

DR HANH H NGUYEN (Orcid ID : 0000-0002-8846-6168)

DR AMANDA VINCENT (Orcid ID : 0000-0002-3760-7266)

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Title: Identifying and Addressing Osteoporosis Knowledge Gaps in Women with Premature Ovarian Insufficiency and Early Menopause: A mixed methods study.

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Authors:

Maylyn Goh ¹, Hanh H Nguyen ², Nadia N Khan ¹, Frances Milat ^{2,3}, Jacqueline A Boyle ^{1,4},
Amanda J Vincent ^{1,4}

Affiliations:

1. Monash Centre for Health Research and Implementation, School of Public Health and Preventive Medicine, Monash University, Clayton, 3168, Victoria, Australia
2. Department of Medicine, School of Clinical Sciences, Monash University, Clayton, Victoria, 3168, Australia
3. Hudson Institute, Clayton, Victoria, 3168, Australia
4. Menopause Unit, Monash Health, Clayton, Victoria, 3168, Australia

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Corresponding author

Clinical Assoc. Prof. Amanda Vincent

E-mail: Amanda.vincent@monash.edu

Tel: +61 3 85722665

Fax: +61 3 95947554

Postal Address: Monash Centre for Health Research and Implementation

43-51 Kanooka Grove

Clayton, 3168

Victoria, Australia

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Summary

Objective: Osteoporosis associated with premature ovarian insufficiency (POI) and early menopause (EM) is a major concern for women. We aimed to (i) identify information and knowledge gaps and behaviours regarding bone health in women with POI/EM; and (ii) co-design an osteoporosis factsheet.

Design: Mixed-methods study: survey of women and online resource appraisals to develop and refine, using semi-structured interviews, an osteoporosis factsheet.

Patients: Women with POI/EM (menopause before ages 40 and 45 years respectively).

Measurements: Demographics, comorbidities, information needs, calcium intake, exercise, osteoporosis knowledge (OKAT), beliefs and self-efficacy, DISCERN appraisal (validated scales). Analysis: descriptive statistics, logistic regression and thematic analysis of interviews.

Results: Median age of survey respondents (n=316) was 54(IQR47-63) years, median age of menopause was 40(IQR38-43) years, and osteoporosis diagnosis was reported in 19%. Most reported inadequate dietary calcium intake (99%) and exercise (65%). Median OKAT score 8[IQR6-10]/19 indicated knowledge gaps regarding risk factors and treatment options. Adjusting for age and education, OKAT predicted calcium intake [OR1.126(CI 1.035-1.225); p=0.006] and screening [OR1.186(CI 1.077-1.305; p=0.001); beliefs predicted screening [OR1.027(CI 1.004-1.050); p=0.019]; and self-efficacy predicted calcium intake [OR1.040(CI 1.013-1.069); p=0.003] and exercise [OR1.117(CI 1.077-1.160); p<0.001]. Current online resources have deficiencies. Five themes identified from 2 interview rounds (n=10/ round) were: content, emotional response, design, perceived usefulness and clinical considerations. The final factsheet was considered acceptable and useful in addressing knowledge gaps, promoting information-seeking, impacting behaviours and facilitating healthcare discussions.

Conclusion: A co-designed factsheet is acceptable and addresses identified osteoporosis knowledge gaps in women with POI/EM.

Keywords: osteoporosis, premature ovarian insufficiency, menopause, knowledge, information

Introduction

Premature Ovarian Insufficiency (POI) and Early Menopause (EM), menopause before age 40 and 45 years respectively, occurs spontaneously or secondary to medical intervention and affects up to 10% of women¹. The premature deprivation of oestrogen can result in multisystem complications², including an increased risk of osteoporosis³, which affects approximately 8-15% of women with POI^{1,4}. As bone loss may remain clinically silent, current evidence-based guidelines recommend screening, prevention and treatment for osteoporosis in the management of women with POI/EM^{1,5}.

However, knowledge gaps are apparent among women with POI/EM⁶. Women with POI are often dissatisfied with the level of information provided, with many expressing a need for greater information provision and education⁷⁻⁹. This is further exacerbated by the limited access to credible, high-quality information on POI/EM¹⁰. Consequently, this may impact negatively upon women's decision-making ability, satisfaction, health-related behaviours and health outcomes^{4,6,8}. Additionally, previous studies of women with POI/EM report that osteoporosis is one of women's greatest fears and concerns contributing to emotional distress^{8,9,11}.

The development of novel educational resources is a valuable means of addressing these knowledge gaps and may help to enhance women's empowerment, knowledge, satisfaction and health behaviours. Current best practice in the development of healthcare resources involves a co-design approach as user-testing of patient information leaflets have been shown to result in improved clarity, quality and readability of information^{12,13}.

Currently, no studies have identified women with POI/EM's information needs regarding bone health and there are few bone health related educational resources specifically tailored for women with POI/EM. Thus, the present study aimed to explore women with POI/EM's current understanding, health-related behaviours and information needs regarding bone health. This informed the development of an evidence-based bone health factsheet/Infographic which was user-tested among women with POI/EM to enhance its acceptability.

