

*“Early Menopause
changes you. You
physically have
changed. You
emotionally
change. You
psychologically
change.”*

NHMRC GNT116008

**Early Menopause:
Implementation Research
Using the Experiences and
Perspectives of Women
and Health Professionals
to Translate Evidence into
Practice**

Final Report

2016–2022



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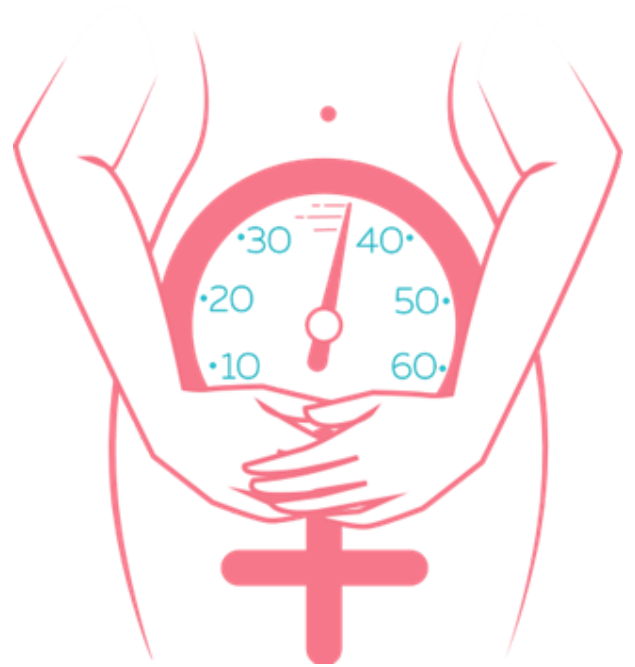
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Why do this research?

Early menopause (EM), menopause before age 45 years, occurs spontaneously or as a result of medical treatment and affects more than 1 in 10 women. EM is associated with negative impacts on physical/psychological/ social functioning, unmet information needs, delayed diagnosis, care variation and dissatisfaction with care. Providing evidence-based information and resources is important for high quality collaborative patient centred care, improved patient experience, promotion of best practice and optimal health outcomes. However, prior to this research project, web-based EM information and resources were lacking.



EM is menopause occurring before age 45 years



EM affects 12% of women worldwide

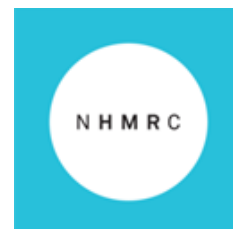
The people involved

Investigators

An interdisciplinary research team, including clinician researchers, biostatisticians, educators and social scientists conducted this research project in collaboration with women with EM and partners including consumer support groups, medical societies, non-government organisations, hospitals, universities and government.

Prof H Teede
Prof R Kokanović
A/Prof A Vincent
Prof R Hart
A/Prof J Boyle
Prof M Hickey
Dr K Johnston-Ataata
Dr J Flore
Dr L Yeganeh
Dr E Thong
Dr J Enticott
A/Prof A Earnest
Dr R Garad
Dr K Huynh

Our Partners



Transformative Research for Social Justice



Monash Partners
Academic Health Science Centre

What we aimed to do

1

Engage women with EM and health professionals

Interviews and surveys to find out women's and health professionals' needs, experiences and knowledge about EM.

2

Learn about the long-term health impacts of EM

Using Western Australian linked data to further investigate the long-term health impacts of EM

3

Develop a best practice care plan for clinicians

Assessment of current clinical EM guidelines to develop a 'best practice' management plan and share it with health professionals to improve EM patient care.

4

Co-develop a high quality EM digital resource

Co-development of a digital EM resource for women and health professionals using the findings of 1-3

5

Evaluate the EM digital resource

Assessment by women with EM and health professionals of the acceptability and the effect of the co-designed digital EM resource

6

Share our findings

Sharing the findings of this research with the community, health professionals and researchers.

What we discovered

1



In-depth interviews with 30 women highlighted low EM awareness, dissatisfaction with the diagnostic process, multiple disabling symptoms, significant personal/social impacts, uncertainty about health impacts and treatment, and difficulty accessing care.



A survey of over 250 women with EM indicated that women had mainly negative perceptions about EM and found it difficult to communicate with health professionals about certain topics including sexual and psychological concerns. Women with EM supported the development of a digital resource which included communication tools and evidence-based information.



A survey of over 700 Australian clinicians revealed knowledge gaps related to EM especially in relation to treatments. These gaps varied depending on the type of specialist or general practitioner. In-depth interviews with 16 multidisciplinary health professionals indicated the need for improved diagnosis, treatment, access and care options as well as quality resources.

