned with women, for women helps the 13% of women with early menopause find evidence-based information, solutions and support. We also published the annual National Women's Health and Wellbeing Scorecard which reports on Australian women's health, wellbeing, economic security and work force participation and we work extensively with the Australian longitudinal Women's Health study data. A targeted call for research via the MRFF into this area would advance knowledge and ensure evidence and women's experience/ preference driven approaches.

b. the physical health impacts, including menopausal and perimenopausal symptoms, associated medical conditions such as menorrhagia, and access to healthcare services;

Experience narrative: Claire: Chemotherapy for Hodgkin's lymphoma at age 31.
"In terms of the symptoms I felt the hot flushes were just insane and also scary at the time because one of the symptoms of Hodgkin's lymphoma is night sweats, so there was a bit of a fear of, has the cancer returned?" "…I was hot. I was lacklustre. I felt fatigued, libido, zero. Is that after cancer, or is it menopause, you don't know at the time but when you're partnered, that's not a very nice feeling and even down to things like trying to wipe yourself at the toilet was just so painful. I'd be in tears it was, it was a pretty tough time."

Issue:
(i) The menopause symptom experience and health impacts vary widely between individuals, can last for many, many years and is influenced by multiple factors. Additionally, the menopause and menopause transition is a time of accelerated cardiometabolic and osteoporosis risk[1]. These adverse impacts are even greater in women with early menopause, especially those with medically induced early menopause. [7-9] [10,11]. Thus, the menopause is a critical juncture for evidence-based information, access to tailored healthcare and for lifestyle interventions for women (not just those who are symptomatic) to reduce the incidence of chronic disease, particularly, cardiovascular disease and osteoporosis.
(ii) Primary care is preferred for many women with menopause-related care needs as it enables continuity of care. However, access to (general practitioners) GPs who are sufficiently skilled/educated and confident to manage peri/menopause is a significant gap. Therefore, a large number of individuals with moderate to severe menopausal symptoms are not being offered informed care or recommended treatment and/or lifestyle interventions for improved postmenopausal health and quality of life. This issue is of even greater importance for individuals residing outside metropolitan areas.

(iii) A small but significant number of women will have severe peri/menopause symptoms[1], complex concurrent health conditions or early menopause/POI and require more specialised care. However, access to GPs or specialists who can provide this specialised care is limited. We have previously shown inadequate knowledge and primary care screening of co-morbidities in women with premature menopause/POI[12].

(iv) The COVID 19- pandemic necessitated the rapid introduction of telehealth services into the tertiary Menopause clinics at Monash Health, Victoria's largest health service. The key finding of formal evaluation of the menopause service was that women wanted choice[13,14]. They preferred a face to face consultation for the first consultation or where they believed this was necessary but telehealth was appropriate for review of investigation results or treatment response. Telehealth overcame geographic access barriers for some

women.

(v) Accessibility of menopause hormone therapy (MHT) is a problem including the availability and affordability of GPs to prescribe MHT, affordability of medications (there are fewer MHT formulations available on the PBS) and ongoing MHT shortages. International POI guidelines[3] recommend that women with premature menopause promptly initiate and continue MHT until at least the usual age of menopause at age 51 years; for a woman diagnosed in her 20's this means using MHT for up to 30 years. In addition, those who need MHT to manage moderate-severe symptoms or early menopause/ POI might not be able to access the best formulation for them.

RECOMMENDATIONS:

- Community awareness and workplace campaign to increase menopause related knowledge and reduce stigma.

- Support for development and dissemination of evidence-based patient information and self-management strategies such as the MCHRI co-designed and evaluated NHMRC funded digital resource for early menopause which has evidence of improvement in health literacy, symptoms, illness perception, knowledge and health behaviours[15]. Our Ask Early Menopause App provides trustworthy information of the highest quality from leading experts to help them learn about the condition, support and empower them and their families with tools including a question prompt list to facilitate shared decision making, a personal dashboard to help track symptoms, find the healthiest possible lifestyle and decide on the best management options. Read an Impact Analysis of the Ask Early Menopause App . This and other freely accessible tools could be promoted.

- Undergraduate medical and health professional education must focus on early menopause, menopause and other neglected health conditions relative to the proportion of the population affected and the impact of the condition.