Materials and Methods

This mixed-method study involved two phases: (I) An initial needs-analysis which informed (II) The development, evaluation and refinement of a factsheet and infographic. Women with a self-reported diagnosis of POI/EM, who resided in Australia and were at least 20 years of age were eligible to participate. Ethics approval for this study was obtained from Monash Health Human Research Ethics Committee (Reference Number: 07062A).

Phase 1

To assess the need for a bone health factsheet and to inform potential content, Phase 1 of the study was divided into: i) A survey determining the information needs and current practices regarding bone health among women with POI/EM and ii) An assessment of current online consumer resources related to POI/EM and bone health.

Survey

Women were recruited from the general community, medical clinics, online support groups and cancer registries. The survey, available either as a hard-copy or online questionnaire, was available to women from March 2017 to April 2018. Completion of the online survey indicated implied consent. Responses that were incomplete or where the diagnosis of early menopause was unclear were excluded. The survey comprised: (i) devised questions adapted from previous POI/EM studies^{6,8} assessing medical history and health-related behaviours; (ii) information needs regarding bone health (perceived importance of seven different osteoporosis topics assessed using a Likert Scale); validated questionnaires assessing (iii) dietary intake of calcium and physical activity^{14,15}; (iv) Osteoporosis Knowledge Assessment Tool (OKAT)¹⁶; (v) Osteoporosis Health Beliefs Scale (OHBS)¹⁷; and (vi) Osteoporosis Self-Efficacy Scale (OSSES)¹⁸.

Information Appraisal

An appraisal of existing online information related to POI/EM and bone health was conducted. Websites included in this analysis were derived from (i) a 2016 study evaluating the quality of EM-related websites¹⁰; and (ii) a systematic Google search of keywords (EM/POI/premature menopause/premature ovarian failure combined with Osteoporosis/bone health) undertaken in March 2018. Any new websites in the first two pages of search results were included. The quality and readability of online resources were assessed using the validated DISCERN tool¹⁹ and Flesch-Kincaid Grade level test²⁰ respectively, by 2 authors (MG and AJV).

Phase 2

Informed by (i) findings from Phase 1 of the study and (ii) current osteoporosis and POI/EM evidence-based guidelines^{1,5,21}, an initial bone health factsheet was developed, Factsheet Version 1 (V1) and used during Round 1 interviews. Factsheet V1 was professionally developed into an Infographic and trialled during Round 2 interviews.

Semi-structured individual (in person or telephone) interviews involving women with POI/EM, explored the acceptability of the factsheet and assisted in refinement of the factsheet. Women were recruited through social media platforms, online websites, medical clinics and follow-up of previous survey participants who had expressed further interest in the study. Prior to the interview, women were screened to confirm their eligibility and e-mailed a copy of the factsheet/Infographic.

To attain the final factsheet (Factsheet V3), two rounds of interviews were conducted, with data collection and analysis occurring concurrently. After each round, women's suggestions were reviewed (authors MG and AJV) and changes were made if additional information was relevant to a range of women, consistent with the focus on osteoporosis and not available in the web-links provided in the factsheet. Interviews were conducted till the point of data saturation²² and transcripts were thematically analysed using NVivo version 12 (QSR International) (authors MG and NNK).

Statistical Analysis

Survey data was analysed using IBM SPSS Statistics V25 (IBM Corp, Armonk, NY, USA). The distribution of the data was explored using the Shapiro-Wilk test. Non-parametric continuous data are expressed as medians with interquartile ranges (IQR), and Mann-Whitney u test was used to compare continuous variables. Categorical data are presented as frequencies (%). To analyse results from osteoporosis-related tools, several outcomes as used in previous studies were used to assess women's osteoporosis knowledge, self-efficacy and health beliefs²³⁻²⁵.

A multivariate logistic regression model was used to assess the relationship between women's scores to the osteoporosis-related tools and their health-related behaviours (dietary intake of calcium, exercise, osteoporosis screening). Calcium, exercise and osteoporosis screening were expressed as binary categorical outcomes [calcium: ≤ 600 mg versus > 600 mg; exercise: ≤ 90 minutes/week versus > 90 minutes/week; screening: yes versus no]. A p-value < 0.05 was considered statistically significant.

Results

Phase 1: Survey

Participant characteristics: The median age of the 316 eligible respondents (Table 1) was 54 years (IQR: 47-63 years), and the median age of menopause was 40 years (IQR: 38-43 years). Most women had completed post-secondary education. There was a greater proportion of women with iatrogenic POI/EM (%) compared to spontaneous POI/EM (%) and most were diagnosed more than five years ago. Nearly one-fifth of the women reported a diagnosis of osteoporosis, and most reported sub-optimal dietary calcium intake and physical activity. Most women were screened for osteoporosis (80%) but only 27.3% of eligible women (women < 51 years without breast cancer) were current users of hormone

replacement therapy (HRT) with systemic HRT being the most commonly used (83.3%). The most commonly cited reasons for not using HRT were personal beliefs that oestrogen therapy is not required (23.3%), a previous diagnosis of oestrogen-dependent cancer or medical condition (16.7%) and previous experience of side effects (16.7%).

