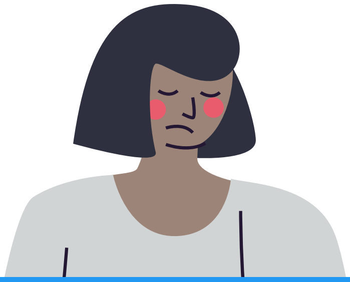
2022 ImpediMed Lymphedema Prevention Awareness Survey

> **I do my best to stay positive** but there are times when I get so angry at the daily challenges of this disease.



58%

of cancer patients diagnosed with breast cancer, melanoma, or pelvic area cancers are at risk for developing limb lymphedema.

Introduction

Lymphedema is a very common sequela of cancer treatment. According to the American Cancer Society, Cancer Facts & Figures, 58% of cancer patients diagnosed with breast cancer, melanoma, or pelvic area cancers are at risk for developing limb lymphedema.[1] 1 in 3 at-risk patients will develop lymphedema.[2] Lymphedema of the arms and legs can occur at any time after cancer treatment but 75% of incidents develop in the first three years following surgery.[3]

This poses several significant healthcare challenges to clinicians as they seek to inform and educate patients about lymphedema, diagnose at the early subclinical stage, and deliver timely intervention to prevent the development of chronic lymphedema.

Lymphedema has significant economic implications for patients. The annual health-related out-of-pocket costs for patients diagnosed with breast cancer-related lymphedema are estimated at $3,325 including treatment and productivity lost.[4] Patients diagnosed with chronic stages of lymphedema are left with not only a reduced quality of life, but the loss of economic resources. The opportunity to mitigate advanced stages of lymphedema clearly offer an economic benefit to the patient long term.

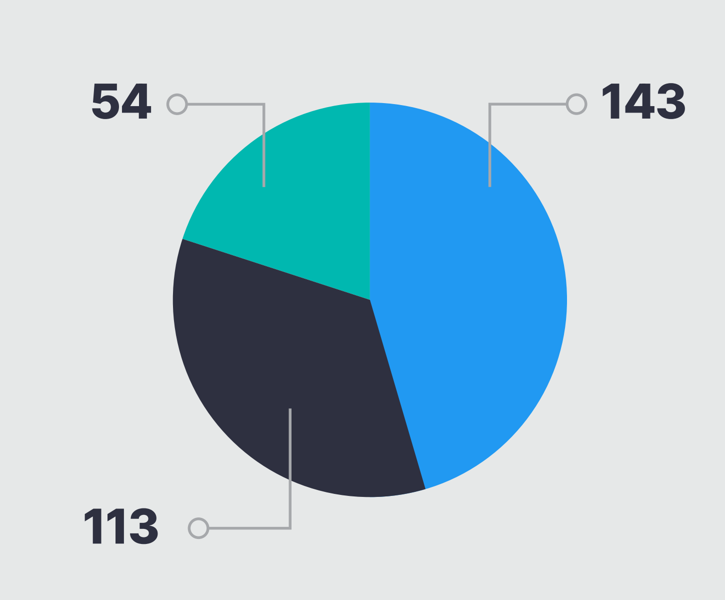
An effective lymphedema prevention program, which includes timely education to the patient, effective use of technology for early surveillance, and an early detection and intervention protocol has been proven to deliver the best clinical outcomes. But while a prevention model-of-care has been well established in leading cancer care guidelines, the concept of lymphedema prevention is relatively unfamiliar to patients.

A January 2022 survey of 143 secondary lymphedema patients and 54 healthcare professionals (HCPs) provides insights and informs key challenges that make the case for improved patient access to a lymphedema prevention program. Findings from the survey point to the devastating impact lymphedema has on the lives of cancer survivors, with many patients commenting on their reduced quality of life and well-being. While HCPs reported that they almost always discuss lymphedema risk factors with their patients, patients responding to the survey overwhelmingly reported that they did not receive adequate lymphedema education. Patient access to programs that aim to educate the patient and leverage the recommended model-of-care for lymphedema prevention is broadly needed.

Methodology

The survey was fielded by the **Lymphatic Education & Research Network (LE&RN)** in January 2022.

Participation was voluntary and an honorarium was not offered. Respondents to the survey included three subgroups and each subgroup were presented with question sets relevant to their role with lymphedema management.



SURVEY PARTICIPANTS

- 🟦 Secondary lymphedema patients that developed lymphedema post cancer treatment **(n=143)**
- ⬛ Primary lymphedema patients, family, advocates, other **(n=113)**
- 🟩 HCPs **(n=54)**

For the purpose of this analysis, responses from HCPs and secondary lymphedema patients were assessed.

