

Welcome!

Digital Storytelling and Theater in Health Research and Knowledge Translation

Friday, March 26, 1:00 – 2:00 pm (NDT)

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Below the slide area is a presentation control bar. On the left, it says "PRESENTATIONS" next to a monitor icon. In the center, it shows navigation arrows, "Slide 1", and a dropdown arrow. On the right, it shows zoom controls: a minus sign, "100%", a plus sign, and a full-screen icon.



Digital Storytelling and Theater in Health Research and Knowledge Translation

NL SUPPORT Webinar

March 26, 2021

Kathleen C. Sitter, PhD, Canada Research Chair in Multisensory Storytelling Research and Knowledge Translation

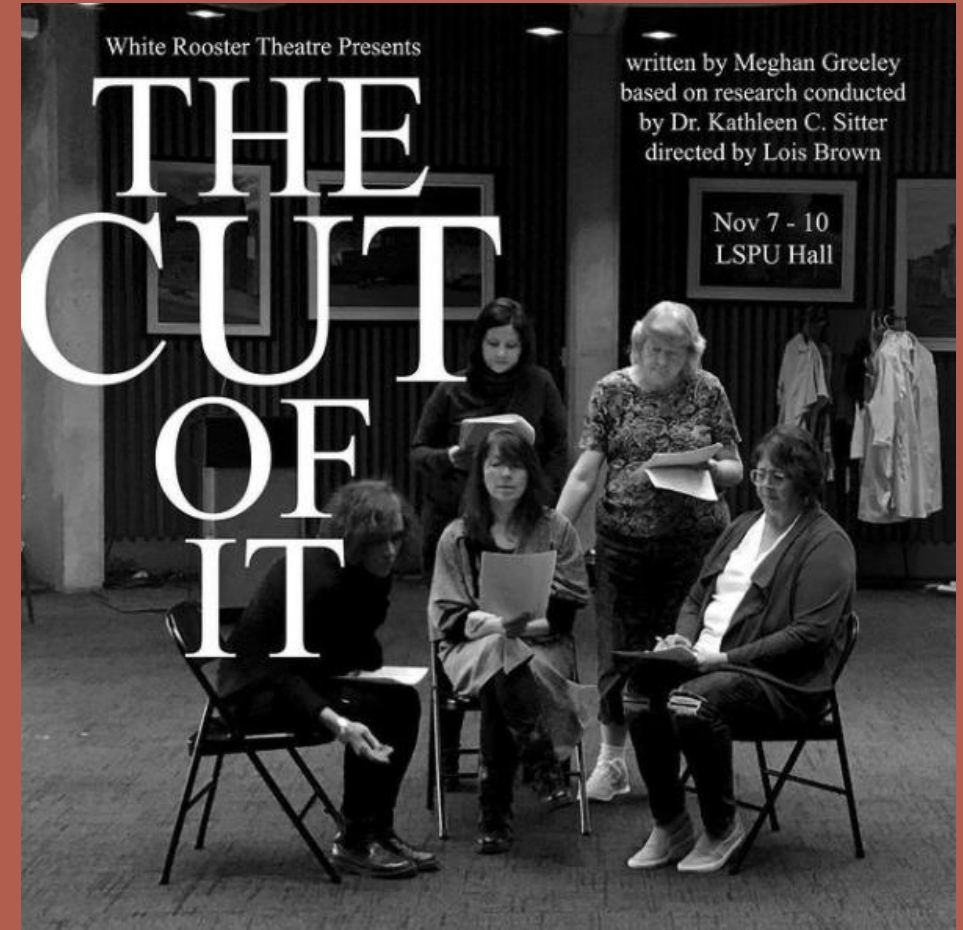
Natalie Beausoleil, PhD, Professor of Social Science and Health

Amy Burke, MSW, RSW, Research Coordinator



Overview

- Arts and Health
- Background
- Research Design
 - Role of digital stories
- Outcomes
- Knowledge Translation
 - Process and role of digital stories
 - Theatre production and panel
- Learnings and Considerations