Osteoporosis knowledge: Only 8/19 items were correctly answered by more than 50% of women (Table 2) and the median OKAT score was 8 (IQR: 6-10). Main areas of osteoporosis knowledge gaps related to prevalence, signs and symptoms, risk factors, treatment options and post-menopause bone loss. After adjustment for age and educational status, a higher total OKAT score was predictive of calcium intake [OR: 1.126 (CI: 1.035-1.225), $p=0.006$] and screening [OR: 1.186 (CI: 1.077-1.305), $p=0.001$] but not exercise (Supporting Information Table 1).

Osteoporosis health beliefs: The overall median OHBS score was 128 (IQR: 121-135.7)/210 and Figure 1 demonstrates the median score for individual sub-scales. Women with a higher total OHBS score were more likely to have been screened for osteoporosis [OR: 1.027 (CI: 1.004-1.050), $p=0.019$]. Analysis of individual OHBS domains (Supporting Information Table 1) revealed that reported exercise level was predicted by perceived benefits of exercise [OR: 1.081 (CI: 1.007-1.160), $p=0.031$], perceived barriers to exercise [OR: 0.880 (CI: 0.824-0.941), $p<0.001$], calcium intake [OR: 0.918 (CI: 0.859-0.980), $p=0.010$] and health motivation [OR: 1.095 (CI: 1.022-1.174), $p=0.010$]. Whereas osteoporosis screening was predicted by perceived susceptibility to osteoporosis [OR: 1.106 (CI: 1.042-1.173), $p=0.001$] and perceived benefits of exercise [OR: 1.083 (CI: 1.018-1.152), $p=0.011$]. These values remained significant after multivariate adjustment for age and educational status

Osteoporosis self-efficacy: Women reported high levels of confidence in undertaking osteoporosis health-related behaviours (Figure 1). The median calcium sub-scale score was 23 (IQR: 18-26)/30 and the median exercise sub-scale score was 22 (IQR: 18-25.5)/30. Overall, the median OSES score was 44 (IQR: 38-50)/60. A higher total OSES score was predictive of calcium intake [OR: 1.040 (CI: 1.013-1.069), $p=0.003$] and exercise [OR: 1.117 (CI: 1.077-1.160), $p<0.001$].

Information needs: All the 7 topics listed in the survey, including aetiology, prevention and management options for osteoporosis in POI/EM were considered essential or very important to include in the factsheet by >75% of women (Supporting Information Figure 1).

Phase 1: Information Appraisal

Thirty-five websites were initially identified and 15 were suitable for analysis (20 websites were excluded due to lack on information regarding POI/EM and bone health). Only 3/15 websites had the maximal DISCERN score of 5, with 8/15 rated as moderate quality or lower (Score ≤ 3) (Figure 2 and Supporting Information Table 2). Online written information readability did not meet the current recommendations of Grade 8 level or lower (Figure 2).

Phase 2: Refinement of factsheets

Twenty women participated in 2 rounds of interviews (Table 3). More women had idiopathic EM/POI and were within 10 years of menopause in Round 2 interviews. In both rounds of interviews, 20% of participants have been diagnosed with either osteoporosis or osteopenia. Five central themes emerged regarding acceptability of the factsheet with associated sub-themes (Figure 3). To assist in the refinement of the factsheet, 'content' and 'design' themes were analysed separately after each round of interview (Supporting Information Table 3). Similar findings from both rounds of interviews were obtained for the other themes and are presented together. Women perceived the factsheet as being 'informative', 'comprehensive', 'easy to understand', set out in a logical manner and relevant to their circumstances. *"It covered all the things that I wondered about with early menopause, and the risk of osteoporosis"* (P10). Most participants believed that the length of the factsheet was appropriate. *"I think the length of the [factsheet] is good because it does allow someone who isn't familiar with a lot of this information to get that information"* (P2). Compared to the factsheet, women were more interested in the infographic as it was more 'visually appealing', 'engaging' and easier to read. *"It's striking to the eye, you can take information without even trying, because the infographics really help you see straight away"* (P14). Positive emotional responses women reported after reading the factsheet were feeling 'empowered', 'motivated' and 'reassured'. No women reported negative emotional responses of feeling 'anxious' or 'worried'. However, a minority of women expressed a sense of regret and disappointment for not having similar resources earlier. *"I wish there was something like this two years ago... If I'd been told that earlier, I might have started something earlier you know"* (P3). Women identified four areas in which they found the factsheet useful (Figure 3). Most participants perceived that the fact sheet helped to address their information needs by providing new knowledge or reinforced/ reminded them about various aspects of bone health. *"I'd forgotten the things about vitamin D and weight bearing and resistance exercise is good for your bones. I'd forgotten about that sort of thing, so it was good to give myself a refresher about what I should be doing"* (P20). The fact sheet was perceived as a platform to seek further information. *"I really like websites that were already on there, so that you could immediately go off and find more information if you wanted to"* (P3). Three behaviour change sub-themes

