



THE UNIVERSITY OF  
MELBOURNE



## Challenges in developing low literacy e-health interventions: Research in practice

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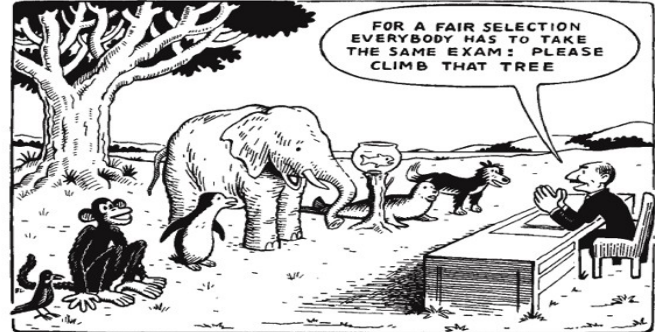
@DrPeate

Dr Peate and this study is supported by an Early Career Fellowship from the National Breast Cancer Foundation.



~ 60% of adults  
have Low Health  
Literacy (LHL)

Do not have the  
minimum literacy skills  
required to 'meet the  
complex demands of  
everyday life'.<sup>2</sup>





## Low Health Literacy<sup>1,2</sup>

Lack skills to gain access to, understand and use information to support good health



Health  
disempowerment<sup>3</sup>



Adverse health  
outcomes<sup>4,5</sup>



# Two components of health literacy

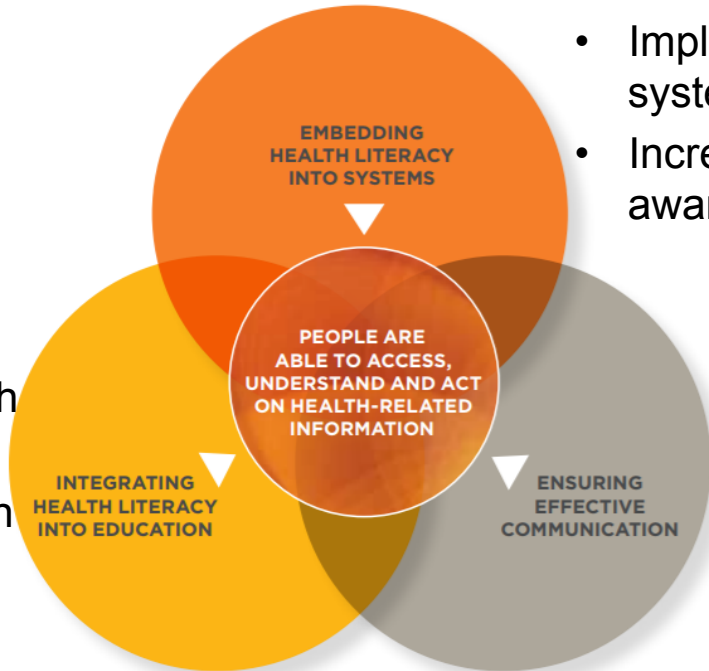


Source: Parker R, *Measuring health literacy: Why? So what? Now what?* In: Hernandez L (ed), *Measures of Health Literacy: Workshop Summary; Roundtable on Health Literacy*. 2009.



# Addressing Health Literacy

- Educating consumers and healthcare provider
- Population health programs
- Health promotion strategies
- School health education
- Social marketing



- Implementing systems/ policies
- Increasing awareness
- Providing appropriate resources
- Supporting effective partnerships

