

Sexual Wellbeing After Cancer

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RUSH UNIVERSITY
MEDICAL CENTER

IT'S HOW MEDICINE

SHOULD BE



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SYDNEY



- Update on Rekindle in Australia
 - Overview of design and content
 - Feasibility and acceptability
 - Lessons learned
- New innovations in the US
 - Novel psychosexual resource for Latina cancer survivors
 - Training clinicians to address sexual concerns

Principles for Intervention



- ✓ Facilitate communication with the partner
- ✓ Treat the underlying cause where possible (physical, psychological, social)
- ✓ Minimise effects of anatomical changes, e.g. use of vaginal dilators
- ✓ Provide symptom relief (e.g. lubricants, moisturisers)
- ✓ Provide information/advice on alternative methods for showing intimacy, and for giving and receiving sexual pleasure
- ✓ Refer to specialised services where required

Rekindle Stakeholders

Phyllis Butow
Ilona Juraskova
Judy Kay
Kevin McGeechan
Haryana Dhillon
Fran Boyle
Zac Seidler



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SYDNEY

Annie Miller
Amelia Beaumont
Trisca Kumar



Lori Brotto



Lee Ritterband



Sylvie Lambert



McGill

George Fishman



Kim Hobbs
Sandra Turner



Health
Western Sydney
Local Health District

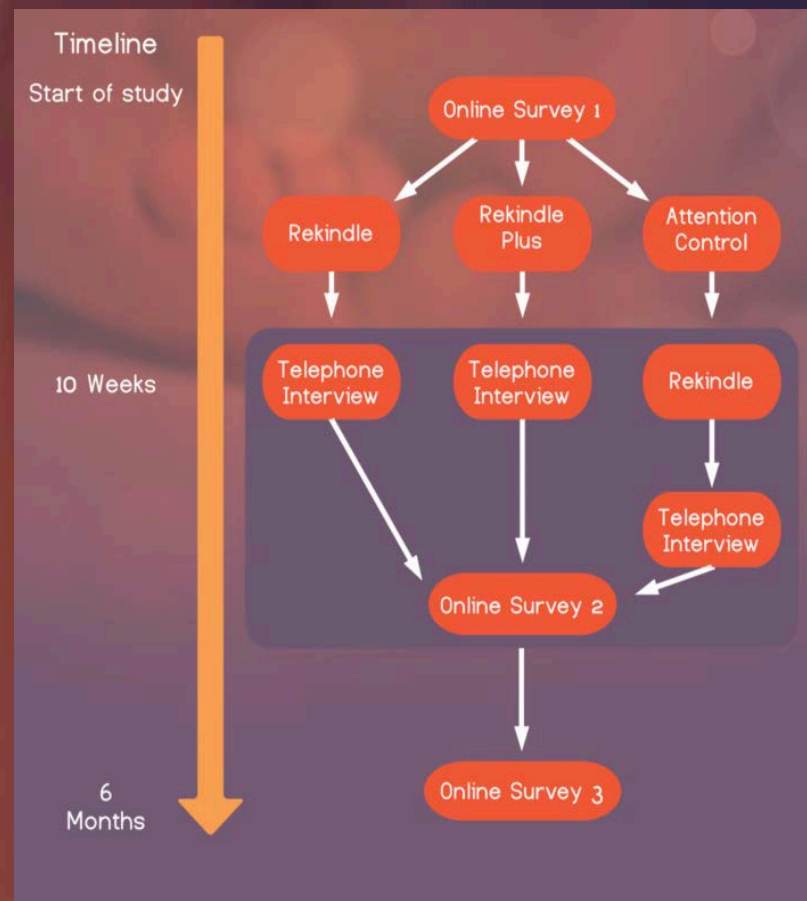
Wanda Lawson



Australian Government
Australian Research Council

Rekindle's Aims

- 1) Develop *Rekindle* as a personalized, intelligent web-based psycho-educational resource that is theoretically guided to support users' long term learning to address sexual concerns for cancer survivors and their partners, and demonstrate its acceptability.
- 2) Determine which modality of *Rekindle* (self-led or self-led plus telephone support) is most feasible and encourages greater completion of the prescribed intervention.
- 3) Provide preliminary estimates of the effect size needed to demonstrate the efficacy of *Rekindle* to improve sexual satisfaction, to inform sample size calculations in a future Phase III trial.