were identified and included: (i) factsheet may promote behaviour change (improving lifestyle habits, encourage screening) *“I might actually have more calcium in my diet”* (P18); (ii) factsheet is unlikely to change behaviour (due to prior knowledge), and (iii) factsheet reinforced current behaviour. Most women agreed that the factsheet would be useful in promoting healthcare discussions, particularly relating to osteoporosis screening and treatment options. *“Yes, after reading I thought I probably should go and speak to my GP and look at getting a bone density scan”* (P17). Participants also believed that the factsheet would equip women with the knowledge required for them to make more informed healthcare choices. Thus, women often found the “Questions to Ask My Doctor” section of the factsheet relevant and helpful.

Women’s feedback and suggestions from the two rounds of interview were used to refine the factsheet (Supporting Information Table 3) to produce the final factsheet and infographic available at: [https://www.monash.edu/__data/assets/pdf_file/0009/1515186/FACT-SHEET_Early-Menopause-POI-and-Osteoporosis.pdf] and [https://www.monash.edu/__data/assets/pdf_file/0010/1515187/Early-Menopause_POI-and-Osteoporosis.pdf].

Discussion

This is the first study to provide a detailed assessment of Australian women with POI/EM’s knowledge gaps, health-behaviours, beliefs and information needs related to bone health. Women with POI/EM have significant knowledge gaps in their understanding of osteoporosis, unmet information needs and sub-optimal bone health related behaviours. Furthermore, deficiencies were identified in currently available online bone health related resources. These findings contributed to the development of a factsheet/Infographic, subsequently refined via interviews with consumers. Women with POI/EM perceived the factsheet/Infographic as an acceptable, user-friendly and informative educational resource.

A diagnosis of osteoporosis or previous fragility fracture was reported by approximately 20% of respondents, reflecting the increased risk of osteoporosis associated with POI/EM^{1,3}. Current guidelines recommend “measurement of BMD at initial diagnosis of POI should be considered for all women, but especially where there are additional risk factors”¹. In Australia, government reimbursed bone densitometry scans are available for women under age 45 years with hypogonadism. Bone densitometry will assist with identification of women with low BMD at potentially increased risk of fracture and by raising awareness for women and clinicians may facilitate prompt institution of HRT and aid adherence with HRT. Although lifestyle interventions and HRT are recommended as primary prevention strategies for

osteoporosis¹, few women with POI/EM reported adequate dietary calcium intake, physical activity and HRT use. This demonstrates the need for an overarching assessment of bone health and fracture risk that encompasses more than bone mineral density as determined by bone densitometry. Calcium intake < 1000 mg/day, lack of regular exercise HRT non-adherence, Vitamin D insufficiency and smoking were risk factors associated with low BMD in women with spontaneous POI⁴. Compared to previous studies^{6,9}, the frequency of HRT use by women was lower. This may reflect the prevalence of cancer diagnoses in our cohort, age >51 years of many participants, knowledge gaps (only 22.5% of participants answered the relevant OKAT question correctly), concerns regarding the risks of HRT^{6,9} or clinician knowledge gaps²⁶.

In accordance with previous studies in both pre- and older post-menopausal women^{16,24-26}, significant knowledge gaps regarding osteoporosis were apparent across multiple areas. A study of 467 Australian women aged 25-44 years reported an average OKAT score of 8.8¹⁶. Our findings are consistent with a previous systematic review²⁶, which identified knowledge gaps regarding osteoporosis consequences, treatment, prevention and risk factors apart from lack of exercise and low dietary calcium. Although women reported feeling confident in their ability to exercise and consume adequate calcium, poor awareness may have contributed to women's sub-optimal health behaviours. Consistent with previous literature regarding the relationship between osteoporosis knowledge, health beliefs, self-efficacy and health-related behaviours^{25,27,28}, a similar pattern of mixed results was observed in our study as some, but not all behaviours, were predicted by women's osteoporosis knowledge, health beliefs and self-efficacy. Positive associations between education interventions, knowledge and behaviour were observed in other populations at risk for osteoporosis^{26,29,30} and the potential benefits of addressing knowledge gaps in women with POI/EM should not be undermined.

Our study identified substantial shortcomings in current POI/EM bone health related resources consistent with a previous study of EM literature¹⁰. Thus, women with POI/EM may receive incomplete, conflicting and inaccurate information which may negatively impact upon their health choices. This reinforces the need for more evidence-based, comprehensible information regarding POI/EM and bone health.