Arts and Health

- Arts have been used around the world in areas of healing and wellness
- Increased recognition within healthcare
- UK leading this area
- NLCAHR Research Exchange on Arts and Health

Provincial Resources:

https://www.nlcahr.mun.ca/Research_Exchange/NL_ARTS__HEALTH_COMPENDIUM.pdf

Arts-Based Research

- Using the artistic genres in research (visual, sound, performance, writing, etc.)
 - Fieldwork, data collection, method and methodologies
- Consideration to process/engagement and product
- Increased accessibility with participants and with audiences in knowledge translation
- Supports different ways of knowing

Using Digital Stories to Explore the Experiences of Breast Cancer Patients

- Breast cancer is the most frequently diagnosed cancer in Canadian women
- The combination of age, income, and travel time can influence variations in treatment options
- Challenges with making an informed decision: identified gaps in delivery, format and timing of information about options
- History: Cameron Inquiry
 - Erroneous and delayed results 1997-2005
 - Inquiry May 2007, report released in 2009

Research Background and Design

- Two-year study
- Patient-Oriented Research
- Team members included a patient advisor, interdisciplinary scholars and health care practitioners

Dr. Kathleen Sitter

Dr. Natalie Beausoleil

Dr. Erin McGowan

Dr. Erin Cameron

Dr. Gail Wideman

Dr. Alex Mathieson

Rosemary Lester

Amy Burke



Why Digital Storytelling?

NL Healthcare Paradox

Research Background and Design

- Three Phases
 - P1: Digital story workshop: 18 digital stories
 - Deductive and inductive analysis of digital stories (narrative and visual) to identify key themes. Findings informed the questionnaires and guided focus group discussions
 - P2: Screenings with health care practitioners: 117 Knowledge Users
 - P3: Focus groups with health care practitioners: 13 Knowledge Users
- Knowledge Translation:
 - Screenings, presentations, website, articles, and theatre production

Research Outcomes

1. Identified determinants influencing patient treatment decisions:
 - 1) Life stages and personal circumstances, 2) personal values, 3) previous experiences, 4) sense of control, 5) sexual health, 6) medical advice, 7) information received/sought out, 8) doctor-patient relationship
2. Patient identified priority #1: Focus on consistent information delivery to minimize emotional distress
3. Patient identified priority #2: Develop the role of patient navigators to sustain access to consistent information during and after treatment
4. Patient identified priority #3: A whole person care approach is needed to improve overall patient well-being
5. Creating and viewing digital stories: pedagogical impact on viewers and therapeutic process for the participants

DECISION MAKING AID TEMPLATE

BREAST CANCER TREATMENT AT EASTERN HEALTH

The grey boxes are examples of potential information.

Diagnosis → Surgery
Estimated Time:

Type of Surgery:

MASTECTOMY: removal of the whole breast
LUMPECTOMY: removal of the cancerous tumour and some surrounding healthy tissue. You may need surgery to remove lymph nodes from your armpit. Your surgeon will help you with these decisions.

Planning:

Generally, the first step in breast cancer treatment is surgery. However, some people might first require additional treatment.

When you meet with the oncologist, you might want to ask to record the conversation so you can refer to it.



After Surgery:

Signs Incision Has Healed:

Healthcare Supports:

Connect with Eastern Health's Patient Navigator:
<http://cancercare.easternhealth.ca/patients-and-family/patient-navigation/>

Community Supports:

To help you through these decisions visit: <https://bethedchoice.org/en/>

Pathology → Additional Treatment
Estimated Time:

Additional Treatment Options:

Depending on the type of cancer and surgery, you may need one or more forms of treatment. Your oncologist will go over these options with you:
RADIATION THERAPY:

CHEMOTHERAPY:

HORMONAL TREATMENT:

TARGETED THERAPY:

Potential Side Effects:

Decision Point Additional Treatment

Healthcare Supports:

Community Supports:

Follow-up & Aftercare →
Estimated Time:

Reconstruction:

Estimated Time of Referral:

With a plastic surgeon, you will decide if you are a good candidate. It is important to talk about the type and timing of surgery, the recovery process, how your new breasts will look and feel, as well as your own expectations.