The Devastating Impact of Lymphedema for Cancer Patients

Lymphedema continues to devastate a patient's survivorship post cancer treatment. Patients described lymphedema as a daily struggle, with their condition taking over every aspect of living. From physical, mental and emotional well-being, to the financial toxicity related to loss of work and cost of treatments. This leaves a heavy burden on the patient and negatively impacts their quality of life.

Pain

Pain caused by lymphedema itself

QOL

Reduced QOL due to physical limitations imposed by LE, additional stress

Emotional Toll

Feeling hopeless, helpless, no control over lymphedema, feeling disabled, diminished self-image, loss of confidence

Reduced Mobility

Limited ability to walk, stand/sit, bike, be active, participate in social activities

Garments

Discomfort wearing compression garments

Financial

Limited/unable to work, impact on career, cost of garments, inadequate medical and financial support

Time Consuming

Planning day around lymphedema (loss of spontaneity), spending hours per day managing lymphedema

Secondary lymphedema patients agree that the disease has had a significant adverse affect on their daily lives. Most patients reported that they struggle to take care of their family or work. Additionally, patients are left with lower confidence and the psychological burden of worrying about their condition on a daily basis.

Quality of Life

64%

"I struggle with lymphedema on a daily basis"

63%

"I worry about my lymphedema on a daily basis"

61%

"More challenging to work or manage my career"

53%

"More challenging to take care of my family"

61%

"I am less confident about life"

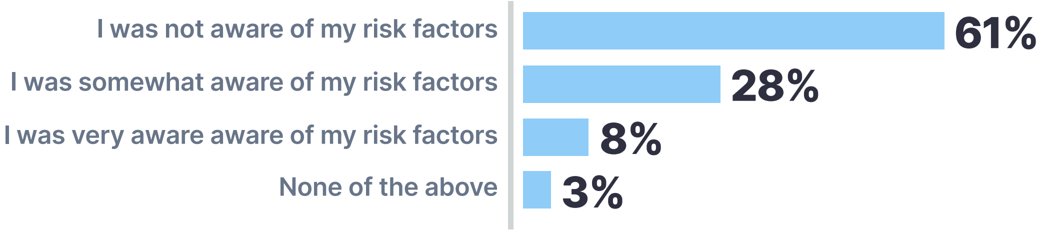
> "I feel like I went from a death sentence (cancer) to a life sentence living with lymphedema."

The Lymphedema Education Gap

Patients overwhelmingly reported that the level of education they received throughout their cancer treatment journey, from diagnosis on through to survivorship, was not adequate.

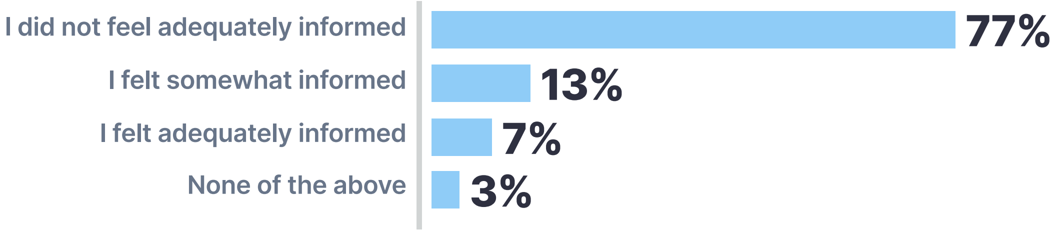
Diagnosis

"Were you aware of lymphedema factors at the time of your cancer diagnosis?"



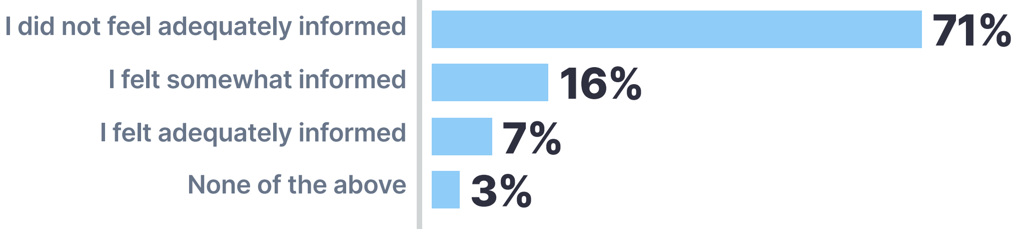
During Treatment

"Did you feel adequately informed of lymphedema risk factors at the time of your cancer treatment?"



