

#SexEndo2019

# SEXUAL PAIN & ENDOMETRIOSIS WORKSHOP

Report



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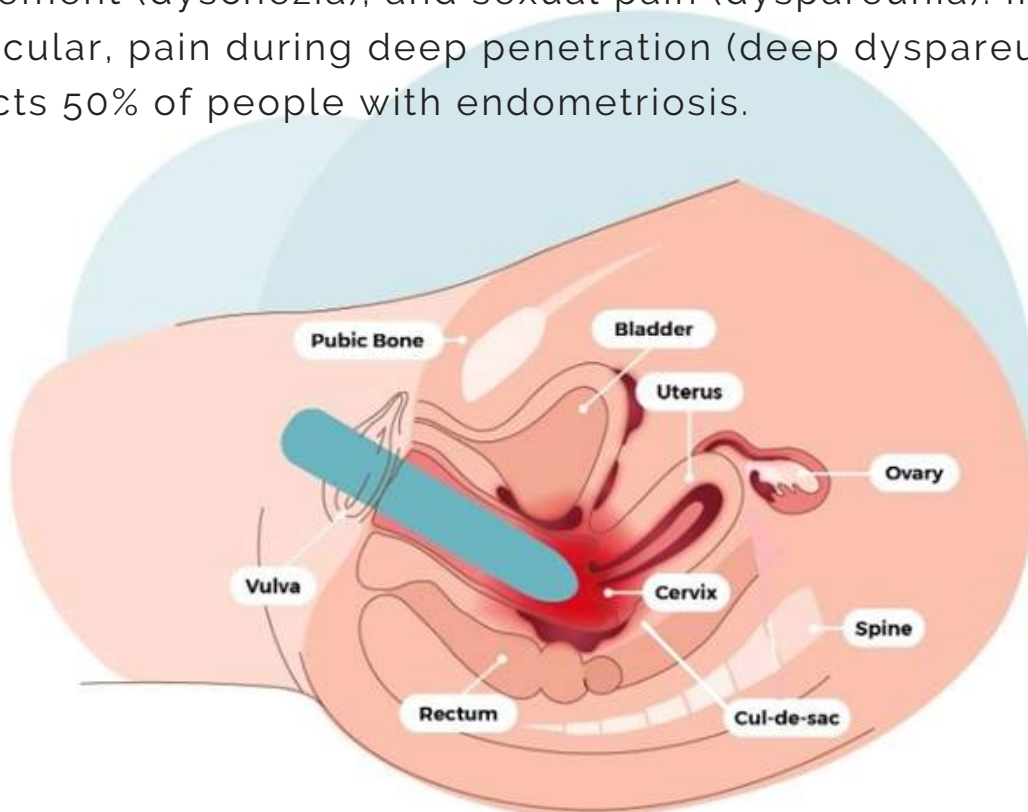
# SUMMARY

The purpose of this workshop was to describe the multiple causes of sexual pain in endometriosis and provide tools to help manage this pain. This workshop was developed in collaboration with patient partners to ensure the needs of patients were met. This report summarizes how the workshop was developed and the results from the workshop questionnaires.

## WHAT IS ENDOMETRIOSIS?

Endometriosis affects approximately 1 in 10 females. It is when endometrial-like tissue grows outside of the uterus.

Endometriosis can cause severe pain, including menstrual pain (dysmenorrhea), chronic pelvic pain, pain during bowel movement (dyschezia), and sexual pain (dyspareunia). In particular, pain during deep penetration (deep dyspareunia) affects 50% of people with endometriosis.



# WHO?

## EVENT ORGANIZERS



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**DR. PAUL YONG** is a gynaecologist and Research Program Director at the BC Women's Centre for Pelvic Pain & Endometriosis, and an Assistant Professor in the UBC Department of Obstetrics & Gynaecology. His research interests are on sexual pain and endometriosis.

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**NATASHA ORR** is a PhD student at the BC Women's Centre for Pelvic Pain & Endometriosis. Her research focuses on the central nervous system and somatic mutations in endometriosis-associated sexual pain. This workshop was spearheaded by Natasha.



