



Determining the Education and Engagement Needs of Individuals with or at Risk of Breast Cancer Related Lymphedema

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INTRODUCTION

Breast cancer-related lymphedema affects approximately 1 in 5 individuals with breast cancer and is a **chronic condition requiring ongoing management**.¹

Clinical Practice Guidelines (CPG) are essential for synthesizing research and clinical expertise to improve patient outcomes.^{2,3} A Canada-wide multidisciplinary team is updating the CPG for breast cancer-related lymphedema.⁴

As part of the CPG process, this study aimed to determine the best methods for communicating CPG recommendations to individuals with, and at risk of breast cancer related lymphedema.



Figure 1: Visual representation of lymphedema on the left arm.

OBJECTIVES

To determine the **educational and engagement needs of individuals with or at risk of breast cancer related lymphedema**. The findings will inform the future co-creation of knowledge transfer and engagement tools related to dissemination of CPG recommendations.

METHODS

A **mixed methods design** was used involving:

- 1) A national survey was conducted in both English and French, targeting individuals diagnosed with or at risk of breast cancer-related lymphedema (N=131). The survey aimed to gather data on preferred formats for accessing educational resources and digital engagement tools to support future knowledge transfer.
- 2) Virtual focus groups (N=17) were conducted in both official languages and provided further insight into educational needs and preferences.

RESULTS

Survey Results

Key survey findings on preferred educational formats and needs for BCRL patient engagement.

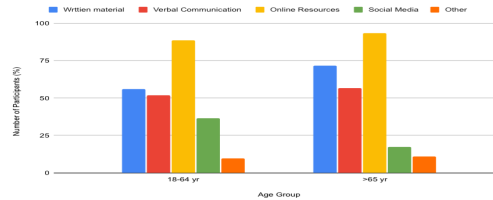


Figure 2: Preferred Formats by Age Group — Shows educational format preferences by age.

Focus Group Results

Key focus group findings on preferred educational formats and needs for BCRL patient engagement.

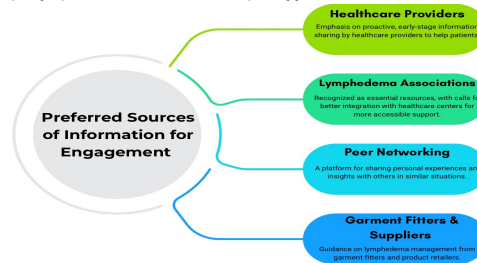


Figure 3: This infographic identifies key sources preferred by participants for engagement and information on lymphedema

1) User-Friendly Formats

A preference for online resources that are easy to navigate, and ensure access across languages and health literacy levels.



2) Culturally Relevant

Educational materials that are culturally sensitive and inclusive to diverse population groups.



3) Strategic Time Points

Educational content in lay language, and in manageable portions over the treatment trajectory to avoid information overload and aid in knowledge retention.



4) Support Self-management

Consistent, reliable resources that foster effective long-term self-management.

CONCLUSION

By involving individuals with breast cancer in the planning, **we can support the future development and sharing of educational materials** that are meaningful to those most impacted by lymphedema.

The survey results and focus group feedback will be used to guide the co-creation of knowledge translation tools that are:

- > User-friendly, accessible and culturally relevant
- > Aligned with key time points in the breast cancer treatment trajectory
- > Focussed on self-management
- > Inclusive to diverse population groups across Canada



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