2

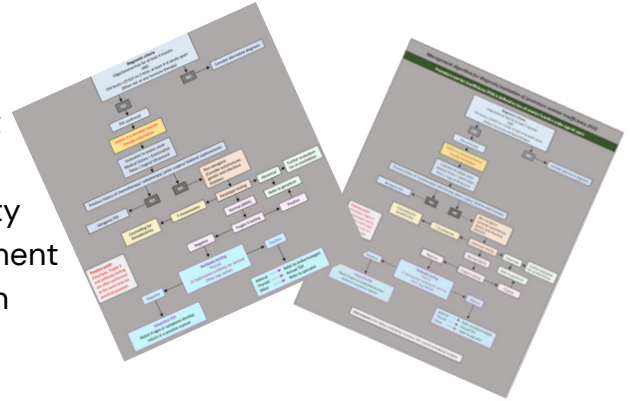


EM due to medical treatment is associated with an increased risk of death compared to women without EM. The risk of other health problems varied according to the cause of EM.

What we discovered

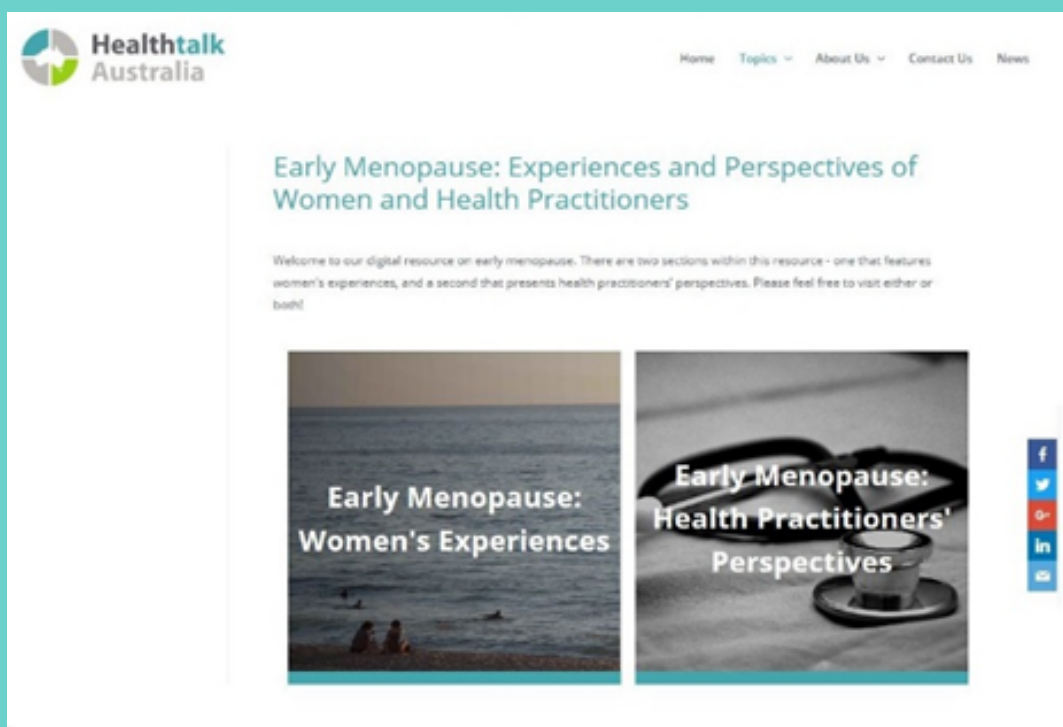
3

EM guidelines varied in quality with significant deficiencies seen. We summarized the recommendations from the two highest quality guidelines to create a diagnosis and management care plan, further refined using expert clinician feedback.



4

Two comprehensive, freely available, evidence-based digital resources, located on the Healthtalk Australia platform, were created based on international Healthtalk/ DIPEX methods, and using the findings from steps 1–3. The digital resource for women includes: video/ audio clips of women's experiences, EM question prompt list (a tool to help patient– health professional communication), evidence– based information, downloadable co–designed factsheets and links to other resources (Australian health and support services). The health professional digital resource includes video/ audio clips of health professionals' experiences, diagnosis/ management care plans and links to other resources. The digital resources were further refined following feedback from women and health professionals.



<https://healthtalkaustralia.org/early-menopause-experiences-and-perspectives-of-women-and-health-professionals/overview-womens-experiences/>

What we discovered

5

A study where 100 women with EM completed surveys before and after viewing the resource, showed that the digital resource was considered acceptable with an average satisfaction rating of 8/10. After viewing the resource, improvements in women's knowledge, illness perception, health related-empowerment, risk perception and menopausal symptoms were seen. Sixteen independent health professionals assessed the digital resource and most considered it useful or very useful and would recommend it to woman or other health professionals.



