The Intersection between Cancer and Disability

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Learning Objectives

Articulate the need for disability competent cancer and support services

Identify physical, informational, and attitudinal barriers to breast cancer screening.

Apply principles of disability etiquette to breast cancer screening

Identify resources to support disability competent cancer screening

Background

61 million Americans live with disabilities.[1]

People with disabilities are ***still*** an unrecognized health disparities population.[2]

People with disabilities are largely absent from the cancer disparities agendas.

People from underserved communities are disproportionately impacted by disability

Providers are biased against PWD and lack skills & confidence to serve.[3]

Cancer Specific Disparities

- People with disabilities are less likely to receive screening mammograms than non-disabled peers.[4]
- ↕ severity or complexity the disability, ↕screening.[5]
- Once diagnosed with breast cancer, women with disabilities have:[6]
  - Lower rates of breast-conserving surgery
  - Less likelihood of receiving radiotherapy or axillary node dissection
  - Lower survival rates (incl. all cause mortality and breast cancer-specific mortality)
- Cancer has been called a “Double Whammy” for people with pre-existing disabilities.[7]

Disability among Cancer Survivors

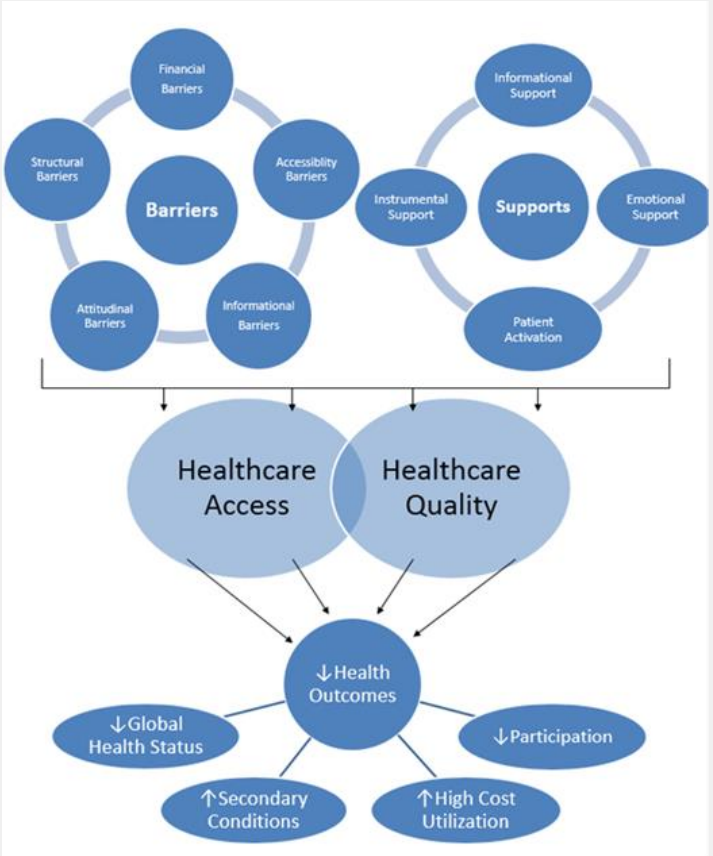
16.9 million cancer survivors in the US[8]

40% experience long-term physical, cognitive, and psychosocial consequences of cancer and its treatment.[9]

This leads to activity limitations and participation restrictions in major life areas **a.k.a. DISABILITY**

Survivors report long-term disabling effect are **inadequately addressed in cancer care continuum**[10]