In response to previous literature indicating that women with POI/EM desired more information⁷⁻⁹ and as indicated by best practice^{12,13}, the co-design approach resulted in the development of a relevant, understandable and readable factsheet which facilitated improved consumer understanding and knowledge. Motivation is a key factor for effective self-management in patients with chronic conditions³¹. As women with POI/EM reported

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feeling more motivated after reading the factsheet, this suggests a potential desire by women to engage in self-management which may include adoption of healthy behaviour patterns. Studies of women with chronic medical conditions (osteoporosis, polycystic ovary syndrome) have demonstrated intention to change or behaviour change after receiving educational resources ^{26,29,30,32}. However, systematic reviews of intervention studies indicated mixed results regarding osteoporosis education and behaviour change with (i) positive effects related to calcium intake, vitamin D intake and BMD testing; (ii) no effect regarding physical activity, medication adherence, fractures or quality of life; and (iii) mixed results regarding pharmacological treatments, including HRT ^{26,30}. This highlights the need for further research involving robust randomised controlled trials in this patient population. Women with POI/EM perceived the factsheet as a useful tool that empowered women to implement behaviour changes. The sense of regret felt by a minority of participants highlights the importance of timely provision of the factsheet as previous studies have identified dissatisfaction with information provided and inadequate knowledge as contributors to patient regret in healthcare choices ^{33,34}. The factsheet may also help to facilitate future patient-health professional interactions by fostering a physician-patient partnership and allowing women to engage more effectively with their doctors. With previous literature highlighting women's unmet information needs and dissatisfaction with care ⁷⁻⁹, the factsheet may help to improve overall management and satisfaction in women with POI/EM. However, our previous work revealing clinician knowledge gaps regarding HRT and bone health²⁶, indicates that health professional education is also required.

A key strength of this study is the mixed-method approach which facilitated the development of a factsheet/ infographic that was tailored to address women with POI/EM's information needs and incorporated evidence-based information. Furthermore, sequential consultative interviews with key stakeholders allowed for user-testing of the factsheet; thus, helping to improve the acceptability of the factsheet. Another strength of this study was the use of a diverse range of recruitment platforms to include women of varying aetiologies of POI/EM.

Limitations of this study include the use of non-probability sampling techniques which may have contributed to the disproportionate representation of women who have completed post-secondary education. This may have impacted upon the study's findings, particularly regarding: (i) osteoporosis knowledge and information needs and (ii) comprehensibility of the factsheet. However, information was present as a text dense fact sheet and an infographic which may be more acceptable to women with lower health literacy. Future research involving women of lower literacy levels and translation to languages other than English would be beneficial to ensure that the factsheet is applicable to a broad range of women. This study also relied upon women's self-reported menopause status. Nevertheless, several

different questions in the survey and interview screening process were used to confirm women's eligibility for the study. Recall bias was a potential limitation as most women were 5 or more years post POI/EM diagnosis; however, this enabled the exploration of women's experiences at different stages along the POI/EM journey.

Despite women with POI/EM's heightened risk of developing osteoporosis, women had significant knowledge gaps in their understanding of osteoporosis and sub-optimal bone health related behaviours. The novel co-designed bone health factsheet/infographic is an acceptable tool that addresses women with POI/EM's information needs, improving women's knowledge, empowerment and risk perception. In addition, the factsheet may also promote health-related behaviours in women and facilitate discussions with health professionals. Ultimately by promoting informed decision-making and greater partnership in care, the factsheet may ideally help to improve the health care and outcomes for women with POI/EM.

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Table 1: Demographic and clinical characteristics of women with Premature Ovarian Insufficiency (POI)/ Early Menopause (EM). The response rate was 300-316 for all variables except where specified.

Variable	Median (IQR) or Count (%)
Demographic Characteristics	
Age (Years)	54 (47-63)
Overseas born	67 (21.2)
Length of residence in Australia >10 years	309 (98.1)
Aboriginal /Torres Strait Islander descent	3 (0.9)
Metropolitan dwelling	193 (61.3)
Post-school qualification	227 (75.7)
Medical History	
Age of menopause (Years)	40 (38-43)
Time since POI/EM diagnosis	
Less than 1 year ago	6 (1.9)
1-4 years ago	49 (15.6)
More than 5 years ago	242 (76.8)
No diagnosis of POI/EM by a doctor	18 (5.7)
Aetiology of POI/EM	
Iatrogenic	174 (55.6)
Spontaneous	139 (44.4)
Diagnosis of cancer	178 (56.7)
Previous chemotherapy	138 (43.7)
Previous oophorectomy	66 (20.9)
Previous hysterectomy with oophorectomy	85 (26.9)
Diagnosis of osteoporosis	61 (19.3)
Osteoporosis Risk Factors	
Previous fragility fracture	65 (20.7)
Family history of osteoporosis	76 (24.1)
Diagnosis of vitamin D deficiency	81 (25.6)
≥2 co-morbidities ^a associated with osteoporosis	68 (21.5)
Loss of height >3cm	26 (8.4)
Current/past smoker	97 (30.8)
>3 alcoholic drinks/day	35 (11.2)
Dietary calcium intake <1200mg/day ^b	312 (98.7)
≤ 90 minutes of strenuous exercise per week ^c (n=240)	156 (65)
Osteoporosis Management	
Screened for osteoporosis	250 (79.9)
Current use of HRT ^d in women <51 without breast cancer (n=43)	12 (27.9)
Present or past use of other osteoporosis medicines ^e	55 (17.6)
Use of Other Medications	
Calcium supplement	113 (35.8)
Vitamin D supplement	171 (54.1)
Calcium and vitamin D supplement	95 (30.1)

CAM	126 (39.9)
Tamoxifen	20 (6.3)
Aromatase inhibitors or Zoladex	37 (11.7)

Data is presented as either median (IQR) or count (%).