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### **PATIENT RESEARCH ADVISORY BOARD**

at the BC Women's Centre for Pelvic Pain and Endometriosis is composed of people with lived experience with endometriosis.

# WHO?

## TRAINEES

Our group of hard working trainees were invaluable to the success of this workshop.



The trainees shared their research findings through posters!

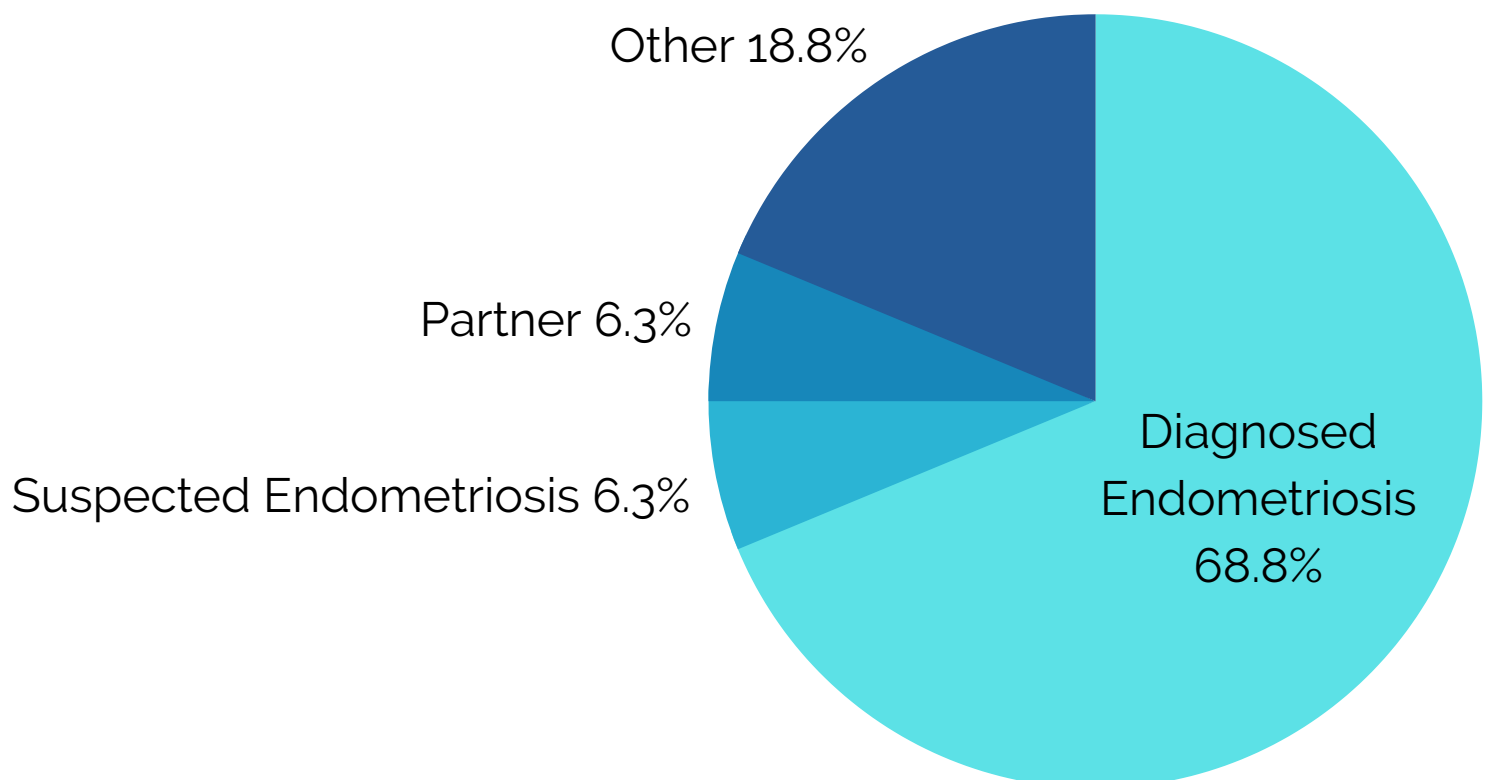
# WHO PARTICIPATED?

