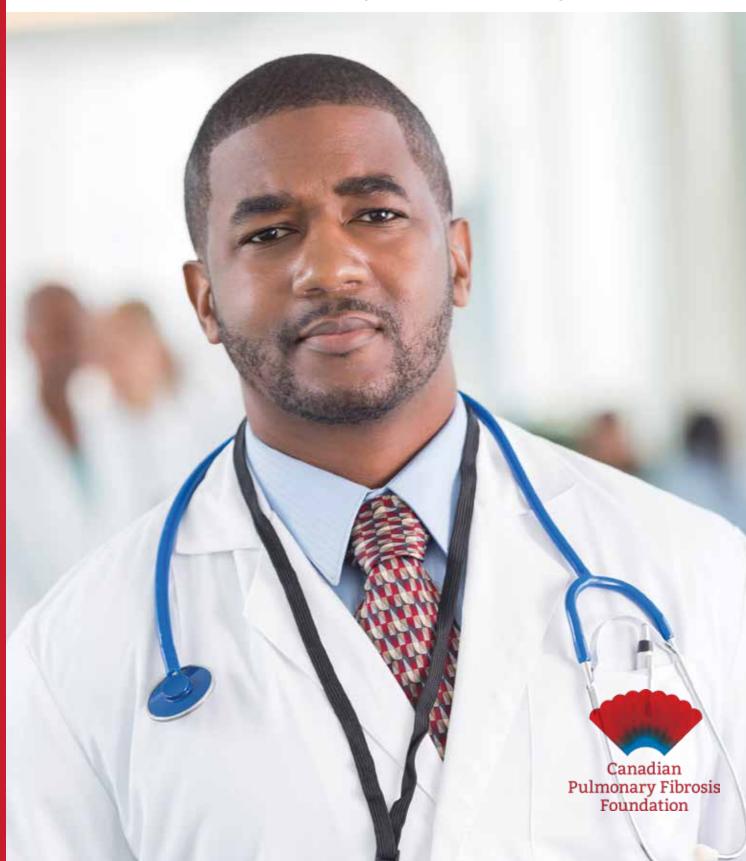


ACCESS TO OXYGEN THERAPY IN CANADA

Healthcare Professional Survey



A 360° VIEW

A message from CPFF's Board Chair and Executive Director

To fully comprehend the issues facing people with a rare disease like pulmonary fibrosis, the perspective of healthcare professionals on the front lines is key. In 2022 the Canadian Pulmonary Fibrosis Foundation (CPFF) asked Canadians living with pulmonary fibrosis and their caregivers to complete a survey about the impact of the disease on their lives. Many respondents felt worse off in 2022 than they did in 2020. One issue, above all others, demanded further attention: timely and equitable access to home oxygen therapy.

To fully understand the issue, CPFF commissioned **two groundbreaking national research surveys** – with medical professionals *(detailed in this report)* and oxygen providers.



Patients and Caregivers



Summary Report



Oxygen Providers

Scan to read the reports:



Additionally, Dr. Gokul Vidyasankar undertook a comprehensive review of the patchwork policies that guide (and restrict) access to oxygen therapy for Canadians in need. The results of Dr. Vidyasankar's expansive research

are compiled in his "Oxygen

"Harmonization of Oxygen in Canada" by Dr. Gokul Vidyasanka

Therapy in Canada" research paper. Healthcare professionals confirmed what patients and others have been telling us for years: access to oxygen varies dramatically across Canada. Medical criteria needed to qualify for sufficient oxygen is widely criticized, especially exertional oxygen. Frustration is widespread. A heart-felt thank you to all who shared their expertise.

The time to act is now.

In this report, CPFF is uncovering healthcare professionals' views on oxygen access issues for Canadians, taking into account the unique needs of people living with pulmonary fibrosis. No Canadian should be left without the treatment they need to breathe.