- GPs should be incentivised through CPD and funded opportunities (if necessary) to access education and provide evidence based peri/menopause management. An adequately funded midlife health check, that includes social prescribing for lifestyle interventions, is best practice to reduce the burden of chronic disease among Australian women. The existing Health Assessment Check for Chronic Disease (for 45-49 year olds) could be extended to an older age range.

- Up-skill dedicated women's health and community based nurses and midwives, to provide advice on menopause to increase access to evidence-based information for menopause management and post-menopausal health.

- Adequate funding of both primary care and specialist service delivery is needed. Individuals should be able to choose various types of consultation (in person, telehealth video or phone) depending on their needs. Technology constraints often prevents adequate video consultation modalities and telephone may be required. Research shows this is vital for low SES and regional dwelling women to optimise access.

- Multidisciplinary menopause hubs (e.g., in NSW) and existing specialist multidisciplinary public clinics (e.g. multiple public services at Monash Health) could provide educational and clinical support sites to upskill GPs and other specialists providing care for women with severe early menopause and peri/menopause symptoms. MCHRI is codesigning a funded best practice model of care to guide such services as an output of the International POI Guideline and policy involvement is welcome.

- A range of products should be available on the PBS to meet individual needs. This speaks to the fact that different formulations may suit some women more than others and a range gives more clinical options.
- In the broader context social determinants of disease are vital here and financial insecurity for Australian women in midlife is increasing considerably. This is a key determinant of access to health care and of disease burden and impact. Government approaches to support women equitably at this life stage are vital to equitable access to care and for physical and emotional wellbeing.

c. the mental and emotional well-being of individuals experiencing menopause and perimenopause, considering issues like mental health, self-esteem, and social support;

Experience narratives:

Kerry: Early menopause at age 44 following both ovaries removed and hysterectomy for endometriosis. *"Early Menopause changes you. You physically have changed. You emotionally change. You psychologically change."*

Mary : Breast cancer diagnosed age 39y. Chemotherapy and then BSO at age 41.

"At 45 I feel like my grandmother who was early 90s at the time …. …my peers were people like my grandmother." "…it was sort of like I'd gone from 39 - instead of turning 40 I'd almost turned 80. So I'd sort of skipped 40 years and I know it sounds bizarre, but it - it was a

big jump".

Anne: Both ovaries removed and hysterectomy for uterine cancer at age 37.

"The probably toughest part was realising I'd not be able to have children and still be expected to perform as a normal functioning female human, and what life looks like after that. Like, what do you as a female if you don't raise children? [crying] So just trying to find value in yourself and your role is tough."

Issue:

Many women traverse menopause without major health and wellbeing impacts. For others they experience reduced mental, cognitive and emotional well-being during midlife[1] but more research is needed to understand the root causes (including the role of perimenopause/ menopause in the context of other factors) and best management approaches. International studies[16] have highlighted the perimenopause is a time of psychological vulnerability for depression, requiring a focussed approach to those at risk.

MCHRI's studies in Australian women with early menopause/ POI indicate increased anxiety and depression, decreased self-esteem and body image and sexual function problems[7,9,17]. A recent international scoping review identified peer-peer support, mental health counselling, individualised care, continuity of care and compassionate clinicians as important strategies for management of impaired health related quality of life associated with POI[18.]

RECOMMENDATIONS:

- High quality empirical evidence is required to understand the effects, influencing factors and best management strategies of peri/menopause on mental and emotional well-being, incorporating a biopsychosocial model.
- Development of tools to screen for mental health conditions, provide support, facilitate self-management and guide women to the best pathways for care are vital. MCHRI's Ask Early Menopause App provides such free online support and is funded by MRFF to enhance support and shared decision making.
- Education to improve healthcare provider knowledge regarding screening and management of mental and emotional health.
- Support multidisciplinary specialist menopause services which include endocrinologists, gynaecologists and psychologists to provide care and support GPs

(as noted above in b.).

- Our research shows that mental health services are highly skewed nationally and do not meet the needs of those who require the greatest support. Women, rural populations and those most severely affected by mental health conditions have the greatest access barriers. Our mental health equity indicator has been developed using population data and shows GPs are the most accessible and equitable avenue for mental health care.