**35** attendees (not including volunteers and speakers)

**16** research participants

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## Endometriosis Status



# WHAT?

## SPEAKERS

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**Dr. Lori Brotto**, PsychD, is a clinical psychologist, Executive Director of the Women's Health Research Institute, and Canada Research Chair in Women's Sexual Health.

[@DrLoriBrotto](#) [Brottolab.com](http://Brottolab.com)



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**Dr. Paul Yong**, MD, PhD, is a gynaecologist and Research Program Director at the BC Women's Centre for Pelvic Pain & Endometriosis, and an Assistant Professor in the UBC Department of Obstetrics & Gynaecology. [@DrPaulYong](#) [yonglab.med.ubc.ca](http://yonglab.med.ubc.ca)

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**Lana Barry**, MEd, is a Self-Management programs Coordinator at the University of Victoria, Institute on Aging and Lifelong Health. She is also a women's sexual and mental health advocate, coach and speaker. [@selfcare4u](#)



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**Holly Yager**, MEd, is both a Canadian Certified Counsellor and a Registered Clinical Counsellor. She focuses primarily on women's reproductive health, using a variety of psychotherapies including mindfulness-integrated cognitive behavioural therapy.

[@WellWomanCouns](#) [wellwomancounselling.com](http://wellwomancounselling.com)

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**Susannah Britnell**, BScHonsPT, is a Registered Physiotherapist and a Fellow of the Canadian Academy of Manipulative Physical Therapy. She assesses and treats various pelvic pain conditions such as pelvic floor dysfunction, chronic pelvic pain, and endometriosis.

[@SusieBritnellPT](#) [urbanhealingvancouver.ca](http://urbanhealingvancouver.ca)



# WHAT?

## SPEAKERS

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**Becky Weaver**, MPT, is a Registered Physiotherapist with special interest in pelvic health. Her main interest is treating people with pelvic floor dysfunction including sexual pain, as well as bladder and bowel dysfunction. She has been working at the Pelvic Pain and Endometriosis Clinic at BC Women's since July 2018.

[womenspelvicpainendo.com](http://womenspelvicpainendo.com)



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**Dr. Mark Nazemi**, PhD, has an interdisciplinary background in education and pain management with over a decade of experience teaching and developing post-secondary courses. He focuses on reducing the anxiety experienced by chronic pain patients when using immersive 3D compositions of sounds.

[@marknazemi](https://twitter.com/marknazemi) [painbc.ca](http://painbc.ca)

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**Dr. Larry Mróz**, PhD, is a Research Navigator and Patient Engagement Coordinator with the BC SUPPORT Unit. He helps find the right supporters for research teams and assists with patient engagement training. He also works in psychosocial oncology and health behaviour change. [@DrMroz](https://twitter.com/DrMroz) [bcsupportunit.ca](http://bcsupportunit.ca)



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**Dr. Lynne Feehan**, BScPT, MSc, PhD, is a Michael Smith Foundation for Health Research Post-Doctoral Fellow in the Department of Physical Therapy at UBC. She focuses her research on bone health and physical activity in people living with inflammatory arthritis, and is involved with knowledge translation at the BC Support Unit. [bcsupportunit.ca](http://bcsupportunit.ca)



# WHAT?

## TAKE AWAYS

The workshop recordings can be watched [here!](#)

### DR. LORI BROTTA

Being mindful and tuning into pain has been shown to reduce chronic stress and muscle tension.

[#ItsNotInYourHead](#)

Here are some papers about mindfulness: [paper 1](#) and [paper 2](#)

### DR. PAUL YONG

Central sensitization can result in multiple chronic pain conditions, including sexual pain. Treatment for central sensitization should include a multidisciplinary approach.

Book: Understand Pain, Live Well Again by Neil Pearson ([online copy](#))

Here are some papers about sexual pain: [paper 1](#) and [paper 2](#)

### LANA BARRY

By creating dialogue about sexual pain we can advocate for people in pain.