Follow-Up Plan:

Make a plan with your oncologist to monitor side-effects and symptoms.

Decision Point Reconstruction

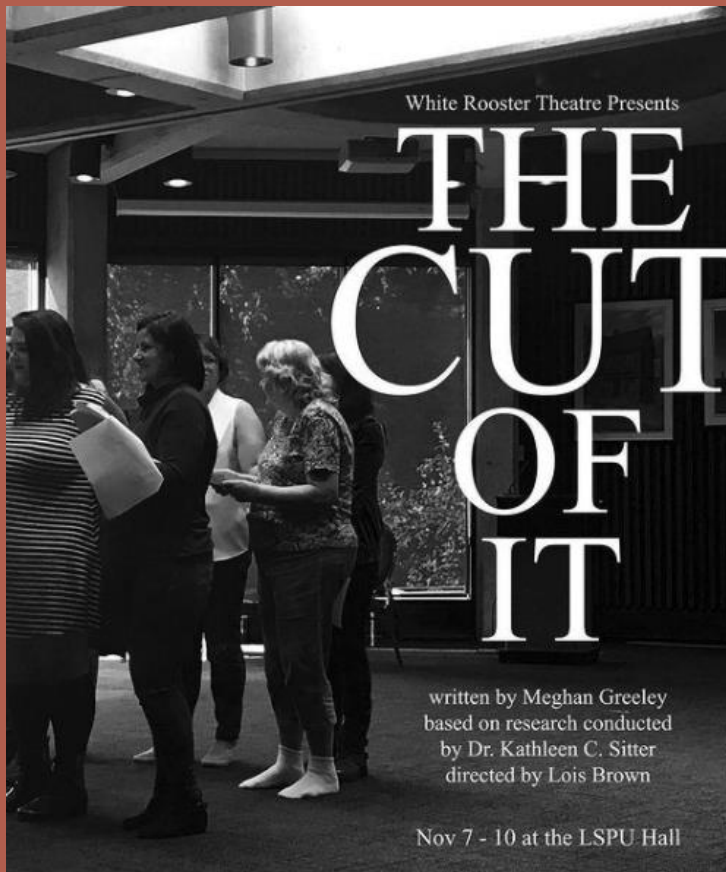
Aftercare:

Through your healing, you will experience physical and emotional changes. There are supports you can access, including complementary therapies, social workers, and counsellors. Health, local, and provincial supports are available to help you develop strategies to lead your life after breast cancer.

Healthcare Supports:

Community Supports:

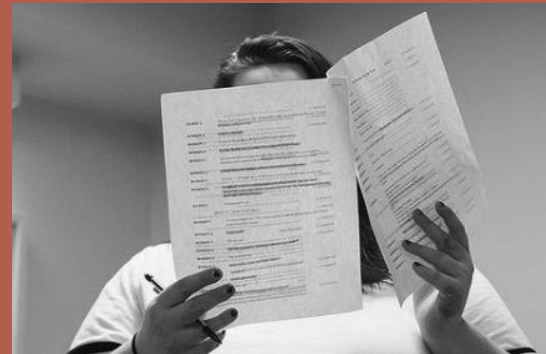
The Cut of it: Research-based theatre performance inspired by the stories of breast cancer patients



- Funder: NLSUPPORT
- Production Company:
 - White Rooster Theatre
 - Ruth Lawrence
- Playwright: Meghan Greeley
- Director: Lois Brown
- Location: LSPU Hall

The Cut of it: Research-based theatre performance inspired by the stories of breast cancer patients

- Script created from digital stories
- Check-ins with participants and research team
- Collaborative theatre:
 - Mix of actors and participants
- Panel discussion



Learnings and Considerations with Theatre as KT

1. Researchers should aim to include theatre in the overall research design from the onset if possible
2. Work closely with production company and playwright is key
3. Contracts: Respecting ownership considerations across different fields and disciplines
4. Ethics: Connect early on
5. Role of participants: Autonomy and empowerment
6. Support for audience



Acknowledgments

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For more information about NL SUPPORT and the kind of research they fund, please visit: www.nlsupport.ca





www.patientstories.ca