Healthcare Access Model for PWD

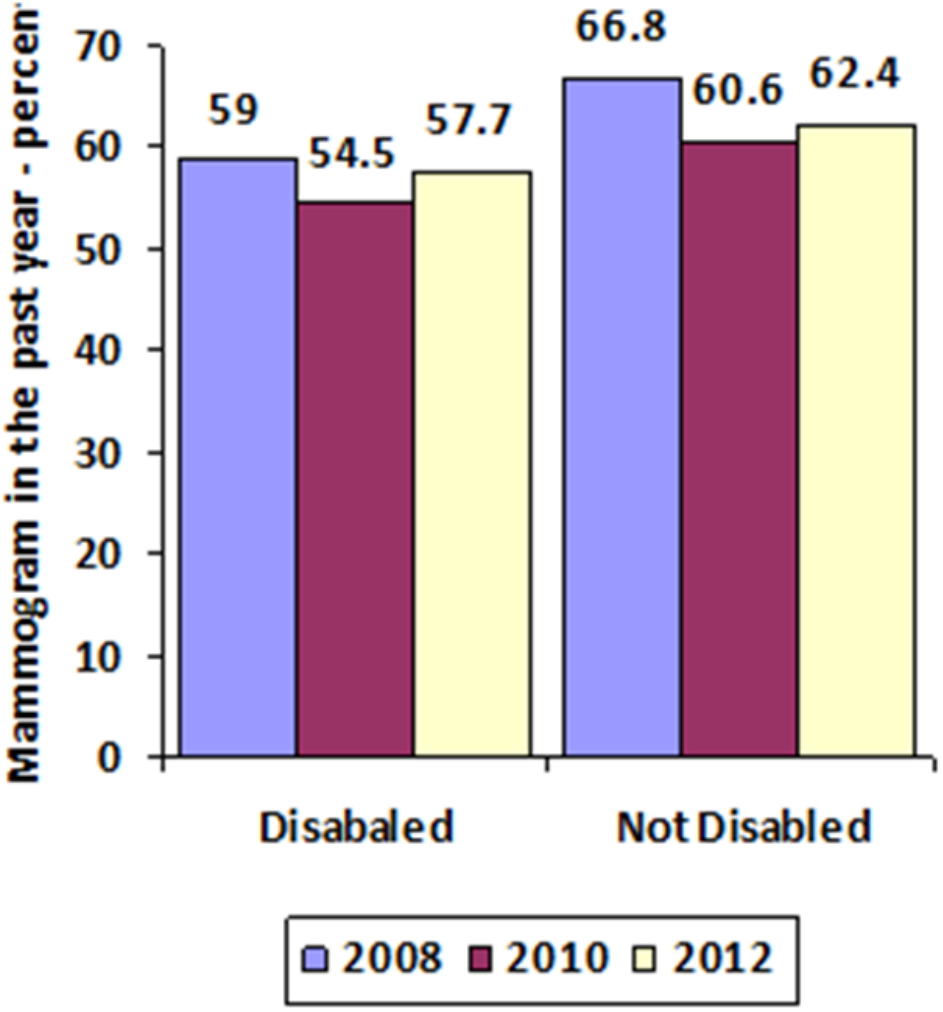


Key Features of Models

- Health Disparities Framework
- Emphasizes modifiable barriers and supports as entry point for intervention
- Highlights critical barriers to care for people with disabilities.
- Identifies supports/strengths that can be mobilized to counteract barriers to care
- Provides opportunities of both individual and environmental/systems level interventions
- Identifies key measureable outcomes (using ICF compatible language) that can be impacted by barrier reduction and patient activation.