[www.selfmanagementbc.ca](http://www.selfmanagementbc.ca)

Chronic genital pain or provoked vestibulodynia: [video](#)

### REBECCA WEAVER

Physiotherapy can help with deep sexual pain caused by pelvic floor muscles.

Find a physio [here](#) (keywords can refine search)

Pelvic pain and endometriosis [resources](#)

# WHAT?

## TAKE AWAYS

### **HOLLY YAGER & SUSANNAH BRITNELL**

Partners can help manage sexual pain by using facilitative responses and encouraging open communication.

BC Women's CPP program: [video](#)

How to support someone with CPP: [video](#)

### **DR. MARK NAZEMI**

PainBC provides free resources for people in chronic pain and their family members.

[Canadian Pain Task Force](#)

<https://www.liveplanbe.ca/>

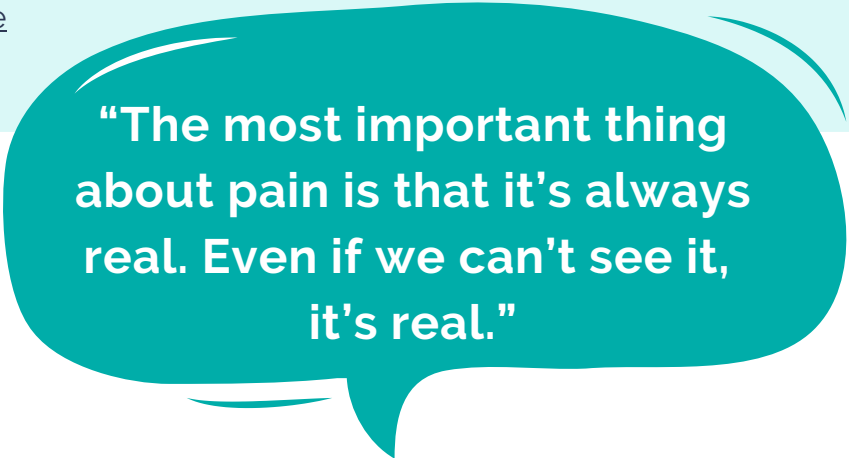
<https://painbc.ca/about/programs>

### **DR. LARRY MROZ & DR. LYNNE FEEHAN**

Patient-oriented research provides research questions that are important to patients.