6

The digital resource was launched by The Honorable Gabrielle Williams, former Victorian Minister for Women, at Women's Health Victoria on November 4, 2019, in association with our partners and women with EM. Engaging our partners, our research has been shared via a wide variety of methods:

- a. Fifteen publications in scientific journals
- b. Publications in other media including newspapers, magazines, and social media
- c. Thirteen international and national presentations to health professionals and researchers (two were cancelled due to the COVID pandemic)
- d. Coinciding with World Menopause Day in 2019, we co-hosted three webinars for women with EM with our partners
- e. Multiple other presentations to the community
- f. Development of an online active learning module about EM for health professionals which includes the developed diagnosis/ management care plans.
- g. Web analytics from 1 November 2019 to August 1, 2022, revealed over 28,000 page views and approximately 6500 users. The top 3 sources for people to access the site were: google search, via invitation or other direct access to the URL and links to the resource from our partner, the Australasian Menopause society website (menopause.org.au). Most users were based in Australia (59%); however, the resource had international reach including the USA, UK, India and NZ. 'The most viewed content pages were 'Resources and information' and 'Early signs and symptoms'.

15

Scientific Publications

12+

Presentations

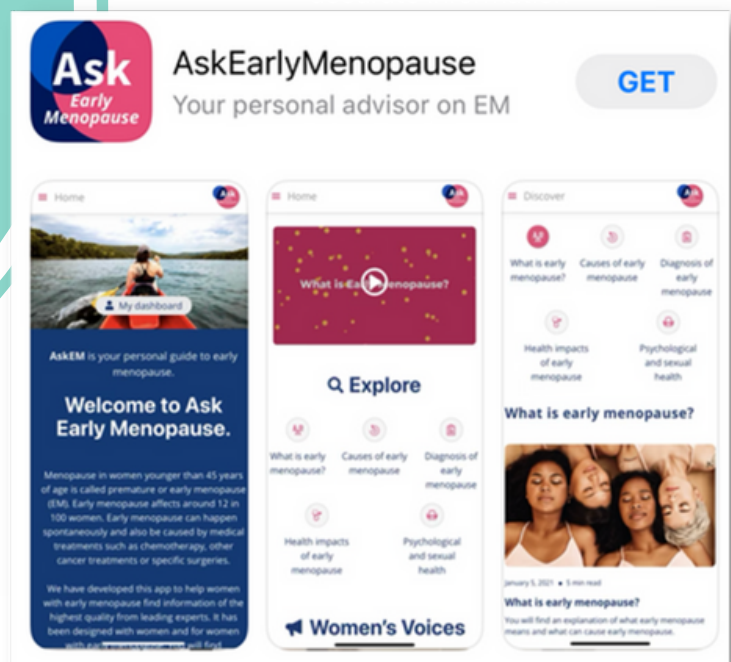
**28000+
Webpage
views**

Our achievements

We generated new knowledge regarding the impact of EM, needs and knowledge gaps of women and health professionals regarding EM

This project provides a model for successful interdisciplinary co-design research and implementation with the translation of findings to practical resources for women with a neglected health condition and the health professionals involved in their care to improve women's health and well-being.

This project has contributed to subsequent successful funding of the NHMRC Centre of Research Excellence: Women's health in Reproductive Life (CRE-WHiRL) and led to the development of a freely available App for women with EM (Ask Early Menopause) and international collaboration for updating international premature menopause guidelines.



Our outputs

Publications:

1. Yeganeh L, Johnston-Ataata K, Vincent AJ, et al. Co-designing an Early Menopause Digital Resource: Model for Interdisciplinary Knowledge Translation. *Semin Reprod Med.* 2020; 38(4-05): 315-22.
2. Yeganeh L, Boyle JA, Johnston-Ataata K, et al. Positive impact of a co-designed digital resource for women with early menopause. *Menopause.* 2022; 29(6): 671-9.
3. Yeganeh L, Boyle J, Teede H, Vincent A. Knowledge and attitudes of health professionals regarding menopausal hormone therapies. *Climacteric.* 2017; 20(4): 348-55.
4. Yeganeh L, Boyle JA, Wood A, et al. Menopause guideline appraisal and algorithm development for premature ovarian insufficiency. *Maturitas.* 2019; 130: 21-31.
5. Yeganeh L, Boyle J, Gibson-Helm M, et al. Women's perspectives of early menopause: development of a word cloud. *Climacteric.* 2020; 23(4):417-420.
6. Yeganeh L, Khan NN, Boyle JA, et al. Development and evaluation of an early menopause question prompt list. *Menopause.* 2020; 27(1): 102-9.
7. Yeganeh L, Vincent A, Gibson-Helm M, et al. Women's perceptions regarding early menopause eHealth resources to facilitate self-care. *Hum Reprod.* 2018; p. 439-40.
8. Flore J, Johnston-Ataata K, Kokanović R et al., 'Hormone replacement therapy and early menopause: Complexity, care and tinkering with medical technique' submitted.
9. Thong E.P, Hart R, Teede HJ, et al. Increased mortality and non-cancer morbidity risk may be associated with early menopause and varies with aetiology: An exploratory population-based study using data-linkage. *Maturitas.* 2022; 164: 60-66
10. Vincent AJ and Laven JS. Early Menopause/Premature Ovarian Insufficiency. *Semin Reprod Med.* 2020; 38 (4/05): 235-236.
11. Johnston-Ataata K, Flore J, Kokanović R. Women's Experiences of Diagnosis and Treatment of Early Menopause and Premature Ovarian Insufficiency: A Qualitative Study. *Semin Reprod Med.* 2020; 38(4-05): 247-255.
12. Johnston-Ataata K, Flore J, Kokanović R, et al. 'My relationships have changed because I've changed': biographical disruption, personal relationships and the formation of an early menopausal subjectivity. *Sociol Health Illn.* 2020; 42(7): 1516-1531.
13. Xu S and Vincent A. Premature ovarian insufficiency. Not 'too young for menopause'. *Medicine Today.* 2019; 20(9): 55-61.
14. Johnston-Ataata K, Flore J, Kokanović K, et al. Personal relationships and gender in the wake of cancer-related early menopause: Women's experiences. *Psycho-Oncology.* 2018, pp. 81-82.
15. Aleksova, J., M. Kuczynska-Burggraf, S. Ranasinha, and A. Vincent. "Information on early menopause: is the internet the place to search?." *Climacteric.* 2017; 20 (3): 248-255.

