

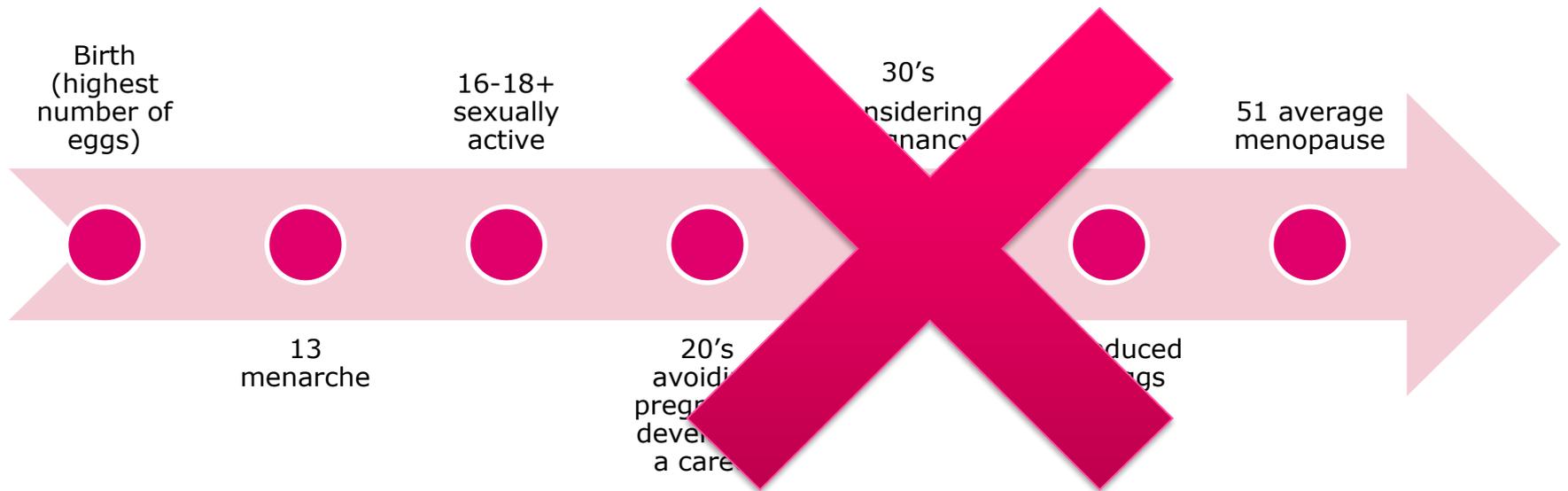
# **MENOPAUSE & FERTILITY INFORMATION NEEDS OF WOMEN WITH GYNAECOLOGICAL CANCERS**

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With Thanks to Prof Martha Hickey, Dr Naomi Thomas, A/Prof Meinir Krishnasamy, Dr Pat Nicholson



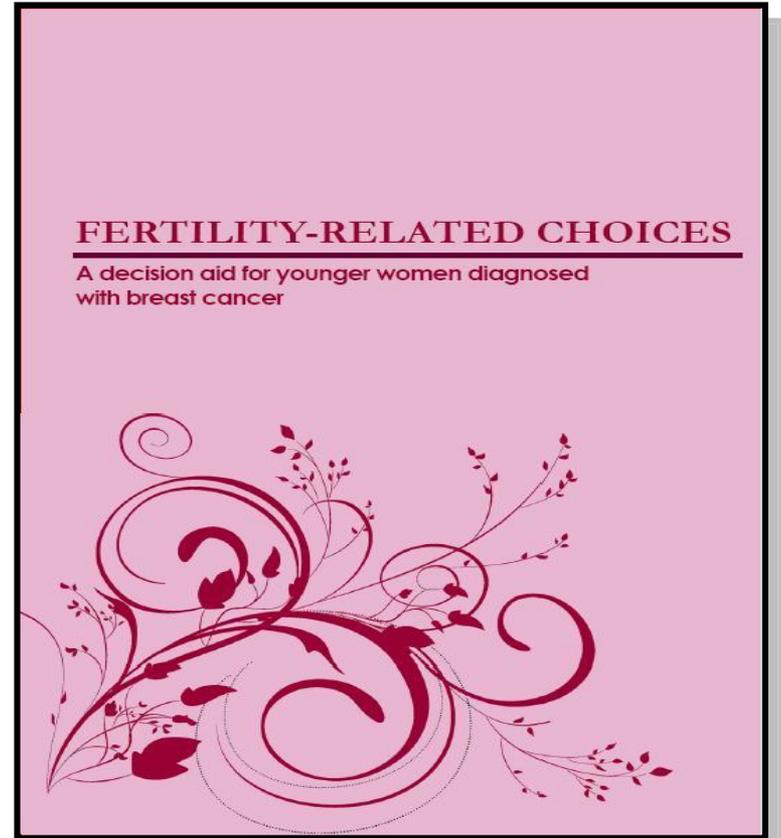
# FERTILITY & MENOPAUSE CONTINUUM



# BREAST CANCER

- Thewes et al (2003) & Thewes et al (2005)
- Fertility and menopause information needs of Australian women with breast cancer.