POI: Premature Ovarian Insufficiency; EM: Early Menopause; HRT: Hormone Replacement Therapy;

CAM: Complementary and Alternative Medicine; IQR: Interquartile Range

^aCo-morbidities included were coeliac disease, chronic kidney disease, chronic liver disease, hyperthyroidism/parathyroidism, low vitamin D, rheumatoid arthritis, epilepsy, diabetes, malabsorption, prolonged glucocorticoid use and low/excess body weight.

^bDietary calcium intake was analysed using a validated calcium food frequency questionnaire.

^cCurrent recommendations regarding exercise by Osteoporosis Australia.

^dHRT use included systemic HRT and the combined oral contraceptive pill (COCP).

^eOsteoporosis medicines included bisphosphonates (oral/intravenous), raloxifene, denosumab and strontium.

Table 2: Women with Premature Ovarian Insufficiency (POI)/ Early Menopause (EM) osteoporosis knowledge

Osteoporosis Knowledge Items	Correct Answer	n	Frequency of correct answers (%)
Osteoporosis leads to an increased risk of bone fractures	True	313	98.7
Osteoporosis usually causes symptoms before fractures occur	False	313	48.6
Having a higher peak bone mass at the end of childhood gives no protection against the development of osteoporosis later in life	True	312	17.3
Osteoporosis is more common in men.	False	312	67.9
Cigarette smoking can contribute to osteoporosis	True	313	70
White women are at highest risk of fracture as compared to other races	True	311	13.2
A fall is just as important as low bone strength in causing fractures	True	311	58.2
By age 80, the majority of women have osteoporosis.	True	312	35.6
From age 50, most women can expect at least one fracture before they die.	True	311	23.8
Any type of physical activity is beneficial for osteoporosis	False	313	14.4
It is easy to tell whether I am at risk of osteoporosis by my clinical risk factors.	True	311	37.6
Family history of osteoporosis strongly predisposes a person to osteoporosis.	True	313	61.3
Sardines and broccoli are good sources of calcium for people who cannot take dairy products.	True	312	86.9
Calcium supplements alone can prevent bone loss.	False	313	64.5
Alcohol in moderation has little effect on osteoporosis.	True	313	26.2
A high salt intake is a risk factor for osteoporosis	True	313	16.9
There is a small amount of bone loss in the 10 years following the onset of menopause	False	311	7.1
Hormone therapy prevents further bone loss at any age after menopause	True	311	22.5
There are no effective treatments for osteoporosis available in Australia	False	313	55.3
Total OKAT score [Median (IQR)]		301	8 (6-10)

Data is presented as either median (IQR) or percentage of women who correctly responded (%). Bold statements are those which were answered correctly by at least 50% of respondents.

OKAT: Osteoporosis Knowledge Assessment Tool; IQR: Interquartile Range

Table 3: Demographic characteristics of participants who participated in Round 1 (n=10) and Round 2 (n=10) interview.

Demographic Details	Median (IQR) or count (%)	
	Round 1 (n=10)	Round 2 (n=10)
Age (Years)	47 (41.5-58.75) ^a	44.5 (42-48.25) ^a
Overseas Born	2 (20)	6 (60)
Highest educational qualification		
Year 12	3 (30)	0 (0)
Undergraduate degree/diploma	6 (60)	9 (90)
Postgraduate Degree	1 (10)	1 (10)
Work status		
No Paid Work	3 (30)	3 (30)
In Paid Work (Casual & Part/Full-Time)	7 (70)	7 (70)
Aetiology of POI/EM		
Iatrogenic due to cancer treatment	6 (60)	3 (30)
Iatrogenic due to non-cancer related causes	3 (30)	2 (20)
Spontaneous	1 (10)	5 (50)
Diagnosis of Osteoporosis/Osteopenia		
Yes	2 (20)	2 (20)
No	8 (80)	8 (80)
Time since POI/EM diagnosis (years)		
1-5	3 (30)	6 (60)
6-10	2 (20)	3 (30)
11-20	3 (30)	0 (0)
21-30	1(10)	0 (0)
More than 30	1(10)	1 (10)

Data is presented as either median (IQR) or count (%).

POI: Premature Ovarian Insufficiency; EM: Early Menopause; IQR: Interquartile Range

^aNo significant differences in age between the two interview rounds ($p=0.569$)

Figure legends

Figure 1: Osteoporosis health beliefs and self-efficacy

1A. Median scores for Osteoporosis health beliefs sub-scales. Data is presented as median (IQR). This 42-item self-reported questionnaire measuring health beliefs related to osteoporosis, is divided into seven sub-scales (shown on y-axis) containing 6 questions in each. Each item is scored subjectively on a Likert scale, from 1 (Strongly Disagree) to 5 (Strongly Agree). The possible score (shown on the x-axis) for individual sub-scales ranged from 6 (low perception) to 30 (high perception).