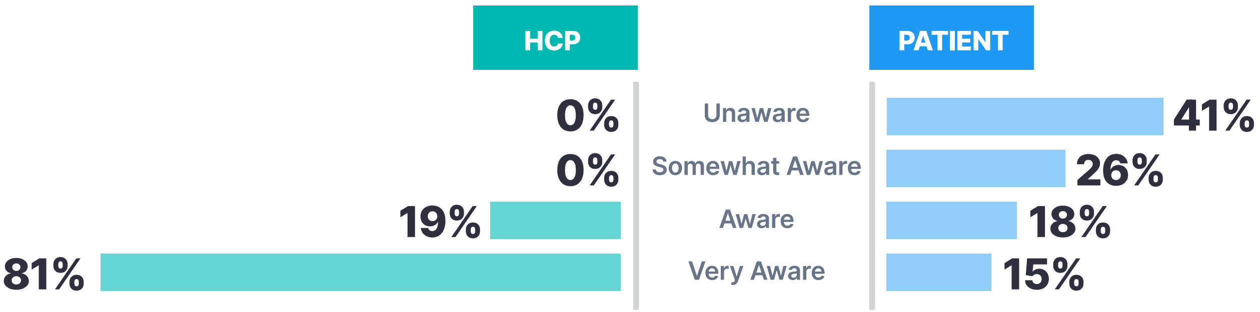
Post Treatment

"Did you feel adequately informed regarding lymphedema risk factors after/post your cancer treatment?"



While all HCPs indicated that they are aware that secondary lymphedema can be prevented, **patient awareness of lymphedema prevention is low.**

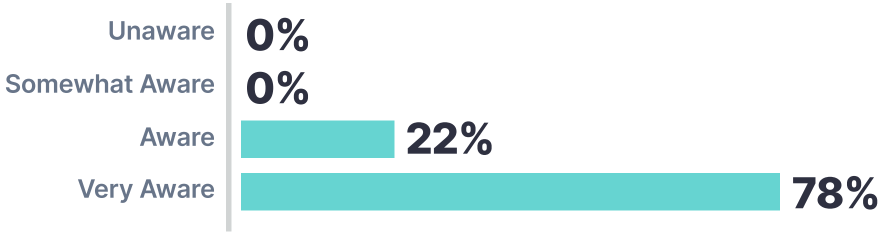
“I am aware that chronic secondary lymphedema can be prevented”



ALL HCPs are aware that an early detection/treatment protocol can mitigate chronic secondary lymphedema. In contrast, **half of patients are not aware** that a lymphedema prevention program can help patients avoid chronic secondary lymphedema.

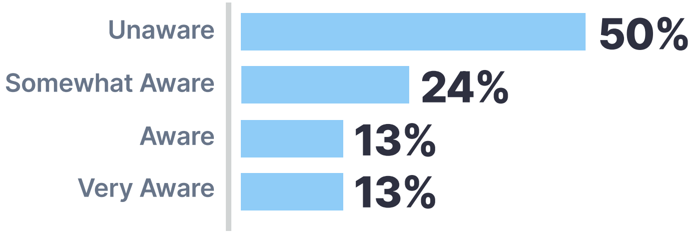
HCP

“I am aware that early detection and treatment protocol can mitigate chronic secondary lymphedema”



PATIENT

“I am aware that a Lymphedema Prevention Program can help patients avoid chronic secondary lymphedema”



HCPs almost always discuss the risk of lymphedema with their patients. However, the majority of **patients indicated that they did not feel adequately informed** of risk factors during their cancer treatment journey.

96%

of HCPs always discuss lymphedema risk factors with their patients

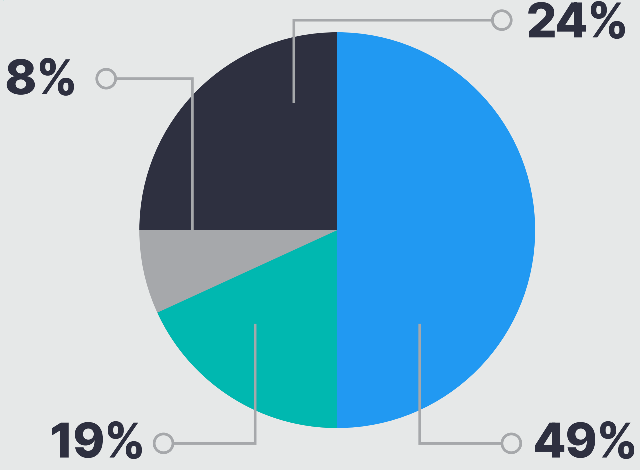
74%

The majority of patients did not feel informed of risk factors

HCPs are indeed challenged when tasked to inform patients that lymphedema may be a potential side-effect of their treatment. **HCPs reported that nearly 50% of patients are more concerned about their cancer treatment** than the risk of lymphedema. However, with the improvement of survivorship rates, timely and regular education to the patient regarding lymphedema prevention is necessary to help them avoid the consequences of lymphedema.