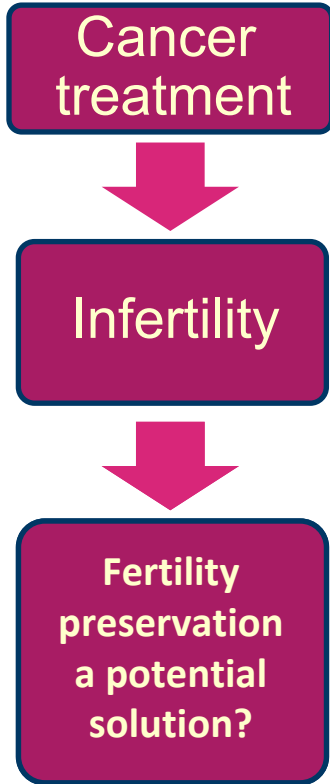


- **Aim:** To develop and evaluate a low-health literacy fertility-related decision aid (DA) for young women with early breast cancer.

fertility  
**CHOICES**



# The setting



“...Aside from my own health, children are the MOST important thing to me now...” – 28 yrs

- Ability to have children in the future is important.<sup>1-3</sup>
- Concerns can influence treatment decisions.<sup>4,5</sup>
- Impaired fertility → quality of life, sexual wellbeing, identity, self-esteem, relationships, distress, regret.<sup>4-7</sup>



- Vulnerable time / time sensitive → reliance on HCP
- No clear best option
- Complex information
- No FP discussion → regret  
→ less satisfaction<sup>4</sup>
- Recommended by clinical guidelines
- Not routinely discussed / no recollection<sup>3</sup>



**NEED DECISION SUPPORT (DA)**





fertility  
**CHOICES**



Breast Cancer  
and Fertility



Fertility  
Options



What's Best  
for Me?



More  
Resources

Results | My Account | Logout

Search



## A fertility guide for women with breast cancer

This website tells you about how breast cancer treatment can affect your chances of having a baby in the future. It also helps you make decisions about fertility preservation treatments - medical treatments that might increase your chances of having a baby after cancer.

 Topics

### Breast Cancer and Fertility

- Breast cancer treatment
- Female fertility
- Breast cancer treatment and fertility
- Pregnancy after cancer treatment

Fertility Options



# Low health literacy features

Year 5 reading level

Allow patient control over information access

fertility  
CHOICE

Breast Cancer & Fertility

Fertility Options

What's best for me?

More Resources

Search

HOME >> FERTILITY OPTIONS >> FREEZING EMBRYOS BEFORE CHEMOTHERAPY

Freezing embryos before chemotherapy

What is IVF?

What are the chances of IVF working?

Will IVF affect your breast cancer?

Other issues

Side Effects

Freezing eggs before chemotherapy

What is egg freezing?

What are the chances of egg freezing working?

Where do you go to have eggs frozen?

## Freezing embryos before chemotherapy

**OVERVIEW**

- This will delay chemotherapy by about 2 weeks.
- This involves drugs and injections, as well as a small surgery that you will be asleep for.
- This is only an option for women with a male partner or a sperm donor.
- If using a partner's sperm, frozen embryos often cannot be used if a couple breaks up.

Embryo freezing involves a treatment called In Vitro Fertilisation (IVF).