The purpose of the Rekindle Plus calls is:

- **RETENTION**

- Orient users to Rekindle
- Foster engagement in Rekindle
- Identify any problems using Rekindle
- Problem solve/address any individual barriers to using Rekindle



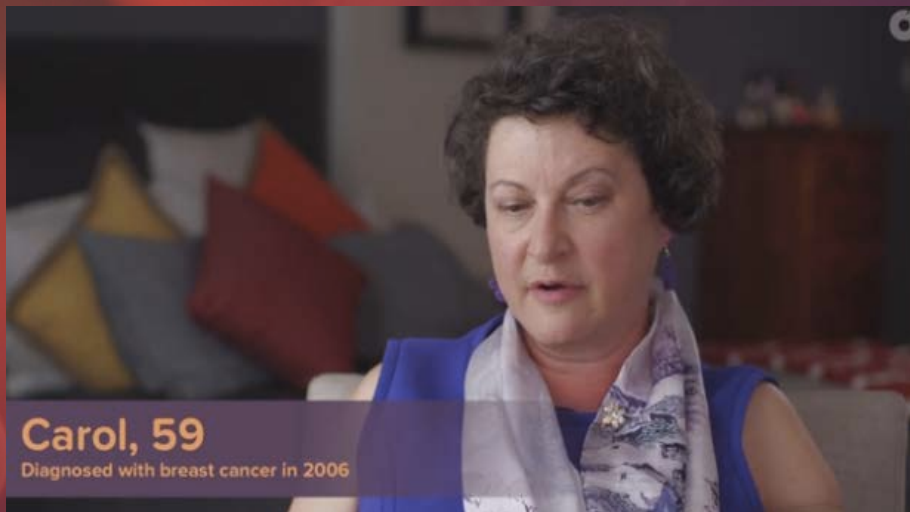
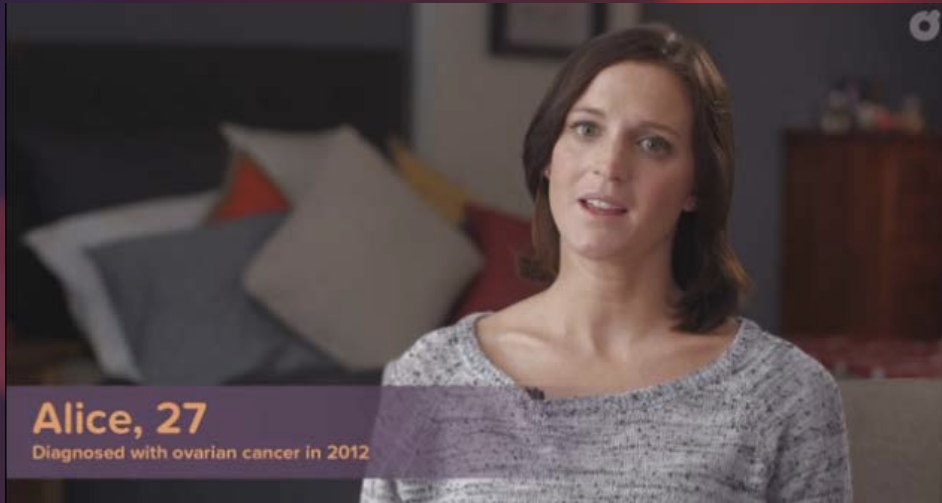
Rekindle is tailored according to:

- ☐ Type of user (patient &/or partner)
- ☐ Gender of user
- ☐ Sexual orientation

➔ 12 Versions

The screenshot displays the Rekindle user interface for a user named Amelia Beaumont. At the top, there is a navigation bar with links to DASHBOARD, TOPICS, DIARY, SUPPORT, and the user's name. The main content area features a large video player with a 'Watch Video' button. Below the video, a 'Your Pathway' diagram shows a sequence of topics: Foundations, Talking About Sex, Embracing Sexuality, Renegotiating Sexuality, Achieving Intimacy, and Moving Forward. A 'Begin Foundations Topic' button is prominently displayed. At the bottom, three sections are visible: 'Your Favourites' (showing no favourites), 'Your Activities' (showing no activities), and 'Your Discussion List' (showing no discussion items). A progress indicator at the very bottom shows '9 Weeks 6 Days' remaining.