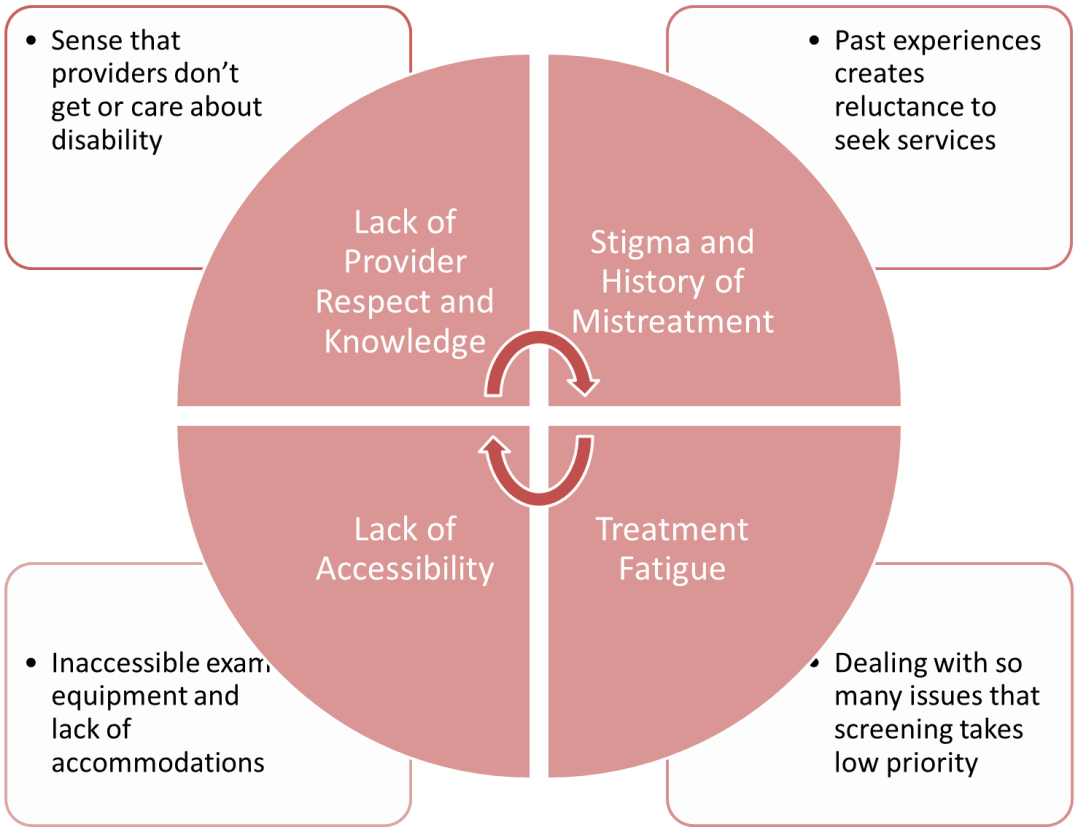
From Community Identified Problem to Community-based Programs

Research Findings



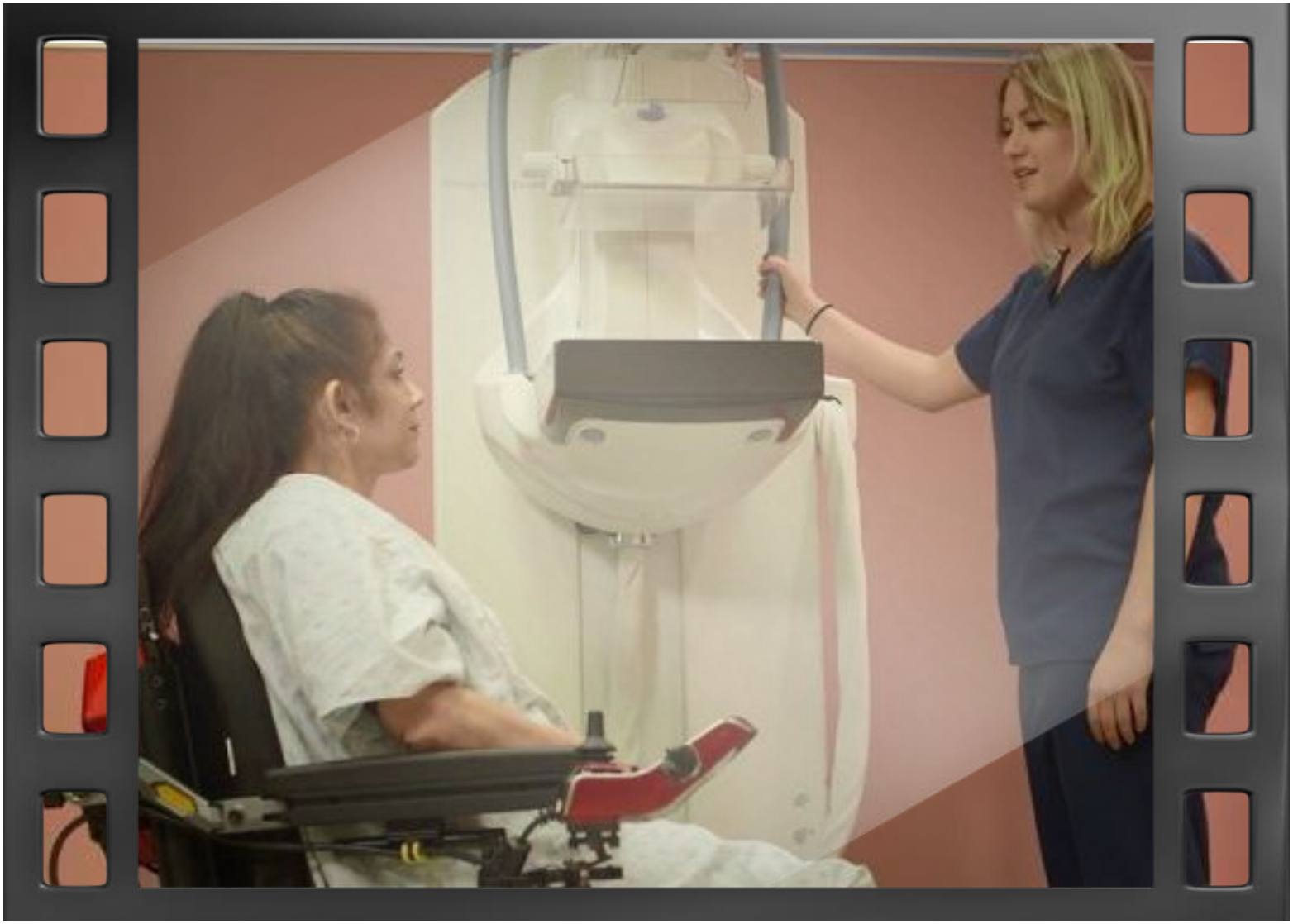
Quantitative Findings - Disability status is significantly associated with a reduction of 22% in the odds of receiving a mammogram, (OR=.78, $p<0.001$)