- Supporting and enabling our GP workforce which is currently being dramatically curtailed, will be a core part of optimising care and support for women generally at menopause and in terms of mental health.

d. the impact of menopause and perimenopause on caregiving responsibilities, family dynamics, and relationships;

Experience narratives:

Harriet: POI at age 37 due to chemotherapy for Hodgkin's lymphoma

" I had started a new relationship and Thea was very upfront from the outset about wanting children and (…) I'd sort of thought, you know, 'I was going to be the one to have children back in the old life, old relationship, everything,' … that was a bit of an adjustment I guess."

Kerry: Early menopause at age 44 following both ovaries removed and hysterectomy for endometriosis.

"You've got to open a whole new conversation up with the loved ones in your lives about this, that things have changed. You're not the person you were before surgery or menopause."

Issue:

There is a lack of high quality studies on these impacts, both in relation to the effect of peri/menopause itself and the impact of other midlife stressors. The experience of women from priority populations, such as multicultural and First Nations communities, and women with disabilities are especially neglected and under-represented groups. Our interview study with women with diverse causes of early menopause described themes of 'disruption' , 're-negotiation' and 'adjustment' in their relationships following an early menopause diagnosis[19]. Partners of Australian women with menopause related to breast cancer reported difficulty talking about menopause, a lack of understanding of menopause, a negative impact on sexual function and intermittent stress on their relationship[20]. The

impact of menopause and work was greater in those with caregiving responsibilities compared to those without caregiving responsibilities.

RECOMMENDATION:

- Targeted calls for research and translation tools and strategies to understand and support these challenges is important.

e. the cultural and societal factors influencing perceptions and attitudes toward menopause and perimenopause, including specifically considering culturally and linguistically diverse communities and women's business in First Nations communities;

Issues:

Research shows that negative attitudes to menopause predict higher frequency and severity of perimenopause symptoms[1]. Thus there is a need to 'normalise', not pathologise, usual menopause and to ensure peri/menopausal does not become a focal point or trigger for gendered ageism, including internalised ageism, by 'othering' peri/menopausal women. Age at menopause and symptom experience vary in different countries globally[1]. Thus, in multicultural Australia, the strong cultural and societal factors around menopause must be considered in the development of information and services to ensure all women receive equitable peri/menopause treatment and support. It is critical we do not focus on improvements that benefit only educated and advantaged women. There is a risk that policy-making in the absence of evidence from all groups could further increase inequities between women.

Our study involving 232 Australian women creating a word cloud using their reported perceptions and experiences of early menopause showed that "hot flushes', 'mood swings' and 'infertility' were the most frequent words associated with early menopause and most had negative connotations[21]. In this setting where menopause is not "usual", increased awareness is important. Empowerment through knowledge reduces fear and influences how others view and treat people going through menopause.

RECOMMENDATIONS:

- High quality research and evidence (quantitative and qualitative) is required to explore the views of priority populations (eg. multicultural and First Nations communities, and women with disabilities) and the impacts of intersectionality. These need to translate to useful and accessible resources to support women and healthcare providers. Examples include the MCHRI Oxford Health Talk Australia, informative resource.

- Co-designed information and services are needed to provide information and care for women from priority populations. Codesign is not well managed in Australia, especially in terms of reaching and partnering with diverse and underserved populations. MCHRI leads the Women's Health Research and TRanslation Impact Network (WHRTN) which is delivering innovative new grant funding strategies contingent upon extensive consumer involvement in codesign and coproduction including at menopause and we can share our knowledge and expertise in consumer and community co-design. MCHRI also leads the MRFF funded Consumer and Community Involvement best practice and knowledge hub program and with Monash Partners and providing expertise into the national consultation on consumer and community involvement policies for MRFF and NHMRC. We are ideally positioned to support genuine best practice involvement and codesign in this area and are already funded to do so.

f. the level of awareness amongst medical professionals and patients of the symptoms of menopause and perimenopause and the treatments, including the affordability and availability of treatments;

Experience narratives:

Jenni, spontaneous POI at age 37:

"It has been 12 years since it all started for me and at no point in that journey did anybody ever validate my experience. I went to doctors. I went to, supposedly 'exclusively focused menopause clinics'. I went to hospitals that specialised in women's problems. I saw so many gynaecologists. I was not able to see endocrinologists. I went everywhere that my finances would allow me to go and my reality was denied again and again and again and it gets to the point that you start to think you're going nuts. You're thinking 'Maybe they're right. Maybe I am a hypochondriac. Maybe it is all in my head. Maybe this isn't really happening?' And you really need someone else that can relate to that to validate that so that you don't start to feel like you're going nuts because then, like when I was diagnosed with the premature ovarian failure initially by the IVF doctor it was such a shock to me to actually have that validated because for five years it had been denied to me. For five years I'd had specialists try to diagnose me with mental disorders but it never was. You know, my gut was right all along. But you need to have that reflected back to you."