Highlight essential information

Limit the number of messages

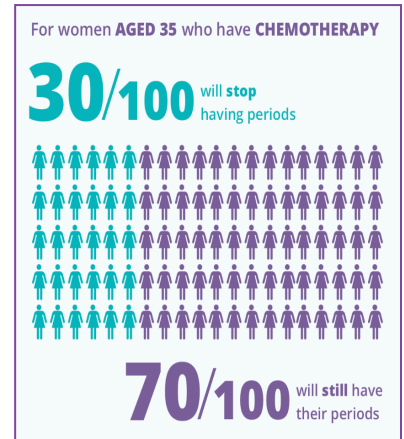
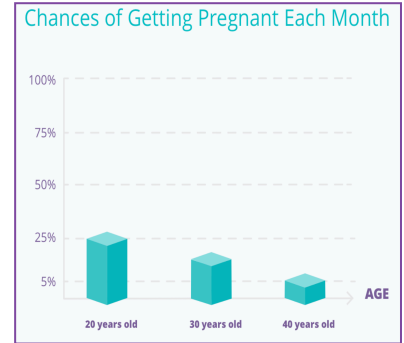
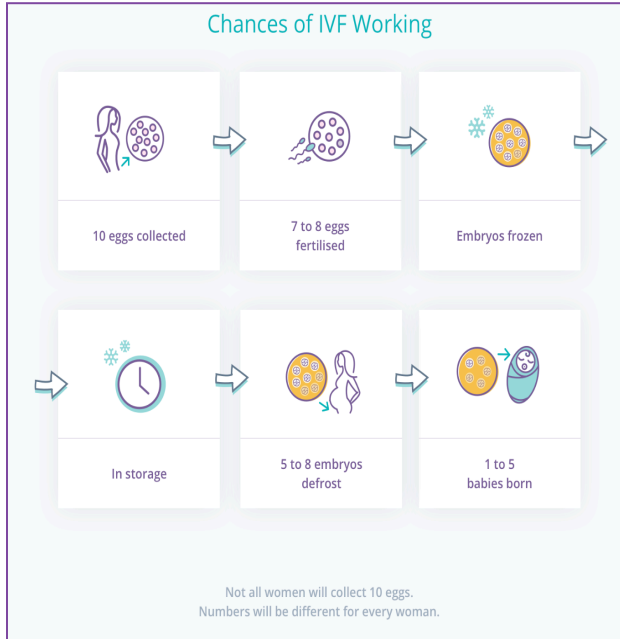
Bullet points



# Low health literacy features

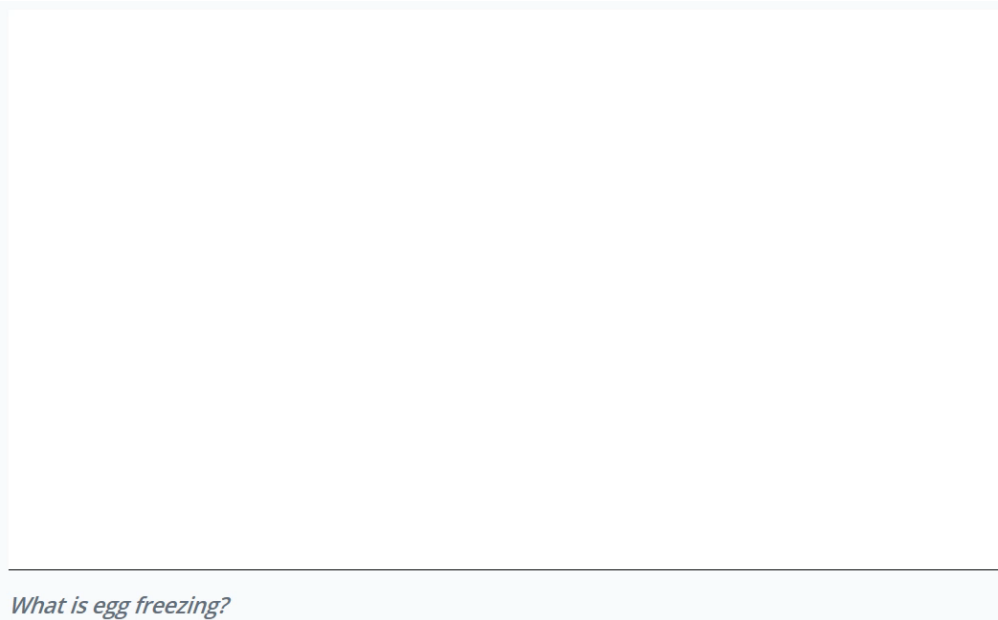
Present numerical information in tables/ pictographs

Easy to follow visuals





## Delivering information in different ways – text, pictures and animations





# Low health literacy features



## Quick Review

Chemotherapy can affect fertility by:

Causing amenorrhoea (stopping a woman's periods)

- ✓ Yes, chemotherapy can affect fertility by causing a woman's periods to stop. Chemotherapy can also damage a woman's eggs.