Research Findings

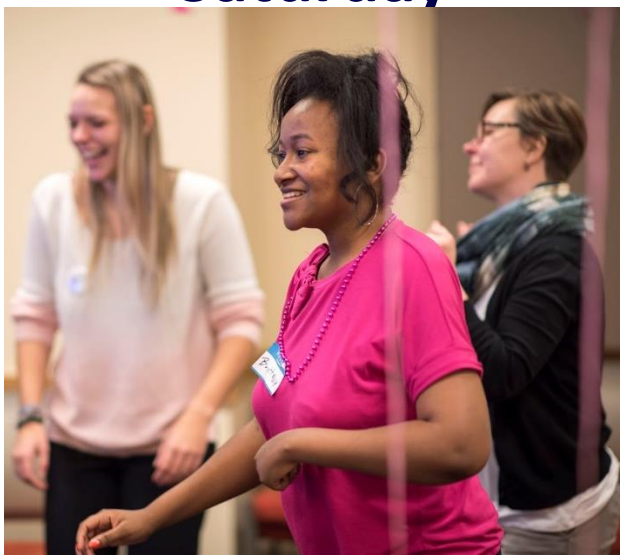


Qualitative Findings – Provider and patient related factors create barriers to breast cancer screening for women with disabilities.

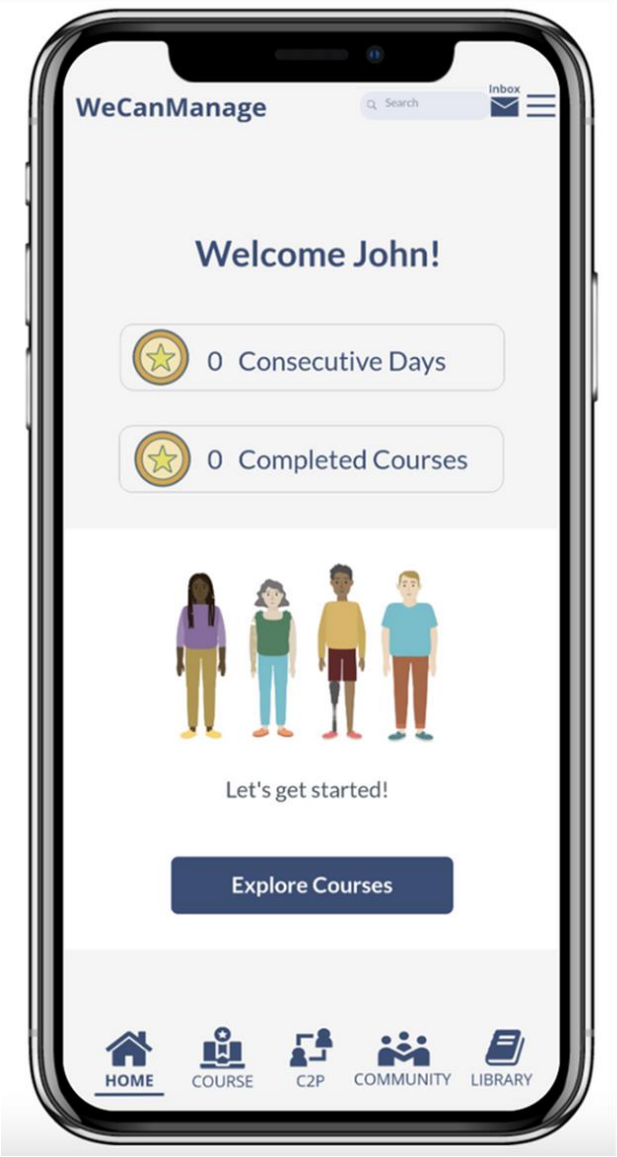
ScreenABLE



ScreenABLE Saturday



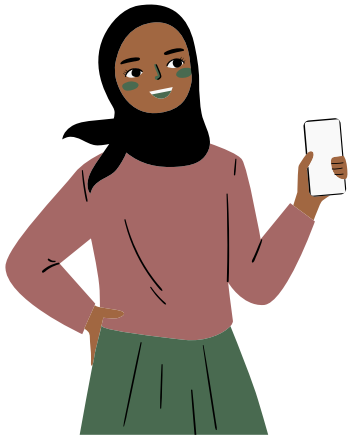
Survivorship WeCan… mHealth tools for cancer survivors with disabilities



The Problem

- Cancer survivorship is increasing
- 40% of cancer survivors experience long-term aftereffects of cancer
- Aftereffects can be physical, cognitive, emotional, social, & financial
- The aftereffects of cancer impact people's ability to return to their activities of daily living and social participation.
- The impact of the aftereffects of cancer are revealed over time when people are no longer nested within the system of care
- <10% of survivors who need cancer rehabilitation services receive them

Background



- Self-management (problem-solving and mindfulness-based) interventions help people live with cancer as a chronic condition
- Mobile and web-based applications can get evidence-informed self-management interventions in the hands of the people who need them

WeCanManage

- Smart phone-based evidence-informed self-management intervention
- Developed by an inter-discplinary team using a co-design process with survivor scientists

Intervention Development

Literature Review

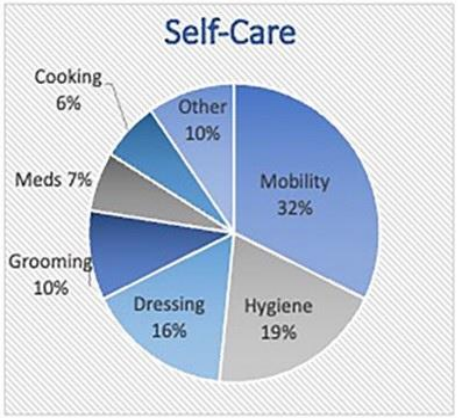
- Reviewed self-management interventions for cancer survivors
- Examined practice guidelines for occupational therapy interventions for cancer survivors