Jenni, spontaneous POI at age 37:

"I have a lovely GP at the moment. But I don't think that she's ever managed anybody going through early menopause. She doesn't really know how to manage it. She is younger than me, so she's never been through it herself. And she agrees that I need to find somebody who can manage the menopause side of things, because it's kind of out of her depth. But I don't really know where to go from there.

Issues:

(i) Understanding and focusing on menopause related symptoms: Women describe a range of symptoms in association with peri/menopause: however, there are few symptoms unique to menopause. Most women have perimenopause symptoms that can be managed without pharmaceutical treatments. There are many groups with conflicts of interest (pharmaceutical companies, labour/ workforce service providers) who would see usual menopause pathologised or medicalised. Many individuals and groups are claiming a plethora of symptoms are related to peri/menopause without evidence, which leads to confusion and risk related to the delayed diagnosis of other or more serious health issues. An international expert group reported criteria to describe the stages of reproductive life, the Straw 10 criteria[22] , and only peri/menopause symptoms, verified by empirical evidence, should be used in advocacy, education and research. It is important for women to understand and recognise verified symptoms, important for clinicians to rule out other

health issues, and important for policy-making related to symptom-management.

(ii) Information and care gaps: Our research has shown that women with early menopause have unmet information and care needs regarding menopause and menopause therapies. They describe delayed diagnoses, variable risk perception, dissatisfaction with information provided and dissatisfaction with care[7,9,23]. Psychological, urogenital and sexual function problems are considered difficult to disclose to a healthcare provider23. Knowledge gaps influence health behaviours; higher level of osteoporosis knowledge was associated with increased calcium intake and bone density screening by women with early menopause[24,25]. Formal evaluation of online content regarding early menopause showed significant deficiencies in quality and content[26] indicating the need for high quality, evidence based information and resources.

(iii) Health professional knowledge gaps: Our research has shown healthcare provider knowledge gaps and care variation in regard to menopause and menopause related bone health[24,27,28]. Health care provider knowledge varied with age since graduation, membership of a menopause society, specialty and area of practice with approximately 40% of clinicians reported limited knowledge regarding menopause -related topics27. Adequate undergraduate and postgraduate menopause education is lacking. Monash University has one of the few undergraduate menopause curriculum (two lectures) in Australia. Monash Health is in a minority of health services in providing menopause training to specialist gynaecology and endocrinology trainees. Formal evaluation of available early menopause/POI guidelines indicate variable quality and poor uptake[29,30]. We are now funded for leadership, development and translation of early menopause international guidelines and this includes a strong focus on medical and health professional education and optimising provider knowledge. The pipeline from research evidence to guidelines to education to care is curtailed in menopause as it is in so many women's health conditions due to a lack of research investment.

(iv) Accessibility of menopause hormone therapy (MHT) is a problem including the availability and affordability of GPs to prescribe MHT, affordability of medications (there are fewer MHT formulations available on the PBS) and ongoing MHT shortages. The new International POI guidelines[2,3] recommend that women with premature menopause promptly initiate and continue MHT until at least the usual age of menopause at age 51 years; for a woman diagnosed in her 20's this means using MHT for up to 30 years. In addition, those who need MHT to manage moderate-severe symptoms or early menopause/ POI might not be able to access the best formulation for them.

(v) Health literacy around the use of complementary and alternative medicines (CAMS) is a problem. We have previously shown that women have poor understanding of the risks and benefits of CAMS[9,31]. The use of unproven and ineffective CAMs, fuelled by

misinformation on social media and the lack of counter balancing accessible evidence based information leads to a major waste of money for women and delays use of effective treatments. Improved public knowledge about menopause management (what is effective and what is not) is needed, as part of improved overall education about menopause.