Damaging a woman's eggs

Some cancer drugs are taken for years. This means a woman's fertility may lower because her eggs will get older in this time.

True

False

- ✗ A woman's fertility will naturally lower over this time.

Use a “teach-back” method to improve comprehension (patient interaction)





## Fertility

Breast cancer treatment

Female fertility

Breast cancer treatment and fertility

Pregnancy after cancer treatment

Is this page helpful?



The most important thing that affects your chances of having a baby naturally is your age.

- Women are born with all the eggs they will ever have. They cannot make more.
- Over time women lose their eggs, either in their period or because the eggs die naturally.
- This drop in the number and quality of eggs leads to **lower chances of having a baby as you get older.**

Less eggs and lower quality eggs as you age could mean:

- Sperm are not able to **fertilise** an egg;
- A **miscarriage**; or
- Medical problems or d

### **Fertilise;**

When a woman's egg joins with a sperm.



Hover over definitions:




## Patient interaction through values clarification:

The screenshot displays a patient decision aid interface. On the left is a sidebar with a red header "What's Best for Me?" and a purple background. The sidebar contains a vertical menu with four items: "The Decision", "Pros", "Cons", and "Your Results". The "Pros" item is highlighted with a red bar. Below the menu is a progress indicator showing "Progress 10 / 10" with a full white bar. At the bottom of the sidebar, there is a feedback section titled "Is this page helpful?" with two circular buttons: one with a checkmark and one with an 'x'.

The main content area contains two survey questions. The first question is "How important is having a baby after cancer treatment?" with a sub-question "How important is this to you?". Below it is a horizontal bar chart with three segments: "NOT REALLY" (teal, approximately 40% width), "SOMEWHAT" (light grey, approximately 30% width), and "VERY" (light grey, approximately 30% width). The second question is "How important is doing something about your fertility now, rather than after your cancer treatment?" with a sub-question "How important is this to you?". Below it is a horizontal bar chart with three segments: "NOT REALLY" (light grey, approximately 30% width), "SOMEWHAT" (light grey, approximately 30% width), and "VERY" (teal, approximately 40% width).



- Feedback – deliver summary information based on patient interaction
- Tailoring – personalised information

What's Best for Me? 

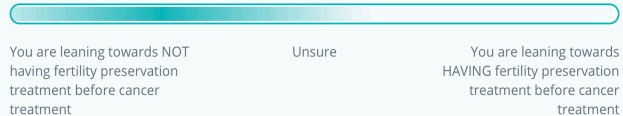
- The Decision
- Pros
- Cons
- Your Results

Progress 10 / 10

[Is this page helpful?](#)

## How sure do you feel?

Based on your answers, the shaded bar below shows how you might feel about having fertility preservation treatment before chemotherapy.



## What does this mean?

*You are leaning towards NOT having fertility preservation treatment before cancer treatment*

- Based on your answers, fertility preservation before cancer treatment may not be the best option for you.
- This means waiting until after cancer treatment to see if you can get pregnant.
- You can talk to your health care team more about this to help you make a final decision.

*We noticed you answered some questions that you might want to look into further:*

- You said that you were worried about fertility preservation delaying your cancer treatment. You can talk to your health care team about the timing of your cancer treatment, and the options that do not delay cancer treatment (ovarian tissue freezing, ovarian suppression).
- You said that you were worried about fertility preservation treatment affecting your cancer. You can talk to your health care team about the chances of fertility preservation affecting your cancer.
- You said that you were worried about passing on a cancer gene to a child in the future.



- **Content:**
  - Turning a lot of information into a concise yet comprehensive tool
  - Consistency and health literacy throughout tool – many revisions needed with small adjustments each time
- **Communication with web designers...**
  - Request a project coordinator with attention to detail → spent a lot of time reviewing and correcting careless errors
- **Time and cost!**

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**Web developers:** Light Creative.

This study is funded by the National Breast Cancer Foundation.

**Special thanks to consumers and participants**