<https://bcsupportunit.ca/resources>

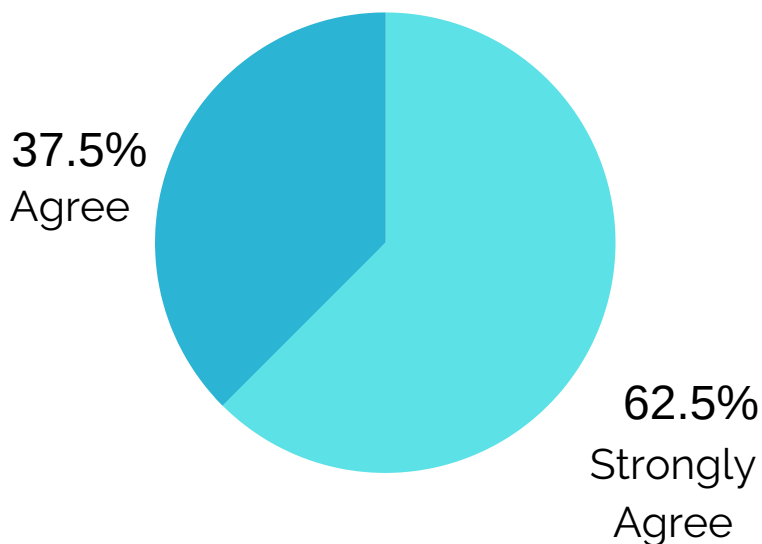
<https://bcsupportunit.ca/conference>



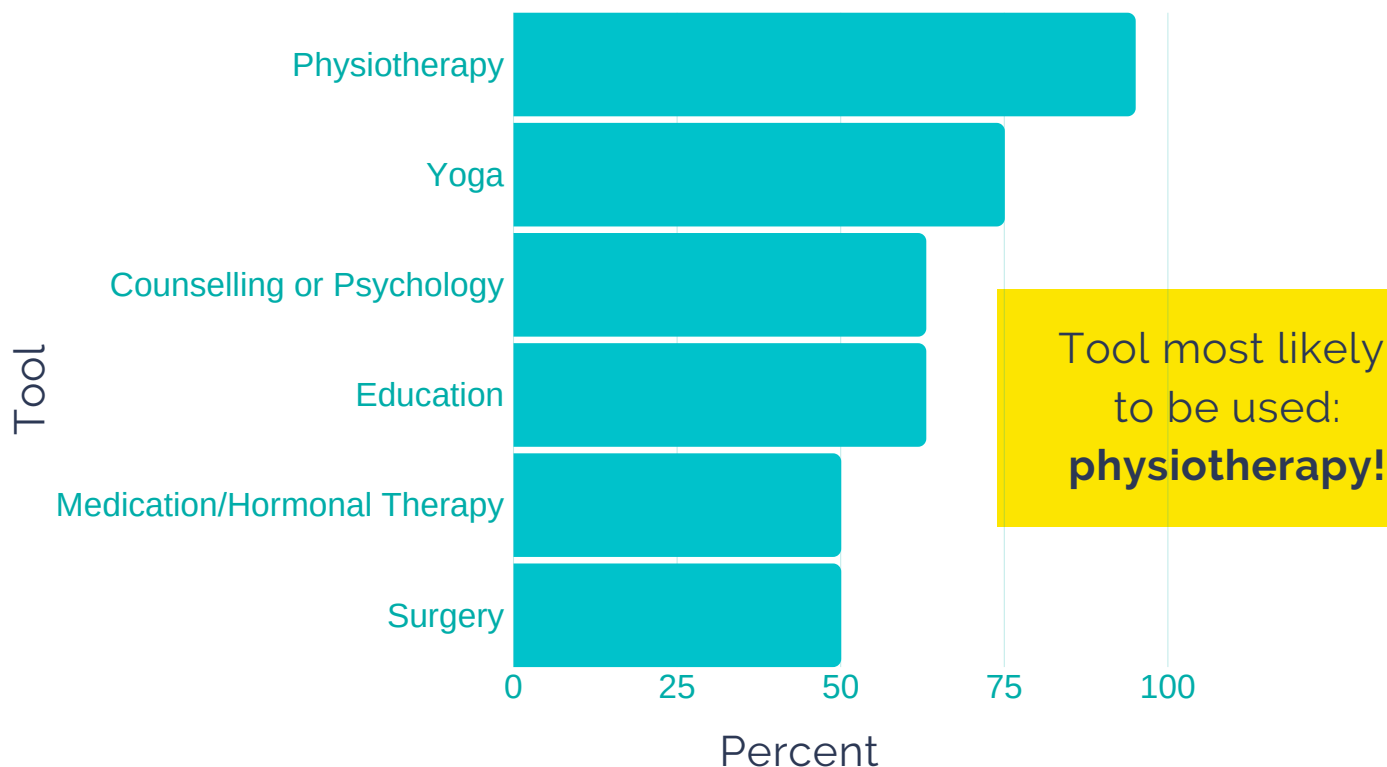
**“The most important thing about pain is that it’s always real. Even if we can’t see it, it’s real.”**

# WHAT DID WE LEARN?

Did you learn new information?



Would you use these tools?



100% of people feel comfortable using a tool from the workshop

# WHEN?

In recognition of **Pain Awareness Month**, we ran this workshop in September 2019.



# WHERE?



“

Your choice of venue was excellent as the access to the garden provided some empowering moments of mindfulness for me...

