# ACCESS TO OXYGEN THERAPY IN CANADA

### Oxygen Provider Survey



### A 360° VIEW

### A message from CPFF's Board Chair and Executive Director

Home oxygen therapy is crucial for people living with pulmonary fibrosis (PF), yet the CPFF 2022 Patient and Caregiver survey revealed that many are challenged to get oxygen therapy when needed.

To fully understand the issue, CPFF commissioned two groundbreaking national research surveys with oxygen providers (detailed in this report) and medical professionals. Oxygen providers, who are frontline professionals for the delivery of home oxygen therapy, expressed the need for more timely and equitable oxygen access.



Report





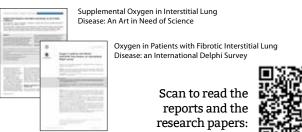


CCESS TO OXYGEN HERAPY IN CANADA

Report

Additionally, a collective of prominent physicians including Dr. Kerri A. Johannson (Department of Medicine, Department of Community Health Sciences, and Interstitial Lung Disease Program, University of Calgary) undertook a detailed review of the issues at hand that guide (and restrict)

access to oxygen therapy for patients in need in two research papers that informed our reports:





While each oxygen access report provides a unique perspective from those surveyed, all reports confirmed what patients and others have been telling us for years: access to oxygen varies dramatically across Canada. Issues of medical criteria to qualify vary widely, as are issues relating to delivery in rural and isolated areas.

#### The time to act is now.

In this report, CPFF is uncovering oxygen providers' 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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## O2 PROVIDER 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 oxygen providers across Canada. Survey respondents were identified through CPFF's database and network across all Canadian provinces and territories, and were solicited through CPFF's communication channels (newsletter, social media, and associations.)

### **27** OXYGEN PROVIDERS

27

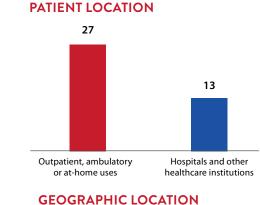
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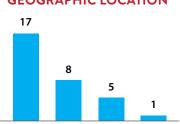
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### Oxygen concentrator system: stationary Oxygen concentrator system: portable Compressed oxygen gas cylinder: portable Compressed oxygen gas cylinder: stationary Liquid oxygen system: stationary and portable cylinders

#### **OXYGEN SYSTEMS PRESCRIBED**

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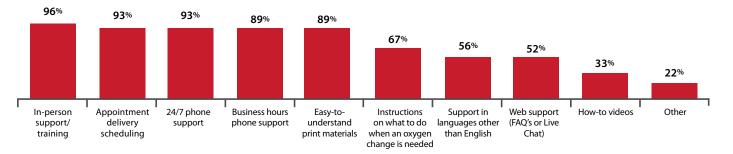
West Ontario East Yukon

# ON THE FRONT LINES OF HOME OXYGEN CARE

Oxygen providers are professionals on the front lines of home oxygen therapy. Their direct contact with patients allow them an unparallelled look into the realities faced by people living with pulmonary fibrosis – including changes in the level of patient breathlessness typical of the disease. Providers care about their client's wellbeing and are witnesses to the constraints of the patient's oxygen therapy prescription, the difficulties many face in receiving sufficient oxygen, and provincial healthcare systems. Many are frustrated by the status quo.



**PATIENT SUPPORT** 



#### **OXYGEN PROVIDER SURVEY**

# **LEARNING HIGHLIGHTS**

#### PATIENTS FACE BARRIERS ACCESSING OXYGEN THERAPY



**41%** Face challenges with getting reassessed Access to **funding** 

#### **PROVINCIAL COVERAGE FOR HOME O2 THERAPY IS INCONSISTENT**

Provincial coverage for

Provincial coverage for oxygen therapy is often rated as **disappointing**.



Face delays in insurance coverage /reimbursement



Limited and reduced coverage for oxygen therapy are the top mentioned reasons for low accessibility ratings.

#### PATIENTS FACE BARRIERS GETTING A NEW PRESCRIPTION

Respirologist accessibility and restrictive ortenia were barriers in ALL provinces.

#### Limited access to physicians is a widespread barrier to getting a new oxygen therapy prescription in the Atlantic provinces.

<u>∎</u>5

Oxygen providers say its not easy for a patient to receive an oxygen therapy prescription **when needed**.

#### **PROVIDERS SUPPORT PATIENTS BUT DELIVERY ISSUES REMAIN**



Most oxygen providers offer in-person training, appointment scheduling, phone support, and printed materials.



Of oxygen providers say patients do not have **equal access** to timely oxygen deliveries.