Survivor and Partner Testimonials



MULTIDISCIPLINARY HEALTHCARE PROVIDERS



This instructional video is narrated by Dr Michael Lowy.



This instructional video is narrated by Kim Hobbs.





Creating an Environment for Safe Sex Talk

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Next >

Dispelling Myths

In the hospital, on the TV and in magazines: myths about cancer are out there and need to be shut down!

'Burst' each of the below bubbles to see the reality behind cancer myths.

MYTH

If I bring up sex, I'll pressure my partner when they're not ready or interested

MYTH

You can transmit your cancer to your partner through sexual intercourse.

MYTH

I'll never enjoy sex again.

MYTH

MYTH

How is this woman feeling?

Can you tell how people are feeling from their expressions? Test yourself by selecting the expression that best suits the image.



ANSWERED 0/14

Disgusted

Worried

Embarrassed

Happy

< Previous

Next >

The Right Treatment for You

Click the statements below that best describe what's important to you about your sexual treatment options.

The treatment is natural (no extra odors, colours, or flavours).

The treatment can be bought without a prescription.

The treatment is applied before bedtime.

A doctor at a medical facility does the treatment for me.

I can do this in the privacy of my own home.

My partner can assist me in using this.

The treatment is convenient.

The treatment is discreet; my partner won't know I'm using it.

The treatment is affordable.

Sexual spontaneity is still able to occur with the treatment.

The device can be used as a sex toy.

The device may take some practice to learn.

The treatment involves genital exercises.

The treatment feels good (gives me sexual pleasure).

The treatment does not involve inserting anything into my body.

The treatment involves surgery.

Based on your priorities, we suggest the following treatments:

75%
match



Vaginal dilator

50%
match



Erotica

50%
match



Vibrator and sex toys

25%
match



Hormone cream

Here are some helpful Questions

Effective communication is key to relationships. However, communicating clearly what's on your mind can sometimes be a challenge, particularly if you're talking about a sensitive topic, such as sex.



Here are some helpful questions to ask your ONCOLOGIST, GP OR NURSE

(Choose the health care provider with whom you feel most comfortable raising your sexual concerns with)

☐ Complete?

1. Where can I get help to improve how I talk about my feelings and needs when it comes to sex?

Add to Your Prompt Lists



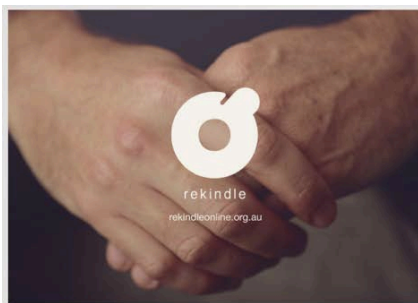
Here are some questions to ask a PSYCHOLOGIST OR SEX THERAPIST

☐ Complete?

1. How can I talk with my doctor/nurse about physical sexual changes after cancer?
2. How can I get my partner to tell me how their feelings about how our sex life has changed after cancer?

Rekindle Launched Dec 2014 at UICC

- 32 Cancer Centers across Australia:
Rekindle posters on walls, billboards and flat screens
- TV, Radio and Internet
- CCNSW
- Support groups
- Promotional Talks
- Social Media



**Had cancer?
Want to have better sex?
Rekindle could be for you.**

Rekindle is a new online resource that aims to help you turn up the volume in the bedroom. Participating in Rekindle is risk free, confidential, and completely voluntary.

By participating in Rekindle you may enjoy:

- Increased knowledge of sex and sexuality as related to cancer
- New and/or improved techniques to talk sexy and change your outlook on sexuality
- Learn fun, practical exercises you can do to increase sexual activity
- Building better future resources for cancer survivors

For more information, complete the return postcard opposite, visit rekindleonline.org.au or call 1300 85 44 37


I would like more information about Rekindle


Name: _____


Email address: _____

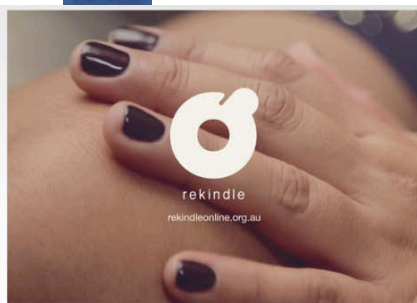
Phone number: _____

Return postal address:
Amelia Beaumont
School of Psychology
Brennan MacCallum Building A18
The University of Sydney NSW 2006

 Australian Government
Australian Research Council

 THE UNIVERSITY OF SYDNEY





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Who's Enrolling in Rekindle?