Our outputs

Other Publications:

1. The Conversation (February 2022)
2. RMIT University and Monash University Media release 'Silent sufferers of early menopause unite' (November 2019)
3. Australasian Menopause Society eChanges article (November 2019)
4. Newspapers– Sydney Morning Herald, The Age, Brisbane Times (3 November 2019)
5. National Breast Cancer Foundation media release (30 May 2022)
6. Online media outlets– Daily mail Australia, 10daily.com.au (November 2019)

Presentations:

1. Flore et al., Early menopause, social stigma and the complexities of embodied ageing. TASA Health Day, UNSW, NSW, Australia, 2017.
2. Vincent et al., Women's perspectives of early menopause: development of a Word cloud. 16th World Congress on Menopause, Vancouver, Canada, 2018.
3. Yeganeh et al., Women's perceptions regarding early menopause e-Health resources to facilitate self-care. The European Society of Human Reproduction and Embryology (ESHRE), 2018.
4. Yeganeh et al., Developing an early menopause question prompt list: women's information needs. 16th World Congress on Menopause, Vancouver, Canada, 2018.
5. Yeganeh et al., Appraisal of clinical practice guidelines of menopause management using AGREE II instrument to inform the development of an early menopause/premature ovarian insufficiency. 16th World Congress on Menopause, Vancouver, Canada, 2018.
6. Johnston-Ataata et al., Personal Relationships and Gender in the Wake of Cancer-related Early Menopause: Women's Experiences, 20th World Congress of Psycho-Oncology and Psychosocial Academy, Hong Kong, 2018.
7. Vincent et al., Experiences of Early Menopause. 16th World Congress on Menopause, Vancouver, Canada, 2018.
8. Johnston-Ataata K et al. Overview of EM project & resources. Sexual & Reproductive Health Community of Practice, Women's Health Victoria, VIC, Australia, 2020.
9. The World Congress of Menopause 2020 was cancelled due to the COVID-19 pandemic and therefore two oral presentations were cancelled. (i) Vincent et al. Evaluation of a co-designed early menopause digital resource Knowledge translation: Development of a co-designed early menopause digital resource. International Menopause Society 17th World Congress, VIC, Australia, 2020; and (ii) Yeganeh et al., Knowledge translation: Development of a co-designed early menopause digital resource. International Menopause Society 17th World Congress, VIC, Australia, 2020.
10. Consumer webinars 2020: Three consumer multidisciplinary interactive webinars were held in October/ November 2020 in association with project partners: Women's Health Victoria, Counterpart and Breast Cancer Network Australia on the topics of Spontaneous early menopause, Early menopause and gynecological cancer and Early menopause and breast cancer respectively which are available on the corresponding organisation websites.
11. Hosted by breast cancer support organisation, 'Think Pink', in person talks and webinars were delivered to women and breast care nurses regarding early menopause.
12. Kate Johnston-Ataata et al., Early Menopause: Experiences and perspectives of women and health practitioners; Overview and evaluation results. DIPEx International Meeting, Oxford, UK, 2019

We thank you for your support of our project



Launch of the digital resource by The Honorable Gabrielle Williams, former Victorian Minister for Women, at Women's Health Victoria on November 4, 2019, in association with our partners and women with EM

Acknowledgements

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- Members of the Reference group
- Members of the Steering Committee
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- Our funders



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Transformative Research for Social Justice



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