To learn more about pulmonary fibrosis and CPFF, please visit our website: **cpff.ca**

Kirk Morrison

Board Chair

Sharon Lee
Executive Director

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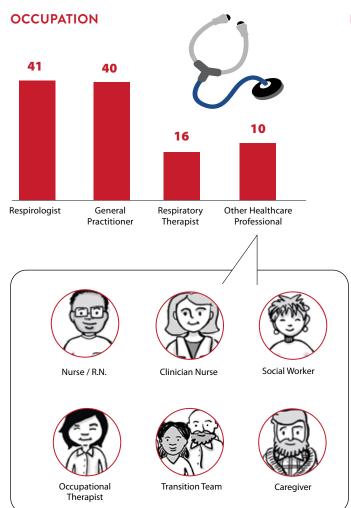
HEALTHCARE PROFESSIONAL SURVEY PARTICIPANTS

OBJECTIVE & METHODOLOGY

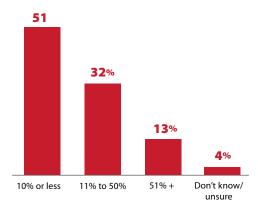
CPFF's objective with this research is to provide insights to help us advocate for better access to home oxygen therapy for patients living with PF. Insights were gathered from a survey sent out to healthcare professionals across Canada. Respondents were identified through CPFF's database and network across all Canadian provinces and territories, and solicited through CPFF's communication channels (newsletter, social media, associations), in English and French.

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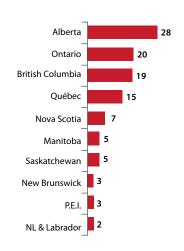
HEALTHCARE PROFESSIONALS



PERCENTAGE OF PATIENTS USING HOME O2



PROVINCIAL BREAKDOWN

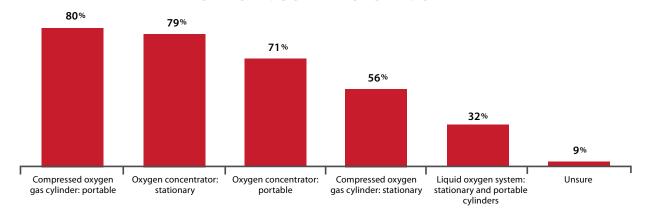


HEALTHCARE PROFESSIONALS WITH LUNG-HEALTH EXPERTISE

Respirologists, respiratory therapists, and other professionals caring for patients who require oxygen therapy are confronted by the patchwork system limiting their ability to provide optimal care. Doctors are often frustrated by existing guidelines when prescribing to patients who do not fit into narrowly-focused medical criteria. Healthcare professionals are witnesses to the difficulties many face in receiving sufficient oxygen, are frustrated by the status quo.



OXYGEN SUPPLY SYSTEMS



LEARNING HIGHLIGHTS

PATIENTS FACE BARRIERS ACCESSING OXYGEN THERAPY



rigid & inadequate qualifying criteria regarding oxygen saturation levels



accessing sufficient oxygen at home, outside the home, and traveling.



exertional oxygen needs are not covered



cost is prohibitive for travelers

2

HEALTHCARE PROFESSIONALS SAY COVERAGE IS INADEQUATE



of healthcare professionals say provincial **reimbursement guidelines** do not allow them to prescribe oxygen therapy to all who need it



Reimbursement criteria are too strict or not appropriate

3

PATIENT SUPPORT & IMPROVEMENT OPPORTUNITIES



Increase coverage
for modern equipment and
enable better access



modify medical criteria for disease-specific oxygen needs



provide training support for patients and other providers

OVER IN

3

HEALTHCARE
PROFESSIONALS
FEEL ACCESS
TO OXYGEN
THERAPY AT
HOME NEEDS
IMPROVEMENT.



OXYGEN ACCESS IS INADEQUATE

Oxygen therapy is a literal lifeline for the approximately 30,000 Canadians living with pulmonary fibrosis. Despite its critical importance, access to oxygen at home and while travelling is rated poorly.

HEALTHCARE PROFESSIONALS SAY PATIENTS EXPERIENCE DIFFICULTIES ACCESSING O2 AT HOME AND WHEN TRAVELLING.

Q: How would you rate pulmonary fibrosis patients' access to oxygen therapy?

"The provincial government does not fund light weight portable oxygen systems and only provides small tanks. This is not convenient for patients and decreases their ability to do exercise and travel"

2% 12% 19% 24% 21% 28% **72**% 25% 25% 23% 17% 38% 17% 10% Home In-province travel In-Canada travel

"Tanks are heavy ... a lot of patients feel it is too much work to leave the house and essentially become house bound"

RESPIROLOGIST, NS

RESPIROLOGIST, NS

Don't know Poor Somewhat disappointing

Satisfactory

Very good



HEALTHCARE
PROFESSIONALS
FEEL THE
PROVINCIAL
REIMBURSEMENT
GUIDELINES
DO NOT
ALLOW THEM
TO PRESCRIBE
OXYGEN
THERAPY TO ALL
WHO NEED IT.