(Peate et al., 2011)



# AIM & OBJECTIVE

## **Aim**

To explore and define the scope of menopause and fertility information needs of premenopausal women with newly diagnosed gynaecological cancers.

## **Objective**

To develop an understanding of women's menopause and fertility information requirements, to guide clinicians in the provision of focused information and ensure women are adequately informed about menopause and fertility prior to commencing treatment.



# RESEARCH QUESTIONS

1. What are the information needs of premenopausal women diagnosed with a gynaecological cancer?
2. To what degree are the menopause and fertility information needs of premenopausal women with gynaecological cancers currently being met?
3. How satisfied are women with the information they receive pertaining to menopause and fertility prior to commencing treatment?



# OVERVIEW OF STUDY

- Focus groups and satisfaction scale
- Facilitated by nurse and psychologist
- Recorded and transcribed
- Who?



| Characteristics           | N  | %    |
|---------------------------|----|------|
| <b>Age</b>                |    |      |
| 20 – 24                   | 2  | 9.1  |
| 25 – 29                   | 3  | 13.6 |
| 30 – 34                   | 5  | 22.7 |
| 35 – 39                   | 3  | 13.6 |
| 40 – 45                   | 9  | 40.9 |
| <b>Marital Status</b>     |    |      |
| Single, never married     | 11 | 50.0 |
| Married                   | 8  | 36.4 |
| Separated                 | 1  | 4.5  |
| Divorced                  | 2  | 9.1  |
| <b>Number of Children</b> |    |      |
| None                      | 13 | 59.1 |
| 1                         | 4  | 18.2 |
| 2                         | 4  | 18.2 |
| 3                         | 1  | 4.5  |



| Characteristics                    | N  | %    |
|------------------------------------|----|------|
| <b>Cancer Diagnosis</b>            |    |      |
| Uterus                             | 1  | 4.5  |
| Endometrium Corpus                 | 2  | 9.1  |
| Cervix                             | 6  | 27.3 |
| Endocervix                         | 2  | 9.1  |
| Ovary                              | 10 | 45.5 |
| Genital Tract                      | 1  | 4.5  |
| <b>Treatment</b>                   |    |      |
| Hysterectomy, BSO                  | 2  | 9.1  |
| Hysterectomy, ovarian conservation | 6  | 27.3 |
| Hysterectomy, BSO, chemotherapy    | 5  | 22.7 |
| Hysterectomy, BSO, chemoradiation  | 1  | 4.5  |
| Chemoradiation                     | 2  | 9.1  |
| USO, chemotherapy                  | 5  | 22.7 |
| Chemotherapy, BSO                  | 1  | 4.5  |



| Degree of Satisfaction                       | N | %    |
|--|---|------|
| <b>Impact on Future Fertility</b>            |   |      |
| Not applicable                               | 2 | 9.5  |
| I can't remember being given any information | 1 | 4.8  |
| Not at all satisfied                         | 0 | 0.0  |
| Slightly satisfied                           | 3 | 14.3 |
| Moderately satisfied                         | 6 | 28.6 |
| Very satisfied                               | 5 | 23.8 |
| Completely satisfied                         | 4 | 19.0 |
| <b>Fertility Preservation Options/Offers</b> |   |      |
| Not applicable                               | 4 | 19.0 |
| I can't remember being given any information | 4 | 19.0 |
| Not at all satisfied                         | 2 | 9.5  |
| Slightly satisfied                           | 3 | 14.3 |
| Moderately satisfied                         | 5 | 23.8 |
| Very satisfied                               | 1 | 4.8  |
| Completely satisfied                         | 2 | 9.5  |

| Degree of Satisfaction                       | N | %    |
|--|---|------|
| <b>Impact on Menopause Status</b>            |   |      |
| Not applicable                               | 1 | 4.8  |
| I can't remember being given any information | 2 | 9.5  |
| Not at all satisfied                         | 0 | 0.0  |
| Slightly satisfied                           | 4 | 19.0 |
| Moderately satisfied                         | 8 | 38.1 |
| Very satisfied                               | 5 | 23.8 |
| Completely satisfied                         | 1 | 4.8  |
| <b>Management of Menopause Symptoms</b>      |   |      |
| Not applicable                               | 5 | 23.8 |
| I can't remember being given any information | 1 | 4.8  |
| Not at all satisfied                         | 1 | 4.8  |
| Slightly satisfied                           | 4 | 19.0 |
| Moderately satisfied                         | 3 | 14.3 |
| Very satisfied                               | 6 | 28.6 |
| Completely satisfied                         | 1 | 4.8  |



# THEMES

7 Key themes identified were;

- Women's experience of menopause;
- Timely interventions for menopause symptoms;
- The emotional impact of infertility;
- Treatment urgency and fertility preservation;
- Timing and delivery of information;
- Addressing unmet information needs; and
- Rapport with clinicians and satisfaction with information.