RECOMMENDATIONS:

- High quality research on the prevalence of verified perimenopause symptoms is needed to inform care and for policy-making related to symptom management and work/life supports. The STRAW +10 criteria should be used as the basis for an agreed list of verified symptoms.

- Need for education/community awareness of perimenopause symptoms, but presented as strengths- and not deficit-based to build normalisation and reduce fear and stigma.

- Need for community awareness and education on women's midlife health generally (menopause and post-menopause health) to promote healthy ageing, especially cardiovascular disease risk and bone loss.

- Need for community awareness and education about menopause management (what is effective and what is not) as part of improved overall education about menopause.

- Support for development, dissemination and uptake of co-designed digital education and self-management resources such as Healthtalk Australia Early menopause resource (www.healthtalkaustralia.org) and MCHRI's Ask Early menopause App(www.askearlymenopause.org) and Ask Heart Health App (under development, www.askhearthealth.org) is needed.

- Women's health generally, and peri/menopause specifically, should be a core part of medical and health professional training. GPs need to be upskilled to provide peri/menopause management.

- Need for high quality evidence-based guidelines regarding menopause and POI applicable to the Australian context. - We are addressing this gap via our Centre of Research Excellence in Women's Health in Reproductive Life (CRE-WHiRL) and are currently leading the 2024 POI guideline update, and codesigned government funded accessible resources. We are keen to work with government to optimise reach and impact of this work.

- Need for development and dissemination of education programs such as MCHRI's: Too young for Menopause? An Evidence-based approach to managing early menopause and premature ovarian insufficiency – with updated new guidelines.

- Increased research investment to feed the Guideline, education and care pipeline.

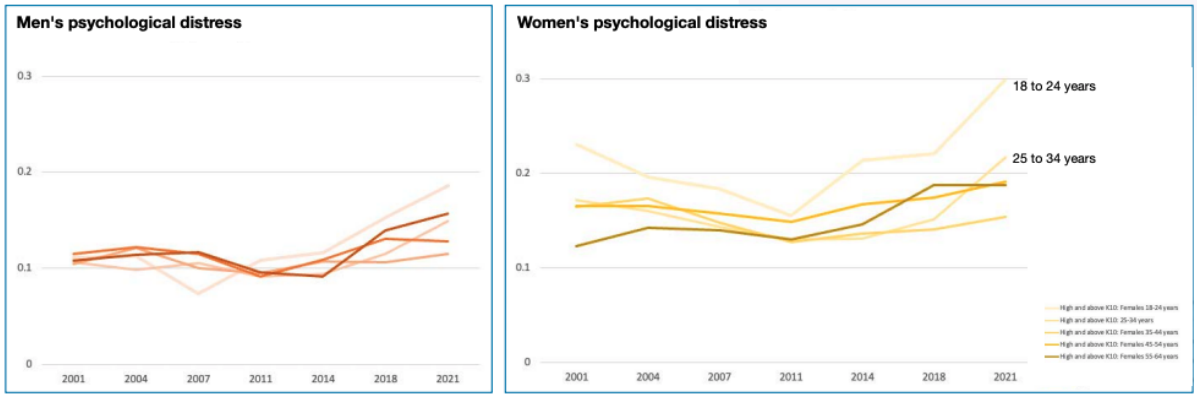
g. the level of awareness amongst employers and workers of the symptoms of menopause and perimenopause, and the awareness, availability and usage of workplace supports;

Experience narrative: A union delegate, Siobhan experienced POI at age 37 following surgeries for ovarian cysts, *and unpredictable, heavy menstrual bleeding and pain. Not wishing to disclose her condition to her 'not very understanding' male boss, the impact of her symptoms and need for repeated sick leave on a 'high pressure job' involving extensive travel and interpersonal interaction reportedly 'caused a lot of tension'. Eventually, despite not having another job and being the primary earner supporting a husband and two children, Siobhan resigned, describing that period as 'a really awful time'. She soon found another job in the same industry.*

Issues:

(i) Specific menopause leave is not recommended as it is likely to have significant unintended consequences that might penalise women as they approach and enter midlife. A survey of n=1092 Australian hospital workers has shown that women do not want to be considered a "problem group" in the workplace. Midlife women are already a highly casualised workforce with major implications for financial security and rental property access, fuelling rising homelessness and disadvantage. Furthermore, whilst menopause has significant impacts on health, it is but one of a raft of common and significant reproductive health issues women face. It is unfair and discriminatory to target but one of these reproductive challenges which is for many women a physiological life stage with relatively limited health impacts. In our extensive engagement in research, patient experience, guideline development and care, women have not prioritised leave for symptoms that can last for decades. Workplace culture, support and flexibility is critical, but this flexibility needs to cover the full spectrum of women's health issues, not just peri/menopause. Changes in menstrual bleeding is one of the biggest challenges for perimenopausal women at work, but these issues also impact premenopausal women who have menorrhagia, endometriosis, PCOS and other conditions. It is critical to ensure women in labour forces, other than office-based knowledge workers, also have workplace flexibility. Furthermore, midlife women whilst experiencing increasing distress over time, experience far better mental health and less distress than young women. MCHRI's annual scorecard Women's

Health and Wellbeing Scorecard 2023 shows that overall, more women than men reported elevated levels of psychological distress and whilst women in menopausal are range have shown increased distress over time, yet the data showed that women aged 18-24 consistently reported the highest levels of distress across all years (see below from page 6 of the Women's Health and Wellbeing Scorecard 2023) Considering the myriad of other reproductive health conditions including the impact of pregnancy and psychological distress, isolating a single normal physiological series of events for menopause leave arguably sets an unfair precedent.



(ii) A plethora of workplace menopause programs are being promoted. However, there are clear vested interests and conflicts of interest here and there is currently no evidence-based workplace intervention improves performance. If we are to subscribe to empowering women, high quality research into needs and preferences of women in the workplace is vital. As yet the limited evidence that exists, suggests that increasing menopause awareness in the workplace and women feeling supported can have positive effects[5]. Whilst this seems intuitive it needs to be done with women and not for or to women. We must ensure menopause programs and 'accreditation' meet women's needs and priorities and normalise, rather than stigmatise, menopause and avoid creating the perception that workplaces need special programs which risk increasing discrimination against older women. Rather evidence based, women's experience and needs driven reproductive health approaches across the working life would be important.

RECOMMENDATIONS:

- Specific menopause leave is not recommended as it has not been prioritised in research to date with affected women. It is likely to have unintended consequences that may penalise and or stigmatise women as they approach and enter midlife.

- Need to be fair and address broader (and often more severe) women's reproductive health issues by codesigned and empowering approaches of all women's health issues so women are empowered to ask for workplace support (for any women's

health issue).

- Independent evaluation of existing menopause programs and 'accreditation' is required and recognition and management if vested interests and financial incentives is vital.

h. existing Commonwealth, state and territory government policies, programs, and healthcare initiatives addressing menopause and perimenopause;

Issue:

Public specialist menopause services are not available in all states or territories of Australia limiting access especially to individuals from disadvantaged communities. The Monash Health Menopause services are codesigned, evaluated and have provided specialist care to Victorian and interstate women who are unable to access these services locally.

RECOMMENDATION:

- A specialised multidisciplinary menopause service (with telehealth remote access) is needed in each state to provide specialist care and support GPs. A best practice framework informed by patient experience, preference and Guidelines is vital to ensure equitable access to high quality care. This work is underway with federal government funding at MCHRI and policy involvement is welcomed. These frameworks can support GP based care and escalation pathways for specialist care. They also support evaluation and optimal patient experience.

i. how other jurisdictions support individuals experiencing menopause and perimenopause from a health and workplace policy perspective; and any other related matter.

Issues:

(i) High quality evidence is lacking regarding many aspects of menopause due limited studies and significant methodological limitations of existing studies. Misleading statistics, low quality and anecdotal evidence can potentially lead to confusion, fear, stigma, inadequate/ incorrect management and financial burden. Measures to overcome this includes: (i) sampling techniques to ensure a broad range of individuals are recruited especially from minority and disadvantaged groups; and (ii) clinical trials of treatments need to include placebo or sham groups so that robust comparisons can be made. A recent international online survey involving 756 midlife women and 500 healthcare providers indicated that >70% of women considered information regarding methodology, media influence and publication ethics very important/essential to include in recommendations on midlife health; a statistically significant greater proportion than healthcare providers. Recent global collaborations have defined agreed outcomes and tools for menopause studies related to core menopausal symptoms[32,33].