A PRESCRIPTION FOR FRUSTRATION

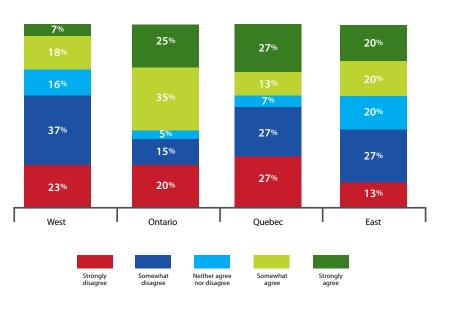
Currently, healthcare professionals ability to prescribe home oxygen is regulated at the provincial or territorial level, resulting in significant variability across the country. This variation places significant financial and emotional strain on patients, leaving many healthcare providers frustrated.

PRACTICE GUIDELINES *Q*: What practice guidelines do you follow in prescribing supplemental oxygen?



REGIONAL BREAKDOWN

Q: Agree or disagree: "My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all who need it"



WHERE YOU LIVE IN CANADA **DETERMINES WHAT YOU GET**

OUT-OF-POCKET COSTS CAN BE THOUSANDS OF \$\$\$ PER YEAR*

of patients say that they pay at least some of their oxygen costs OUT OF POCKET

Misalignment between provincial reimbursement guidelines and patient need is an issue to a majority of healthcare professionals in Manitoba, British Columbia, Alberta, Quebec, and Nova Scotia.

Newfoundland & Labrador have

coverage for home O2 therapy*

"Criteria for reimbursement is not appropriate for this patient population."

REGISTERED NURSE, AB

"Those requiring exertional oxygen after discharge from hospital are not provided for."

RESPIROLOGIST, SK

"There are no criteria for ambulatory O2 either and it needs to be argued every time for coverage."

RESPIROLOGIST, QC

*Source: Dr. Gokul Vidyasankar: "Harmonization of Oxygen in Canada"

"COVERAGE FOR SUPPLEMENTAL OXYGEN AT EXERTION IS THE MAIN PROBLEM"

RESPIROLOGIST, AB

"I WOULD
LIKE TO SEE
IMPROVED
ACCESS TO
EXERTIONAL
OXYGEN FOR
PULMONARY
FIBROSIS
PATIENTS"

RESPIROLOGIST, BC

OXYGEN NEEDED FOR EXERTION IS AN ISSUE

As per issues around reimbursement, medical criteria for the prescription of home oxygen varies widely across Canada. While the threshold for severe breathlessness is fairly consistent, criteria for **exertional needs** is not. Quebec and PEI do not fund oxygen for exertional needs. Canada's territories, plus Newfoundland and Labrador, have no medical criteria for home oxygen, despite providing reimbursement.



Source: Dr. Gokul Vidyasankar: "Harmonization of Oxygen in Canada"

"Those with higher flow rates and need for more than 10 tanks a month or those requiring exertional oxygen immediate after discharge from hospital are not provided for."

RESPIROLOGIST, SK

"I would prescribe more exertional O2."

RESPIROLOGIST, BC

"There are some patients with mild desaturation who may benefit from exertional oxygen, however access is limited."

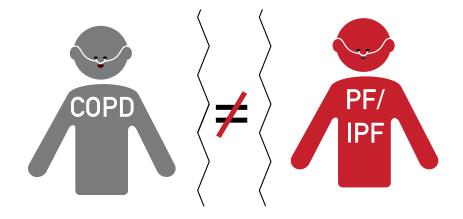
RESPIROLOGIST, ON

O2 THERAPY STUDIES FOCUS ON COPD

Canadian policy for providing oxygen therapy is based on the needs of patients with chronic obstructive pulmonary disease (COPD), which differs widely from pulmonary fibrosis (PF). A lack of distinction between these two diseases creates a significant barrier for people with PF.

"Criteria for qualifying for oxygen in this province is not suitable for patients with exertional dyspnea which is primarily what our patients struggle with."

ILD REGISTERED NURSE



"Criteria for O2 access in Quebec are based on very old COPD literature and not at all applicable to ILD patients."