1B. Osteoporosis Self Efficacy scores. Data is presented as the proportion of women in each category (%). The five categories were condensed into 'Very confident' (combining responses to Score 4 and 5), 'Somewhat Confident' (Score 3) and 'Not Very Confident' (combining responses to Score 1 and 2). N=313

Figure 2: Quality assessment and Readability score of individual websites

Websites are colour-coded according to DISCERN rated quality: High [4-5] (Orange), Moderate [3] (Green), Low [1-2] (Blue). Readability level was assessed using the Flesch-Kincaid Grade level. Current readability recommendation threshold (Grade 8 or lower) is indicated by the bolded red line.

Figure 3: Central themes relating to the acceptability of factsheet

Analysis of the interviews revealed five overarching themes: content, design, emotional responses, perceived usefulness and clinical considerations. Each theme had sub-themes.

Figure 1A: Osteoporosis Health Beliefs Sub-scale Scores

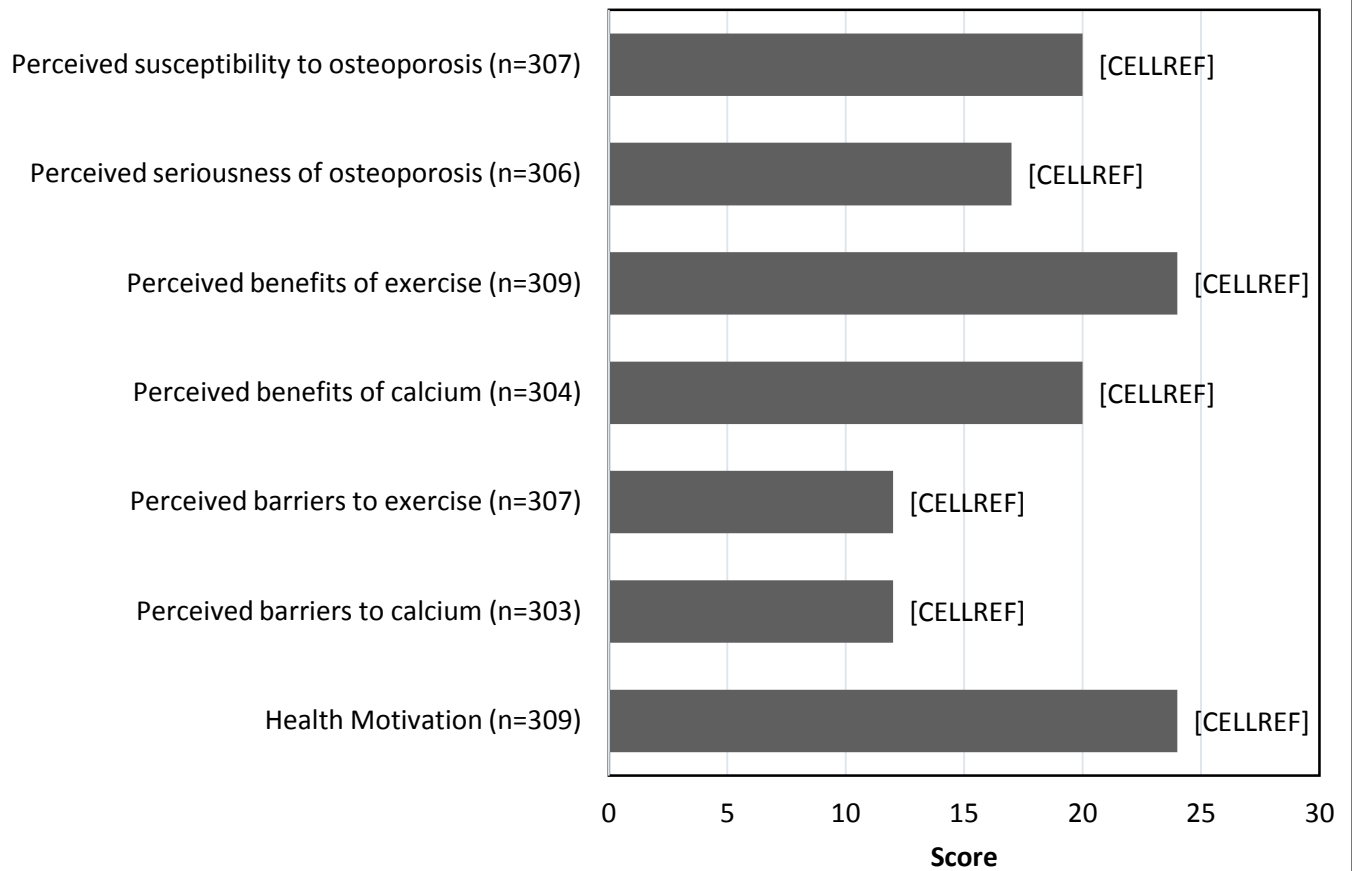


Figure 1B: Osteoporosis Self-efficacy Scores

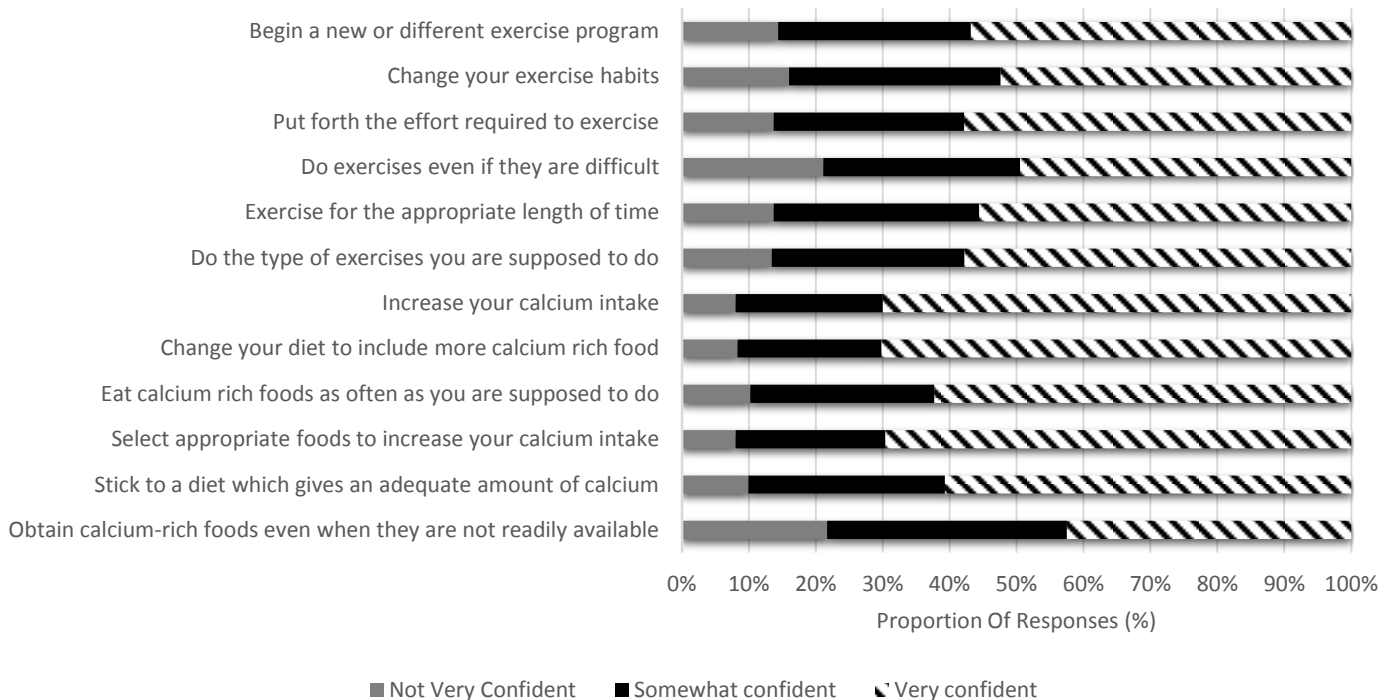


Figure 2 : Quality assessment and Readability score of individual websites



Abbreviations and weblinks:

Cancer Australia (www.canceraustralia.gov.au/sites/default/files/publications/bcmc-breast-cancer-early-menopause);