(ii) There are many people and organisations with commercial interests, large and small, seeking to shape discourse and policy responses. All individuals and organisations making a submission should disclose financial and in kind support (e.g., media relations support, meeting organisation support) from for-profit organisations, and all personal interests in any business related to women's health, generally, and menopause, specifically. These interests are acting both directly and indirectly through lobbying and engagement with a diversity of stakeholders.

RECOMMENDATIONS:

- Studies related to menopause should be high quality with appropriate sampling methods, comparisons and agreed verified outcomes.
- It is critical that evidence-based, accessible consumer health information is promoted.
- Conflicts or interest need to be declared and policy and care decisions driven by the needs and preferences of our diverse population of women, taking a strength based empowerment approach and not by those with vested interests.

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Appendix 1

Early Menopause:

- **Unknown**
- **Underdiagnosed**
- **Undertreated**

- **Early menopause** is menopause occurring before age 45 years**. Premature menopause or premature ovarian insufficiency** is loss of ovarian function before age 40 years *[1,2]*.

- Affects 12% of women *[1,3]*, with **270,206 Australian women aged 15-44 years** potentially affected in 2021 (www.abs.gov.au)

- Early menopause occurs spontaneously or as a result of medical treatments (chemotherapy, radiotherapy, surgical removal of ovaries) *[2]*.
  - For most women, the cause of spontaneous early menopause is unknown.
  - Increasing cancer survivorship and risk reducing or endometriosis surgery means more women are living with early menopause. In 2016, there were **19,147 female cancer survivors aged 20-39** (www.aihw.gov.au/reports/cancer)

- Early menopause is associated with **negative impacts on physical, mental, and social well-being,** including infertility *[3]*
  - 36-87% increased risk of heart disease
  - Increased anxiety, depression
  - 2 fold increased risk of osteoporosis
  - 46% increased risk of dementia
  - 12-67% increased risk of death

(www.eshre.eu/Guidelines-and-Legal/Guidelines/Management-of-premature-ovarian-insufficiency)

- 60-80% of Australian women aged 15-44 years participate in work. (www.abs.gov.au\statistics\labour)
  - Early menopause can adversely influence women's work experience and vocational trajectory *[4]*.

"Early Menopause changes you. You physically have changed. You emotionally change. You psychologically change."

Parliamentary roundtable, Canberra March 7, 2023

MONASH University | MCHRI Monash Centre for Health Research and Implementation | CREWHiRL Centre for Research Excellence in Women's Health in Reproductive Life | Monash Health

AUSTRALASIAN MENOPAUSE SOCIETY EMPOWERING MENOPAUSAL WOMEN

www.menopause.org.au

Women's perceptions of early menopause

Problem:

- Consumer and clinician knowledge gaps with unmet information needs *[5,6,7,8]*
- Delayed diagnosis *[5]*
- Lack of access to care and care variation *[9]*
- Dissatisfaction with diagnosis and care *[5]*
- Suboptimal health related behaviours *[6,10]*
- Suboptimal health outcomes and decreased quality of life *[2]*.

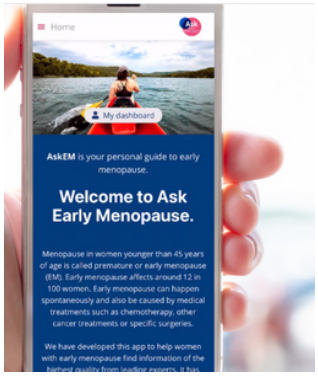
Need for:

- **Empowerment and equity**
- **Education**
- **Evidence**

<u>Recommendations to help meet these needs</u>:

- Include early menopause as part of a national action plan for menopause
- Undertake a national early menopause public awareness and health literacy campaign
  - Co-designed resources to provide information and support self-management: extend Ask Early Menopause App *[11]*
  - Facilitate supportive workplaces
- Health practitioner education to address gaps in diagnosis and care
  - Partner with relevant organisations
  - Link to evidence based guidelines.
- Health service delivery: support new models of care and access
  - State-federal partnerships
  - Support hybrid consults including both in-person and telehealth *[12]*
  - Nurse practitioners- Women's health certificate for nurses aligned to evidence based guidelines
- Support for research to facilitate evidence based care
  - MRFF initiative for menopause research

" Too young for menopause"



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