”



# TWITTER REACH

## #SexEndo2019



**66,843** total unique reach  
**204** total posts displayed  
**191** likes  
**34** re-tweets  
**31** tweets

#SexEndo2019 - Trending in Vancouver



2019-09-21 17:50 UTC : CA\_VAN\_eavmq



**Madison Lackie**  
@LackieMadison



@PaulYongMD expresses the importance of diagnosing the causes of pelvic pain to provide effective treatment at #SexEndo2019

↳ 2    ❤️ 2

17:35, 21 Sep 2019 · View on Twitter ↗



**Kate Wahl**  
@katejwahl



The #SexEndo2019 workshop is about to kick off! Thank you @msfhr for supporting this fantastic event! pic.twitter.com/ex80p1Uepy

↳ 4    ❤️ 7

16:00, 21 Sep 2019 · View on Twitter ↗



**PelvicPainEndo**  
@PelvicPainEndo



Good morning from #SexEndo2019! Our event is supported by a Michael Smith Foundation for Health Research Reach Award @msfhr

↳ 1    ❤️ 4

16:26, 21 Sep 2019 · View on Twitter ↗



**Women's Research**  
@womensresearch



We're at #SexEndo2019 today learning about managing sexual pain and endometriosis! Track the hashtag to follow along.

**PelvicPainEndo** @PelvicPainEndo

Good morning from #SexEndo2019! Our event is supported by a Michael Smith Foundation for Health Research Reach Award @msfhr

↳ 1    ❤️ 4

16:37, 21 Sep 2019 · View on Twitter ↗

# TWITTER REACH

Is sex painful? Come learn about sexual pain in endometriosis - a condition that affects over 1 million women in Canada - at a one day workshop in Vancouver! 🍌 [bit.ly/2XAlzh8](https://bit.ly/2XAlzh8) @PelvicPainEndo @BCWomensHosp

## IS SEX PAINFUL?

Come learn about sexual pain in endometriosis, a condition that affects over 1 million women in Canada.

**When:** Saturday September 21, 2019

9am-5pm

**Where:** VanDusen Botanical Gardens

**Who:** People with endometriosis and their friends and families

We will be covering the efficacy of the workshop using pre- and post-workshop questionnaires that will measure the impact of the workshop. As a workshop attendee, you will have the option to participate in the study.



Use facilitative responses to best support your partner experiencing sexual pain. "What would work best for you right now?", "Let me know what you need", "I love you no matter what happens" #SexEndo2019

 PelvicPainEndo @PelvicPainEndo · Sep 21, 2019

If your partner experiences sexual pain, you can listen and believe your partner, learn about self-management strategies, and keep expectations realistic. Communication is key! #SexEndo2019

If you or someone you know is experiencing chronic pain and needs support here's some @PainBC resources from @marknazemi #SexEndo2019 [painbc.ca](https://painbc.ca)

1. Pain BC's Pain Support Line

PAIN BC™ PAIN SUPPORT LINE

ARE YOU LIVING WITH PAIN? CALL THE PAIN SUPPORT LINE

GET STARTED

Volunteers are available to take your calls from Monday to Friday 9 AM - 4 PM.

Three ways to connect with us:

Call Toll-Free: 1 844 880 PAIN (7246)

Email: supportline@painbc.ca

Online: painbc.ca/supportline

Ready to learn and share at the #SexEndo2019 workshop.

@PaulYongMD describes the role of central sensitization to explain: how can 1 woman have multiple chronic pain conditions? Painful bladder, vulvar pain, pelvic pain, endometriosis...#SexEndo2019 @BCWomensFdn @PelvicPainEndo @ubcOBGYN @SOGCorg

in spinal cord + brain

spinal cord

pain sensors

Treatment is multidisciplinary

- Physiotherapy
- Psychological
- Medications/Surgery

Pearson, 2007. Understand Pain, Live Well again. [http://www.becominghealthynow.com/topics/brain\\_cord\\_bh](http://www.becominghealthynow.com/topics/brain_cord_bh)

Today is the #SexEndo2019 workshop at the beautiful @VanDusenGdn, and @DrLoniBrotto is starting it off with her talk on mindfulness for women's sexual pain. Here she is describing the raisin exercise.