Variable (N = 224)	% or M (SD), Range
Gender	67% Female
Age (years)	Median 53, 20-70
Heterosexual In a relationship	91% 86%
Relationship length (years)	22.30 (13.04), 0.67-59.25
Partner NOT Involved	85%
Common Cancers	70% of Females BC 72% of Males Prostate
Most Common Reported Sexual Concern	Strategies to Manage Sexual Changes: 64% <i>"Help is Here!"</i>
Modules Prescribed	Ave= 6.1
Accessed Rekindle	88% Desktop

How did you hear about Rekindle?	%
Cancer Council	21%
Online	16%
Register 4	10%
Radio	9%
Newspaper	9%
Clinician Referral	7%
Friend or Family	6%
Support Group	6%
News-online	5%
Non-profit group	2%
Post card	2%
TV	1%
Other/Conference	5%

Rekindle is Reaching Across Australia

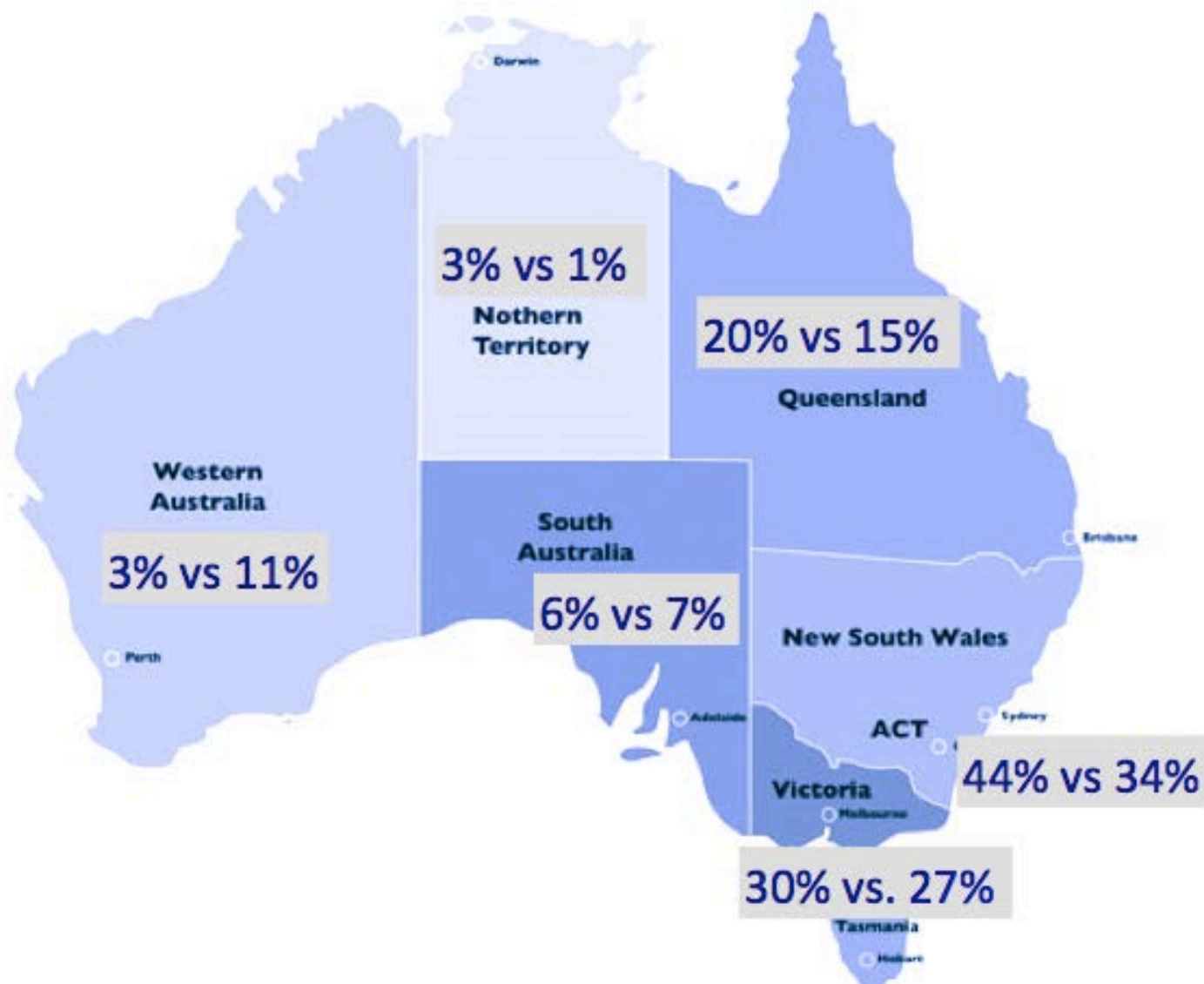


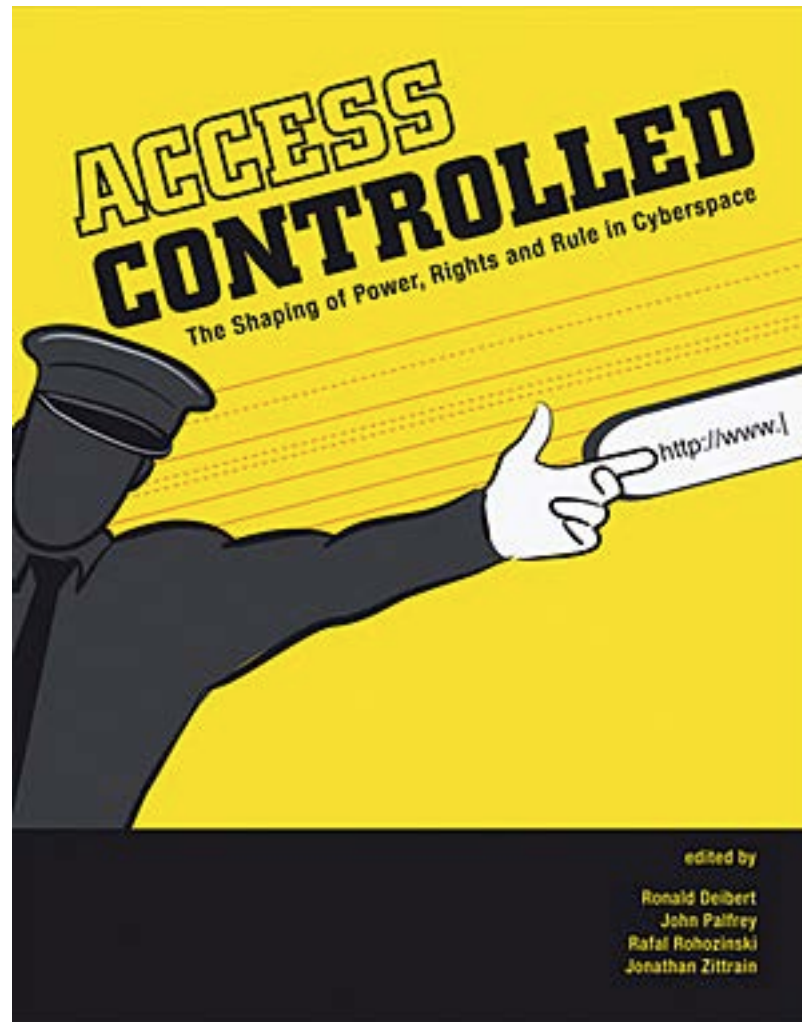
Figure 1 Australian population distribution vs Rekindle participants

Recruitment was looking good

...**BUT**

Amongst the 189 prescribed at least 1 module:

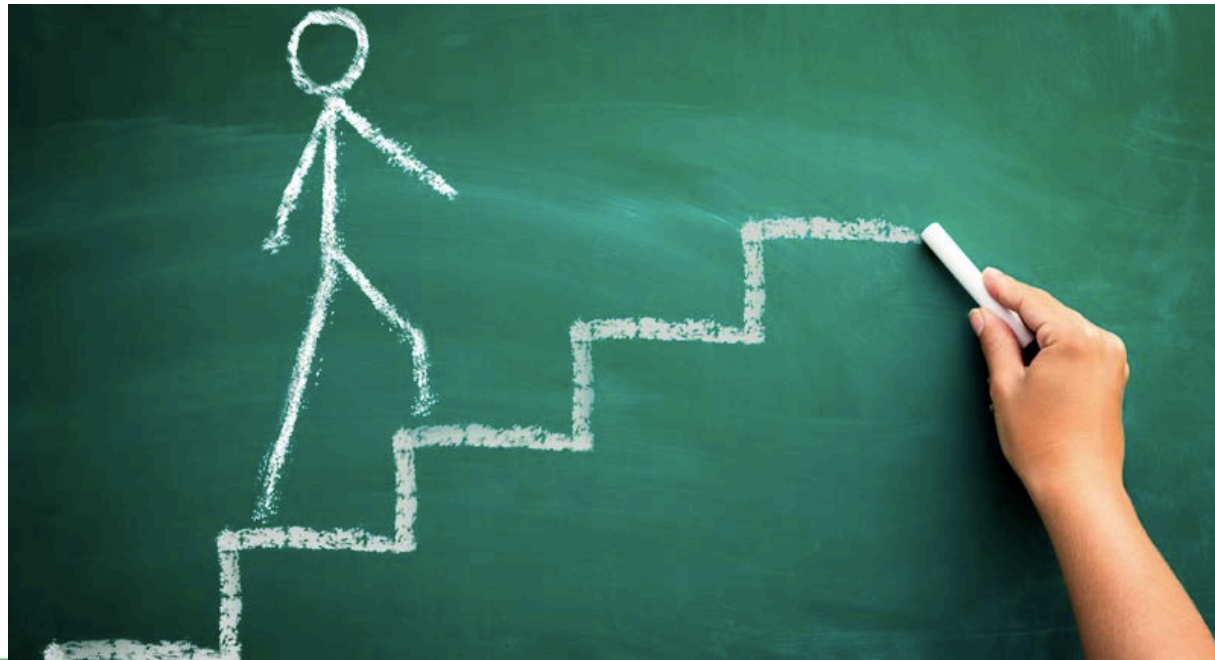
- 50% Began at least one module at any time
- 42% Completed at least one module at any time
- Follow-up assessments were 20% at T2



Current Status of Rekindle

Variable (N = 98)	% or M (SD), Range
Gender	65% Female (n=51)
Age (years)	71% 50-69, 20-70
Most common cancer	33% Breast
Heterosexual	95%
Relationship length (years)	22.30 (13.04), 0.67-59.25
Partner NOT Involved	85%
Sexual Satisfaction	LOW: 15.5 (7.4)
Sexual Self-Disclosure	LOW: T= 45.8 (21.9)

- Adapting Rekindle for the US
- Developing a Latino version of Rekindle
- Training clinicians to assess, address and refer sexual concerns



Development of a Novel Web-Based Psychosexual Resource for Latina Cancer Survivors