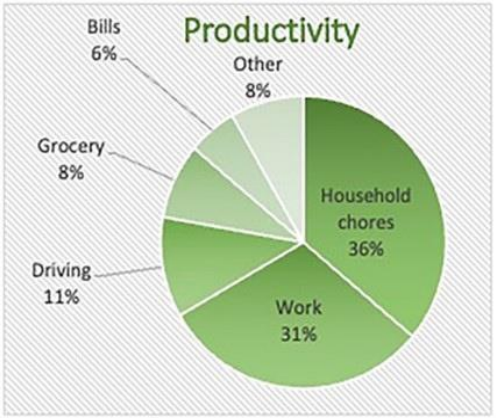
Formative Stakeholder Interviews

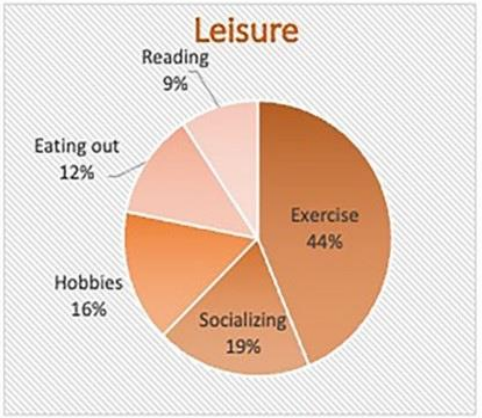
- Conducted qualitative interviews with cancer survivors (n=30) and supportive cancer care providers (n=5)
- Survivor interviews were supplemented with the Canadian Occupational Performance Measure to assess impact on social participation

Findings - Performance Deficits

COPM: performance problems







Supporting quotes from interviews

I used to wash my back with my washcloth by seesawing the washcloth across my back.... I no longer have the strength. I'm finding that my grasp and my sense of touch... is not the same. (S27)

I have difficulty with the strength in my left shoulder and difficulty with range of motion. So certain items of clothing are harder to get off. Lifting is still a struggle and I still have neuropathy in that shoulder. (S18)

There were times I couldn't work, but then I decided I'm done complicating thing is I was an elected official, and I just didn't want to go through the whole election cycle again, so it just worked out that I was able to retire. (S30)

Sorry it's emotional. I have a hard time learning new skills. I'm an educated person and I had a functioning life, and I can't function anymore. (S24)

[My] inability to work and bring in income. That's major...you can't live in this country. (S15)

I have a kayak, which I used to be extremely active, but I have not taken it out since 2015 when I had my mastectomy and reconstruction" (S8)

I can't garden, which is a great source of enjoyment for me, so I just had to shut down and be quiet and be still." (S23)

"We would bowl a lot. I was on a league. I was a really good bowler and that's one thing I'm like, I just gave it up. (S22)

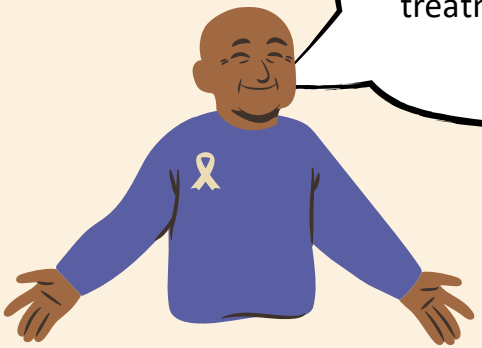
Winters et al. (2023)

Survivor Voices

I just feel like a slacker for not being able to move on.

Even when I finally applied for disability plates and I thought, well, I'm not really disabled. I could just park down there and just take my time and walk.

The only thing worse than going through cancer treatment...is after cancer treatment



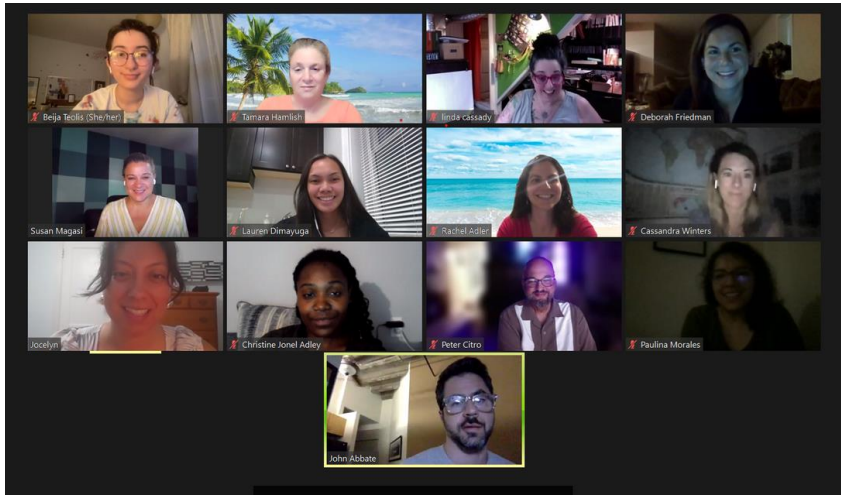
I started to see my condition as a disability and in the larger context as something that doesn't have to be fixed.