Physiotherapy has tons of approaches for managing physical pain: Stretching, guided imagery, biofeedback, massage, joint mobilization, breathing practice, & dilators. #SexEndo2019

# IMPACT

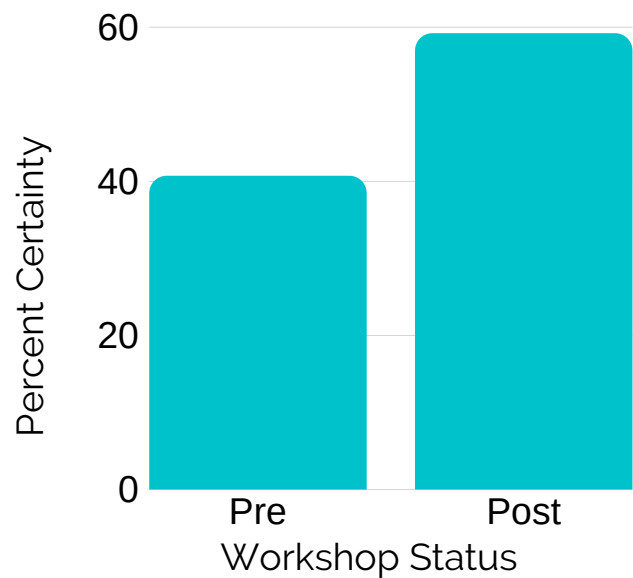
## PAINFUL PENETRATION SELF-EFFICACY SCALE

Pre-workshop  
questionnaire

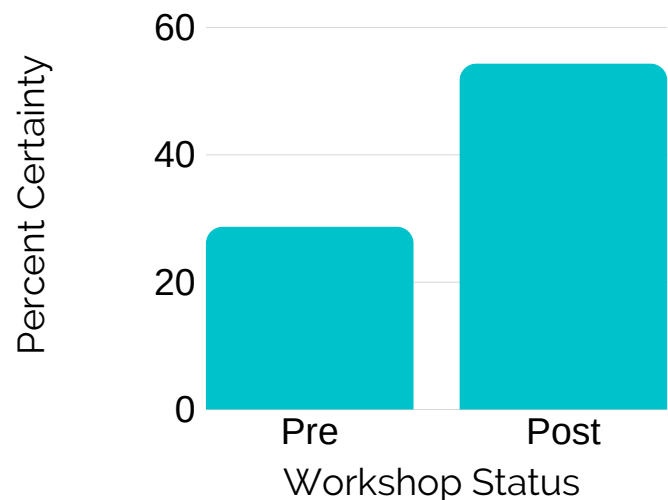


Post-workshop  
questionnaire

**How certain are you that you can continue most of your sexual activities?**



**How certain are you that you can keep pain during penetration from interfering with your relationship?**



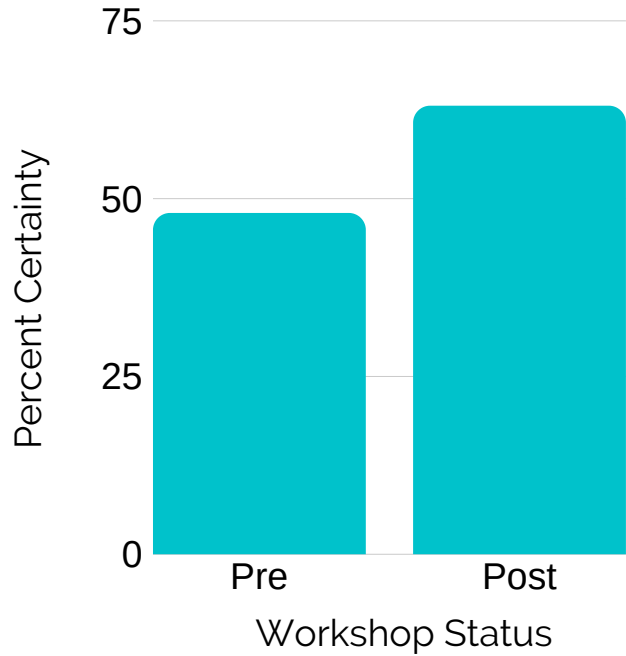
There was a significant difference between pre- and post-workshop questionnaire for both questions.