# EXPERIENCE OF MENOPAUSE



- Commonly women wanted more information about what to expect from menopause.
- Felt concerned and unprepared for menopause.

*Amanda: "I didn't really have too much of a concept of it [menopause] so I didn't know how it would affect me until it hit."*

(Sekse et al., 2010)

## EXPERIENCE OF MENOPAUSE

*Fatima: "I'm really getting mad in the night time, oh no, I can't sleep, ... like water pouring on my body, all my body is sweating"*

*Emma: "I think you need to be aware of the difference between what's happening because of the chemo and what's happening because of the menopause ... she (menopause specialist) said, 'Hot flushes', I said, 'Yeah but that could be from the chemo'"*



# TIMELY INTERVENTION FOR MENOPAUSE SYMPTOMS

- Unprepared for symptoms
- Most significant for women who had a BSO or concurrent chemoradiation
- VMS most commonly reported
- Broad range of symptoms attributed to menopause
- Confusion about what was treatment side effects, cancer symptoms and menopause



# TIMELY INTERVENTION FOR MENOPAUSE SYMPTOMS

- Women want access to menopause specialists but frustrated by waiting times
- Symptoms are linked to distress

*Eva: "I was having all the hot flushes and night sweats and everything and I was like, I didn't initially realise it was going to be that bad ... I had an appointment with the menopause clinic but it was months down the track, at least two months...Why am I feeling like this?"*



# EMOTIONAL IMPACT OF INFERTILITY

- Women experience a range of feelings
- Frequently expressed regret
- Some women weren't bothered by their lack of choice
- Potential to change over time (↑ regret)
- Regardless of having children or not, women felt regret about not having had the discussion about fertility preservation, expressing a desire to know what options were available.

(Armuaud et al., 2012; Carter et al., 2010).



## EMOTIONAL IMPACT OF INFERTILITY

*Rachel: "It's probably more important now than it was then ... I've had time to sort of think about it all a bit more ... when you're diagnosed during the throes of it you just do what you're sort of told almost, and it wasn't important to me then whereas now I've sort of thought, oh that's a real shame that I didn't - I wonder if I should have looked into it a bit more to see what they could have done"*

(Carter et al., 2010; Nakayama et al., 2009; Thewes et al., 2005)



## EMOTIONAL IMPACT OF INFERTILITY

*Lauren: "But as far as fertility, I think that it didn't really come up as a question of whether I wanted to know or wanted to do anything about it, it was sort of a discussion that the doctor had kind of decided that I was almost 39, didn't have a partner, didn't have any children, the window was closing and in fact his words were 'the window is closing' ... it was kind of taken off the table as say – there was no discussion about preservation"*

(Tschudin et al., 2010)



# TREATMENT URGENCY & FERTILITY PRESERVATION

- Balancing urgency of treatment and fertility preservation
- Desire to get it out

*Melissa: "And then it sort of – I guess by that time it was I'd rather get whatever is in there out, and really worry about it afterwards, sort of thing."*



# TREATMENT URGENCY & FERTILITY PRESERVATION

- In-depth information about fertility preservation
- Acceptance and normalisation of FP by oncologists
- Lack of clarity about the what is involved in preserving fertility.

*Emma: "I just said, 'Look it's my understanding that it's going to take months if they want to harvest eggs or whatever' and he said, 'Yeah that's true', and I said, 'Well don't worry about it because surgery's more important', so I had the full hysterectomy"*

(Armuaud et al., 2012; Reh et al., 2011)



# TIMING & DELIVERY OF INFORMATION

- Factors influencing meeting information needs include;
  - specialist referrals,
  - verbal and written information,
  - follow up contacts,
  - age appropriate resources,
  - presence of support person
  - rapport with clinicians.
- Not being able to obtain detailed enough information or only being able to find “motherhood” statements that did not address their needs.



## TIMING & DELIVERY OF INFORMATION

*Susan: "I watched the DVD because they kept hassling me and asking me if I had... I ended up watching it but I kind of ignored that part [menopause] because that wasn't my problem at the time ... but maybe now like straight after your treatment would be a good time, for me, it would be."*



## ADDRESSING UNMET NEEDS

- Shock at diagnosis and limited ability to absorb information about fertility and menopause.
- Younger women identified the the importance of age appropriate information
- Filtering of information
- Most women described searching the internet for information.