RESPIROLOGIST, QC

"Access to oxygen for PF clients does not fit the standards that were made for COPD or cancer patients. Sometimes our clients are not able to exercise or even go about their daily chores because of desaturation but they may not meet the criteria."

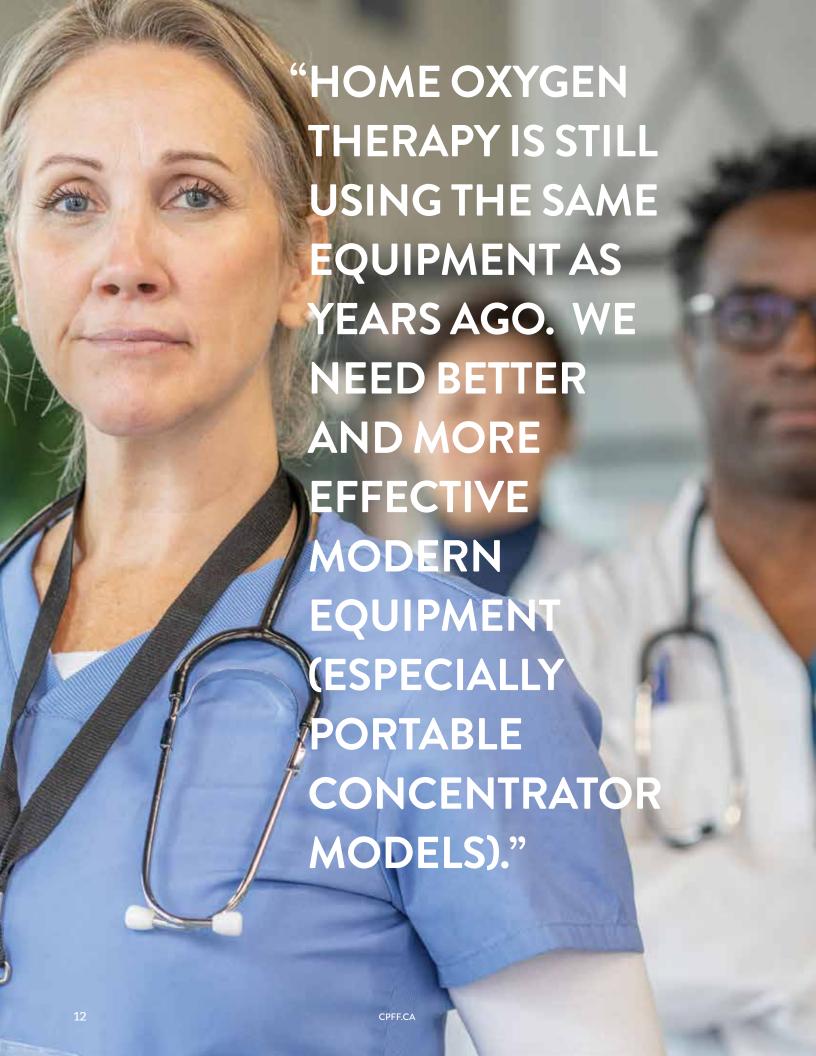
RESPIRATORY THERAPIST, AB

PROVINCIAL GUIDELINES CREATE UNACCEPTABLE INEQUITY



*For adults, the normal range of SaO2 is 95 – 100%. A value < 90% is considered low O2 saturation.

Source: Dr. Gokul Vidyasankar: "Harmonization of Oxygen in Canada"



HEALTHCARE PROFESSIONALS WEIGH IN ON HOW TO IMPROVE HOME OXYGEN THERAPY

Healthcare professionals across Canada echoed common themes of affordability/coverage, qualifying criteria, and better equipment mentioned by all surveyed groups. Their responses were rich in specific medical detail based on their clinical experience.







EDUCATION & TRAINING



BETTER EOUIPMENT

"Provide coverage for more tanks for those on higher flow rates."

- RESPIROLOGIST

"In Manitoba, cylinder oxygen should be covered or at least a certain number of cyl per month for exertional needs. Currently a stationary concentrator is what clients receive for exertion!!"

- RESPIRATORY THERAPIST

"Relax funding criteria and get rid of obstructionist policies. Improve access times. Currently it takes 2-3 months to obtain exertional funding in AB."