I'm still me but I'm different

Magasi et al. (2022)

Co-Design Process and Evaluation

3 co-design workshops were held over Zoom.



- Workshop 1 - Persona Development
- Workshop 2 - Prototype Ideation
- Workshop 3 - Prototype Development

Heuristic Evaluation

Usability Testing

Adler et al. (2022); Adler et al (forthcoming)

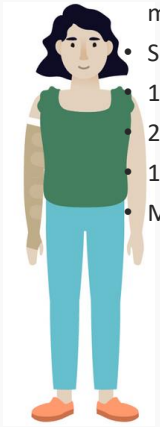
Intervention Content

WeCan Relate

- You are not alone
- WCM is designed to Help
- Long-term effects are common
- Symptoms
- Impact on doing
- Intro to self-efficacy
- Regaining Control
- Breaking down all or none thinking

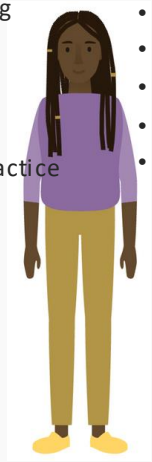
WeCan Adapt

- Defining self-management
- The Science of Self-Management
- Goal Setting
- Task Analysis
- Action Planning
- Planning
- Permission
- Pacing
- Prioritizing
- Setting the Environment Up for Success



WeCan Be

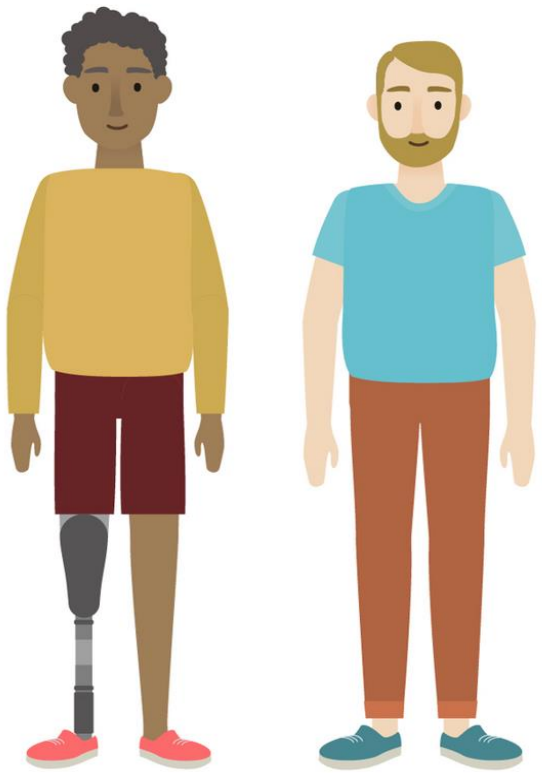
- Defining Mindfulness
- Common reasons for practicing mindfulness
- Science of Mindfulness
- 12-minute breathing practice
- 27-minute body awareness practice
- 12-minute mindful eating
- Mindful student podcast



WeCan SpeakUp

- Communicating your needs
- Knowing your Rights
- Asserting your Rights
- Intro to the ADA
- Work place accommodations
- #SayTheWord

