

Research, Knowledge Translation and the Arts: Using Digital Stories to Explore the Experiences of Breast Cancer Patients



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(Downfall, 2017)

Overview

- Background
- Why digital stories?
- Overview of study
- Key findings
- Considerations

Using digital stories to explore the experiences of breast cancer patients



- Breast cancer is the most frequently diagnosed cancer in Canadian women
- 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

DIGITAL STORYTELLING

Honouring individual voices while recognizing shared experiences.



WHY DIGITAL STORYTELLING?

The NL Health Care Paradox



(Under the knife, 2017)

- Two-year participatory health research study
- Three phases:
 - Digital story workshops
 - Organized KUs screenings with questionnaires
 - Knowledge users focus groups
- Team members included a patient advisor and knowledge users

Under the knife

Key findings

1. Determinants influence treatment decisions

- Life stages
- Personal circumstances
- Personal values
- Previous experiences (family, self, others)
- Sense of control
- Sexual health
- Medical advice
- Information received /sought out
- Doctor-patient dynamic



(The Detour, 2017)

Key findings

Patient priorities focused on:

2. Minimizing emotional distress
3. The role of patient navigators
4. A whole person care approach is needed

5. Creating and viewing digital stories:
Overall impact



(The Detour, 2017)

Upcoming site:

www.patientstories.ca

focus
groups

community

survey
screenings

digital
stories

theatre
production



Considerations

Time commitment

Resources

Responsibility



(My Story, 2017)

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