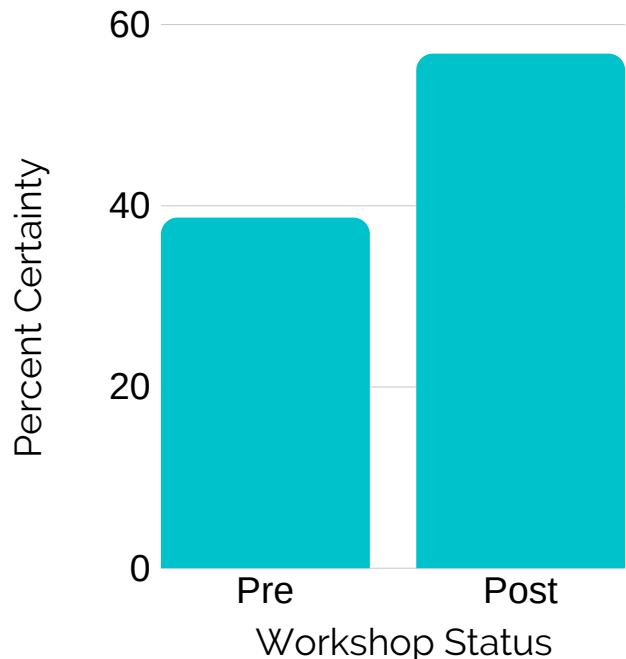
# IMPACT

## PAINFUL PENETRATION SELF-EFFICACY SCALE

**How certain are you that you can make a small-to-moderate reduction in your pain during penetration by using non-surgical methods?**



**How certain are you that you can make a large reduction in your pain during penetration by using non-surgical methods?**



There was a significant difference between pre- and post-workshop questionnaire for both questions.

# PATIENT PRIORITIES

WE IDENTIFIED **12** PATIENT-ORIENTED RESEARCH PRIORITIES!

- 1.** What is the genetic/hereditary component of endometriosis?
- 2.** What helps/hinders the process of navigating the system as a person with pelvic pain?
- 3.** What is the impact on women's health if parents/kids/educators learned about endometriosis early?
- 4.** What are the best treatment options for the perinatal period?
- 5.** Can we create an individualized, multidisciplinary care pathway that addresses the biopsychosocial aspects of endometriosis?
- 6.** Who knows what about endometriosis? Can we have a website with resources?

# PATIENT PRIORITIES

WE IDENTIFIED **12** PATIENT-ORIENTED RESEARCH PRIORITIES!

- 7.** What can endometriosis patients do while they wait for care?
- 8.** What is the average amount of time it takes for a person to be diagnosed?
- 9.** How will patient experience change with more education?
- 10.** What is the relationship between endometriosis and autoimmune diseases?
- 11.** More research on central sensitization, as well as its causes and treatments.
- 12.** Identify a way to diagnose that is non-invasive.

# IMPACT & WHAT'S NEXT?

## **1) Educating people on the causes and treatments for sexual pain in endometriosis.**

Increasing awareness and improving quality of life by providing information about sexual pain and tools for management.

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## **2) Uncovering research goals and tools that are important to patients and producing research priorities based on these findings.**

With these priorities we will be writing a paper that targets researchers and clinicians.

This can help us in guiding future research that maximizes benefits to patients.

# ACKNOWLEDGMENTS

We would like to acknowledge the following people for their contribution to this workshop:

Dr. Catherine **Allaire**

Fahad **Alotaibi**

Dr. Mohamed **Bedaiwy**

Dr. Lori **Brotto**

Lukas **Feil**

Shermeen **Imtiaz**

Madison **Lackie**

Michelle **Lisonek**

Ciana **Maher**

Olena **Maydan**

Jenna **Miller**

Melissa **Nelson**

Heather **Noga**

Nicole **Ng**

Kiran **Parmar**

Sadaf **Sediqi**

Kate **Wahl**

Dr. Christina **Williams**

# FUNDER

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