Approach to Learning



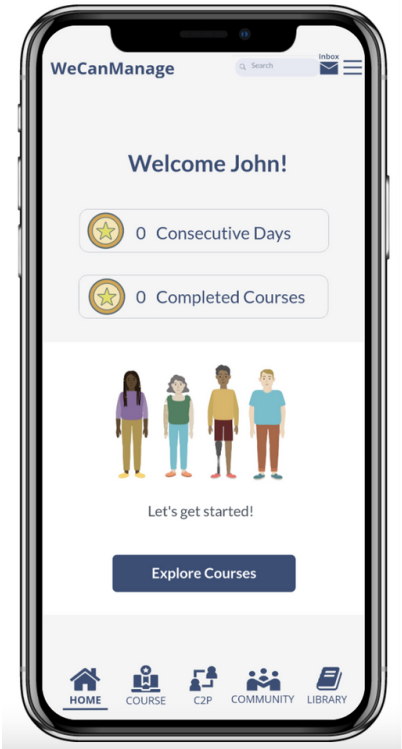
Mobile Micro Modules for Learning Content
+ Info presented in bite-sized pieces
+ Content builds over time
+ Strategic redundancy

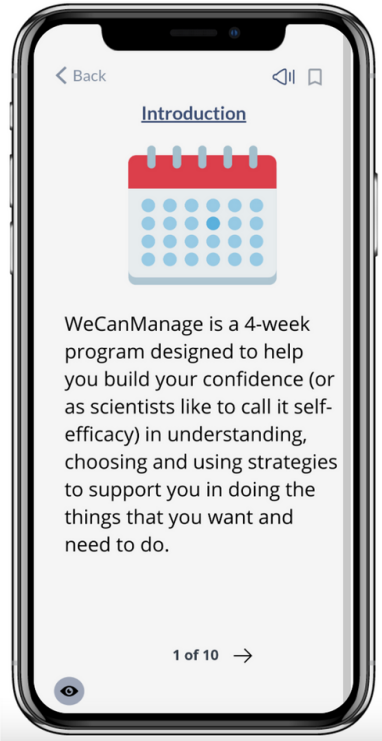
Blend of:
+ Text-Based (w/ text to speech options)
+ Animation (with closed captioning)

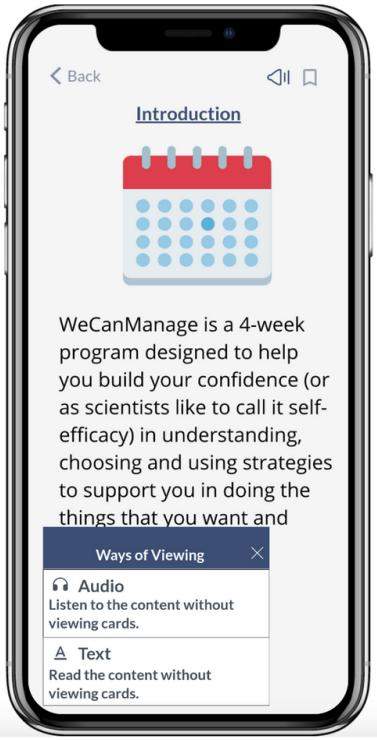
Re-enforcement with:
+ Case studies
+ Application activities

Implement design features to promote
+ Engagement
+ Application
+ Motivation

A sneak peak at the high-fidelity prototype & intervention content







Next Step – feasibility trial (n=60), June 2024

Disability Etiquette

- Pre-plan for accommodations
  - Allow for extra time
  - Have supports available
- Talk directly to the patient
- Do not move their mobility device without asking
- You are the expert in mammography, they are the experts in their bodies and minds
- Ask them how their body moves and adapt accordingly
- Acknowledge your uncertainty
- Work together

Key points

- PWD get cancer; cancer causes disability
- People with disabilities are still unrecognized cancer disparities population
- A multipronged approach is needed to tackle disparities, incl:
  - Clinical services and community programming
  - Clinical and community-based research
  - Training
    - Clinical community
    - Disability community

Resources

- CDC Right to Know Campaign https://www.cdc.gov/ncbddd/disabilityandhealth/righttoknow/index.html
- Breast Health Toolkit for Women with Disabilities https://www.aahd.us/wp-content/uploads/2018/10/Breast-Health-Toolkit-5-17.pdf American Association for Disability and Health
- Breast Health for Women with Disabilities https://www.youtube.com/watch?v=rlb9jVjpJpo Cerebral Palsy Foundation

Discussion

NCI U54CA202995, U54CA202997, and U54CA203000, ACS-Illinois Division, PCORI P2P program

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