Lauren Weibe, MD
Steven Rosthchild, MD



Frank Penedo, PhD
Betina Tanez, PhD



Kenneth Weingart



Kristi Graves, PhD



Rita Melendez, PhD



Phyllis Butow



Women's Health Foundation



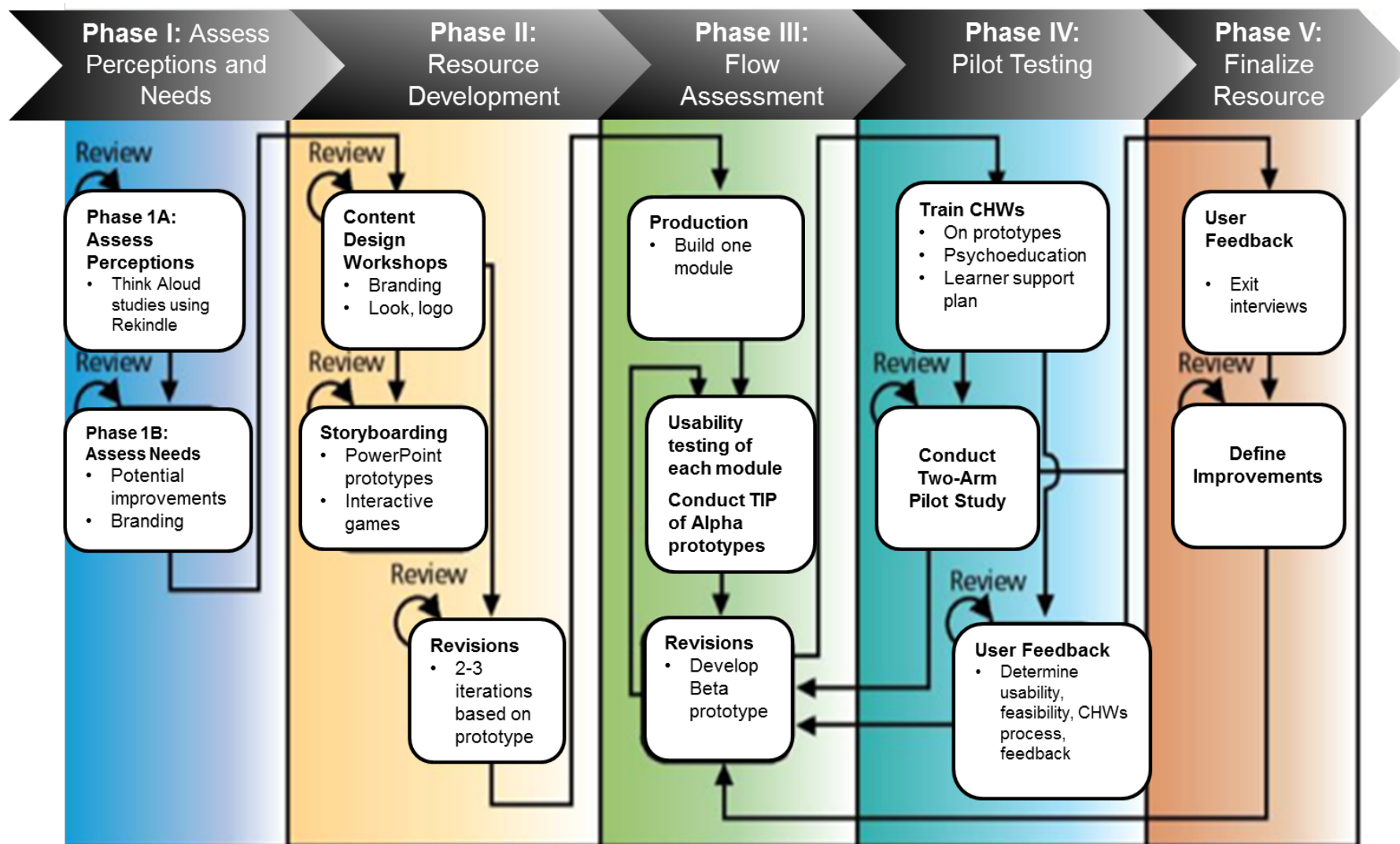
Sexual Wellbeing Amongst Latinas

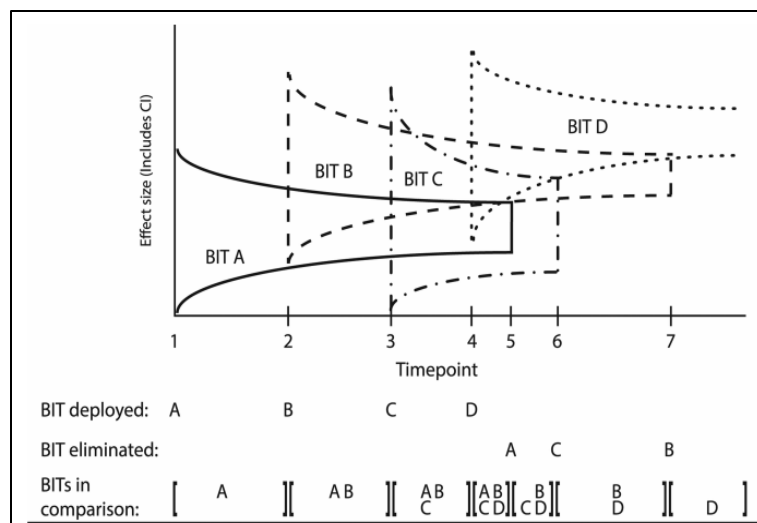
- Latinas were 1.4 times more likely to want information regarding sexual function compared to their NHW and AA counterparts
- Latinas who preferred Spanish were even more likely to desire information compared to those who preferred English (OR 3.7 vs 1.5).
- Latina breast and gynecological cancer survivors are as interested in and more willing to receive care to address sexual issues than NHW and AA survivors
- Sexuality amongst Latinos is diverse
 - marianismo and machismo gender roles
 - Over-sexualized vs Virgin Mary
- To date, NO sex interventions have specifically been developed for Latinas, let along Latina cancer survivors