BMS: British Menopause Society (www.thebms.org.uk/members/full-consensus-statements/premature-ovarian-insufficiency);

ESHRE: European Society of Human Reproduction and Embryology, (www.eshre.eu/guidelines-and-legal/guidelines/management-of-premature-ovarian-insufficiency)

Jean Hailes (www.jeanhailes.org.au/health-a-z/menopause/premature-early-menopause);

34 Menopause (www.34-menopause-symptoms.com/early-menopause-about);

Menopause Matters (www.menopausematters.co.uk/pm-management);

MedicineNet (www.medicinenet.com/premature_menopause_medical_procedural_causes);

Your Hormones (www.yourhormones.info/endocrine-conditions/premature-ovarian-failure);

AMS: Australasian Menopause Society, AMS (www.menopause.org.au/hp/management/early-menopause);

NIH: National Institute of Health (www.nichd.nih.gov/health/topics/poi);

Healthy women (www.healthywomen.org/sites/default/files/nwhrc_healthupdate_menopause.pdf);

Mayo Clinic (www.mayoclinic.org/diseases-conditions/premature-ovarian-failure);

Early Menopause (www.earlymenopause.com/information);

Hormone.org (www.hormone.org/diseases-and-conditions/womens-health/primary-ovarian-insufficiency);

Webmd (www.webmd.com/menopause/premature-ovarian-failure)

Figure 3