- REGISTERED NURSE

"Allow funding for anyone with dyspnea and O2 sat on exertion."

- RESPIROLOGIST

"Improved funding will improve access."

- RESPIROLOGIST

"Lower the bar for exertional oxygen."

- RESPIROLOGIST

"Criteria of coverage that would consider the unique and common reality of patient with lung fibrosis."

- CLINICIAN NURSE

"Have different rules for pulmonary fibrosis patients that differ from the COPDers."

- RESPIRATORY THERAPIST

"The MOH guidelines need to be tweaked...if the diagnosis for IPF is made with a CT SCAN and PFT, then the oxygen should be given as needed."

- RESPIRATORY THERAPIST

"Simplify the criteria, as offered by AHS Quality and Health Care Improvement office to AADL but RBP declined!!! Prescriptions by experts should count and be immediately valid."

- RESPIROLOGIST

"It would be useful as a GP to understand how to access oxygen therapy for my patients."

- GENERAL PRACTITIONER

"More education on managing desaturations especially during exercise. Ways to adjust flow rate without having to go to the concentrator when it is stationary."

- RESPIROLOGIST

"Pamphlet or websites to explain when/how to use Offer O2 sat meters to patient."

- RESPIROLOGIST

"Make the oxygen provider responsible for providing education on oxygen therapy - safety and use as well being more responsible for meeting the changing needs of their clients."

- RESPIRATORY THERAPIST

"Home oxygen therapy is still using the same equipment as years ago. We need better and more effective modern equipment (especially portable concentrator models)."

- NURSE

"1. Remote controlled
Oxygen Concentrators
in home so pt can adjust
flow with exertion without
relying on caregiver;

2. improve portability across provinces/Canada;

3. Higher flow POC's to allow for international travel."

- RESPIRATORY THERAPIST

"Have automated oxygen titration systems to ensure patients achieve the minimum (safe) oxygen saturations at rest and on exertion."

- RESPIROLOGIST



CANADIANS
LIVING WITH
PULMONARY
FIBROSIS
SHOULD NOT
HAVE TO
FIGHT TO GET
ACCESS TO THE
OXYGEN THAT
THEY NEED TO
BREATHE.

PULMONARY FIBROSIS PATIENTS HAVE A RIGHT TO:



- Many Canadians living with pulmonary fibrosis (PF), must complete a resource-intensive "six-minute walk" test to qualify for supplemental oxygen. This test is not suitable for patients with PF who often require higher flow rates of oxygen when active.
- Medical criteria to qualify for supplemental O2 is based on unsuitable COPD data. Exertional needs specific to pulmonary fibrosis are not covered.

Patients and medical professionals are calling for standardized medical criteria based on the unique needs of pulmonary fibrosis patients.



Reimbursement for All

- Misaligned provincial policies mean reimbursement for home oxygen therapy is inconsistent nationally. This is contrary to Canada's committment to an accessible universal healthcare system for all.
- O2 is classified as a drug in Canada, however in many aspects it is managed and funded as a medical device.
 As a result, access to a provincially-funded drug plan does not guarantee access to funding for home oxygen equipment.
- Lightweight, portable equipment is not funded, essentially leaving people housebound.

Patients and medical professionals are asking that costs be fully reimbursed for ALL people receiving home oxygen therapy.



02 in All Communities

- Oxygen delivery to Canadians living with pulmonary fibrosis is a national issue, especially in rural and remote areas.
- •Patients struggle to access the quantity of oxygen they need for higher flow needs (> 10 cylinders per month).

Patients and medical professionals are pleading for the system to provide oxygen therapy they need, regardless of where they live.



The Canadian Pulmonary Fibrosis Foundation is a registered charity established in 2009 by Robert Davidson. The CPFF was created to raise money to research causes and treatments for PF, provide education and support for people affected by PF and their caregivers, raise awareness about PF, and represent Canadians affected by PF to governments, healthcare professionals, the media, and the public.

The Canadian Pulmonary Fibrosis Foundation works tirelessly to:

SUPPORT



EDUCATE



RESEARCH



ADVOCATE



For more information, please contact:

info@cpff.ca

905-294-7645

cpff.ca



The Canadian Pulmonary Fibrosis Foundation works tirelessly to bring the latest news about PF research, resources and more to people living with pulmonary fibrosis as well as the larger community.

For more information, please contact:

info@cpff.ca