## ADDRESSING UNMET NEEDS

*Fiona: "And the most thing I worry about is just like losing my ovaries maybe ... I will become half lady and half man... I think giving more information is good so yeah I don't want to just rely on Google"*

- Beneficial to have;
  - trusted websites,
  - cancer support resources
  - contact numbers for clinicians



## ADDRESSING UNMET NEEDS

*Claire: "I think the big thing with the age-appropriate thing because, you know, when I was told about all this, I was 20 at the time and I was just sort of thinking like I wasn't even considering about anything in regards to you know having kids or not having kids or when or how or whatever"*



## RAPPORT WITH CLINICIANS

- Important to support decision making, information provision and acceptance of referrals.
- Women also described the importance of having consistent care providers.
- Fertility information from appropriate specialists

(Thewes et al., 2005; Nakayama et al., 2009)



## RAPPORT WITH CLINICIANS

*Anne: "think maybe, like, what would have worked for me maybe is a separate appointment purely about that... because every time I was seeing an oncologist, it was all about the treatment... we'd brush over the menopause and fertility and stuff, but if there was a chance to have a separate appointment with one of the menopause staff or fertility staff or something like that, then you'd probably be more prepared and be able to ask all those questions"*

(Lee et al., 2006)



## WHERE TO FROM HERE?

- Catalogue of trusted information resources
- Integration of specialist fertility and menopause services with cancer services
- Explore the beliefs of clinicians working in cancer care about offers for fertility preservation
- Testing of information resources for women with gynaecological cancers in reducing decisional regret
- Future studies should be inclusive of rural and culturally diverse women's experiences



# RESOURCES

AMS: <http://www.menopause.org.au/for-women/information-sheets>

Fertile Hope: <http://www.livestrong.org/we-can-help/fertility-services/>

ASCO: <http://www.asco.org/quality-guidelines/fertility-preservation-patients-cancer-american-society-clinical-oncology>

<http://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/fertility>

The Women's:

<https://thewomens.r.worldssl.net/images/uploads/fact-sheets/Treating-hot-flushes-non-hormonal-therapy.pdf>

<https://www.thewomens.org.au/patients-visitors/clinics-and-services/menopause/menopause-symptoms-after-cancer/>

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| Hormonal Treatment   | Radiotherapy           |
| Cancer Organisations |                        |

# REFERENCES

- Armund, G. M., et al. (2012). Sex differences in fertility-related information received by young adult cancer survivors. *J Clin Oncol*, 30(17), 2147-2153.
- Carter, J., et al. (2010). Cancer-related infertility in survivorship. *Int J Gynecol Cancer*, 20(1), 2-8. doi: 10.1111/IGC.0b013e3181bf7d3f
- Lee, S. J., et al. (2006). ASCO recommendations on fertility preservation in cancer patients. *J Clin Oncol*, 24(18), 2917-2931.
- Nakayama, K., et al. (2009). Receiving information on fertility- and menopause-related treatment effects among women who undergo hematopoietic stem cell transplantation: changes in perceived importance over time. *Biol Blood Marrow Transplant*, 15(11), 1465-1474.
- Peate, M., et al. (2011). It's now or never: fertility-related knowledge, decision-making preferences, and treatment intentions in young women with breast cancer--an Australian fertility decision aid collaborative group study. *J Clin Oncol*, 29(13), 1670-1677.
- Reh, A. E., Lu, L., Weirnerman, R., Grifo, J., Krey, L., & Noyes, N. (2011). Treatment outcomes and quality-of-life assessment in a university-based fertility preservation program: results of a registry of female cancer patients at 2 years. *J Assist Reprod Genet*, 28(7), 635-641.
- Sekse, R. J., Raaheim, M., Blaaka, G., & Gjengedal, E. (2010). Life beyond cancer: women's experiences 5 years after treatment for gynaecological cancer. *Scand J Caring Sci*, 24(4), 799-807.
- Thewes, B., et al. (2003). The fertility- and menopause-related information needs of younger women with a diagnosis of breast cancer: a qualitative study. *Psycho-Oncology*, 12(5), 500-511.
- Thewes, B., et al. (2005). Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *Journal Of Clinical Oncology*, 23(22), 5155-5165.
- Tschudin, S., Bunting, L., Abraham, J., Gallop-Evans, E., Fiander, A., & Boivin, J. (2010). Correlates of fertility issues in an internet survey of cancer survivors. *J Psychosom Obstet Gynaecol*, 31(3), 150-157





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