>> Sexual Silence

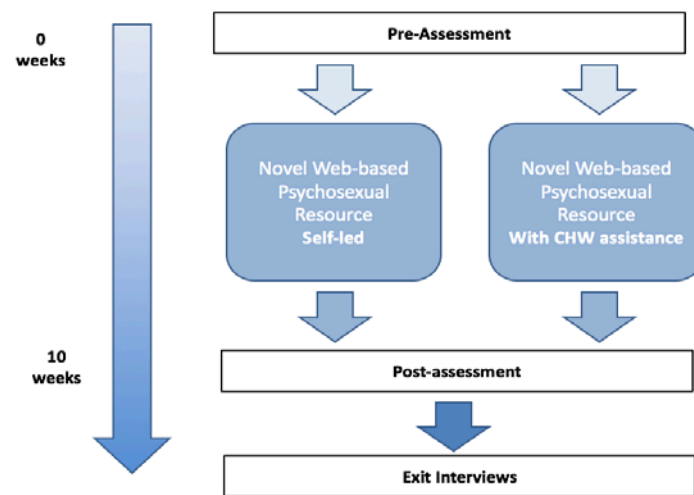
Project Aims

- ✓ Examine perceptions of existing evidenced-based strategies for addressing sexual concerns among Latina cancer survivors.
- ✓ Taking a community-based participatory approach in collaboration with community partners, community health workers and Latina cancer survivors, we will develop a novel web-based psychosexual resource from the “ground up”.
- ✓ Assess the usability, acceptability and feasibility of a web-based psychosexual resource for Latina cancer survivors in a two-arm pilot study by soliciting feedback from 40 Latina cancer survivors.





Trials of Intervention Principles



Pilot Study Design

Empowering Cancer Health Professionals and Primary Care Physicians to Address Sexual Concerns of Cancer Survivors: A Pilot Study to Develop and Test a Specialized Web-Based Communication Skill Training

Lauren Weibe, MD
Steven Rosthchild, MD



Susan Hong, MD
Stacy Lindau, MD
Nita Lee, MD



Richard Frankel, PhD



SCHOOL OF MEDICINE

INDIANA UNIVERSITY

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Provider and patient barriers to uptake of sexual support

- Embarrassment, fear of offending the patient, and underestimation of the impact of changes in sexual wellbeing on quality of life
- PCPs feel ill prepared to address psychosocial issues of cancer survivors,
- Amongst a sample of general internists:
 - 62% reported that they never or rarely addressed sexual dysfunction amongst cancer survivors
 - Physicians who felt prepared were more than twice as likely (OR=2.49) to discuss sexual concerns with their patients.

Empowering Cancer Health Professionals and Primary Care Physicians to Address Sexual Concerns of Cancer Survivors: A Pilot Study to Develop and Test a Specialized Web-Based Communication Skill Training

Aim 1: Develop and test the acceptability and use of two web-based communication skills training modules, one standard (CST) and one specialized (SCST) targeting the assessment and addressing of sexual concerns of cancer survivors.

Aim 2: Compare communication performance between oncology and primary care providers who have been exposed to the CST and SCST modules.

Exploratory Aim 3: Compare uptake of a web-based CST on sexual communication between cancer professionals (e.g. oncologists, urologists and cancer nurses) and primary care physicians to determine the target population for a large-scale intervention.



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