- 🟦 My patients are more concerned about their cancer treatment
- ⬜ My patients are less concerned about their cancer treatment
- ⬛ My patients are indifferent
- 🟩 N/A

"How is the information received by your patient?"



VOICES
from secondary lymphedema patients

> "I have been in cancer remission for over 10 years but I currently spend about 3 hours per day managing my lymphedema and wearing compression 24/7."

> "Surviving with hand and arm lymphedema after breast cancer makes me second guess what I can and can't do on a daily basis."

> "It is a 24/7 nightmare that has consumed every piece of my life, physically, emotionally, mentally, financially."

Limited Patient Access to a Lymphedema Prevention Program

HCPs have strong intent to monitor patients through a Lymphedema Prevention Program with nearly half responding that their institution currently offers an LPP and 39% offer L-Dex® testing or refer patients out for testing. However, of the patients who responded to the survey, only 2% reported that they are enrolled in an LPP and less than 4% have received an L-Dex test in the last 12-months. Patient accessibility to an LPP is a challenge.

HCP

48%
"My institution currently offers a Lymphedema Prevention Progam"

39%
"My institution offers or refers patients out for L-Dex testing"

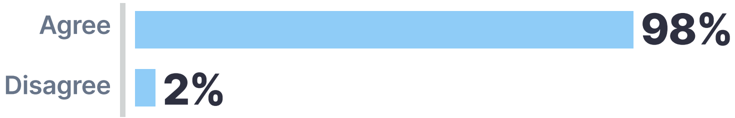
PATIENT

2%
"I am currently enrolled in a Lymphedema Prevention Program"

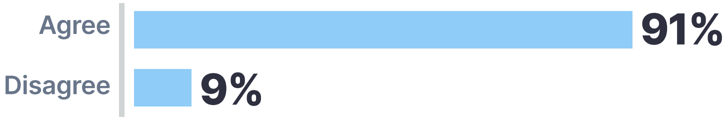
4%
"I have received my L-Dex test in the last 12 months"

Secondary lymphedema patients strongly agree that doctors need to inform patients of the risk of lymphedema and that cancer care teams should offer patients a Lymphedema Prevention Program.

"I believe doctors need to inform patients of the risk of lymphedema"



"I believe cancer care teams should offer cancer patients a Lymphedema Prevention Program"

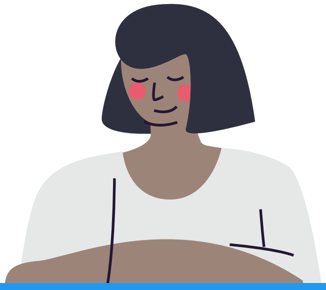


About Secondary Lymphedema Prevention

An effective Lymphedema Prevention Program has been shown to deliver optimal outcomes for patients. Program components incorporate timely education to the patient along with effective use of technology for early and regular surveillance and intervention. As patients are eager to be more informed, this presents an opportunity for clinicians involved in the diagnosis, treatment, and post treatment therapies of cancer patients to introduce and enroll their patients into a Lymphedema Prevention Program as a standard-of-care.

The PREVENT study, the largest randomized trial to assess lymphedema prevention, found that 92% of patients with early detection using L-Dex and intervention did not progress to chronic lymphedema.[5] As the primary endpoint result, the study found significantly lower progression to chronic lymphedema with an early detection program using L-Dex and intervention versus a circumferential tape measure.

In conclusion, improving patient access to a Lymphedema Prevention Program is an effective way to increase education, build patient confidence, and help patients avoid the negative, and preventable condition of lymphedema.



92%

of patients with early detection using L-Dex and intervention did not progress to chronic lymphedema

VOICES

from secondary lymphedema patients

> “Managing lymphedema is a full time job.”

> “Lymphedema has changed my life and confidence completely. I am not the same as I was before lymphedema.”

> “Lymphedema is a constant reminder of my breast cancer.”

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