PATIENTS WERE UNABLE TO RECEIVE AN OXYGEN THERAPY PRESCRIPTION WHEN NEEDED

IN

"I had to fight to get oxygen supplies." PATIENT

**52**%

DON'T KNOW WHEN OR HOW TO GET CHANGES TO THEIR OXYGEN PRESCRIPTION **41%** FACE CHALLENGES WITH GETTING

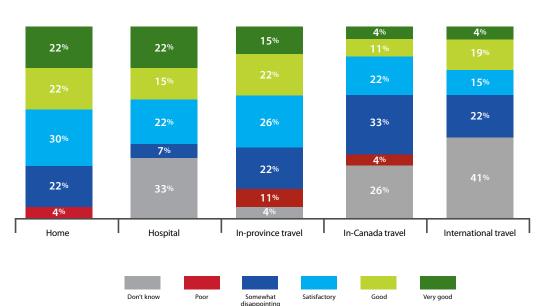
REASSESSED

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# **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 traveling is rated poorly.

#### PATIENTS EXPERIENCE DIFFICULTIES ACCESSING O2 WHEN TRAVELING



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

"Be more lenient with access to oxygen therapy! People should be able to get the oxygen they need to breathe."

CAREGIVER

"I was told to stay home as oxygen isn't covered... Basically if you're not dying you don't get it."

PATIENT

OXYGEN PROVIDERS SAY IT'S NOT EASY FOR A PATIENT TO RECEIVE AN OXYGEN THERAPY PRESCRIPTION WHEN NEEDED.

# COVERAGE IS ALL OVER THE MAP

Regulated at the provincial/territorial level, home oxygen funding in Canada varies widely. If O2 is clinically needed but not covered due to restrictive qualification criteria, patients often must cover the cost themselves, causing significant financial strain.

**OXYGEN PROVIDERS** NOVA SCOTIA WEIGH IN ON **OXYGEN THERAPY** "Income-based coverage. **COVERAGE /** Unaffordable." **REIMBURSEMENT IN IEIR PROVINCE** ALBERTA **ONTARIO** -"Not enough coverage." "Reduced funding." MANITOBA SASKATCHEWAN "Limited coverage and "A reasonable model." distribution." NEWFOUNDLAND YUKON & LABRADOR "Shipping costs are often not "Difficult to qualify." covered for community patients."

# WHERE YOU <u>LIVE</u> IN CANADA DETERMINES WHAT YOU <u>GET</u>

### **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

"Residents of Northern Ontario who do not live in a city have a much harder time accessing oxygen **due to the distance from their provider.**"

OXYGEN PROVIDER, ONTARIO

"Unfortunately there is a family physician shortage in Newfoundland."

> OXYGEN PROVIDER, NEWFOUNDLAND

"The Ontario government has cut funding so severely that we are having a hard time seeing our patients as often as we would like."

> OXYGEN PROVIDER, ONTARIO

Many unnecessary hoops to jump through and frustrating criteria to meet in order to obtain supplemental oxygen... this is Alberta I am speaking about."

> OXYGEN PROVIDER, ALBERTA

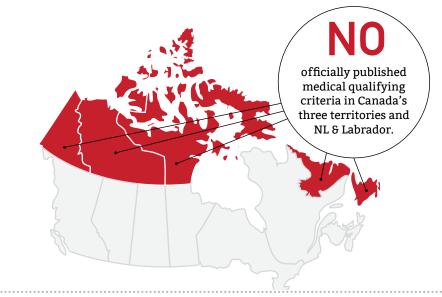
+50% 02 of oxygen providers say patients DO NOT HAVE EQUAL ACCESS to timely 02 deliveries



OF OXYGEN PROVIDERS SAY PULMONARY FIBROSIS PATIENTS NEED SIGNIFICANTLY MORE O2 THAN COPD PATIENTS

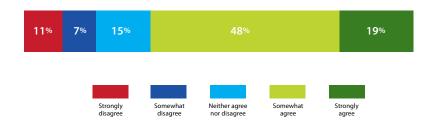
## OXYGEN NEEDED FOR EXERTION IS AN ISSUE

Medical criteria for the prescription of home oxygen vary widely across Canada. While the threshold for severe breathlessness is fairly consistent, criteria for **exertional needs** are not. Quebec and PEI do not fund oxygen for exertional needs. Canada's territories, plus Newfoundland and Labrador, do not have readily available medical criteria for home oxygen, despite providing reimbursement.



### 18% OF OXYGEN PROVIDERS SAY THAT A NEW OXYGEN PRESCRIPTION IS DIFFICULT TO GET

*Q*: "Patients can easily get a new oxygen prescription – agree or disagree?"



## 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.

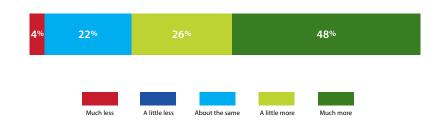
"Pulmonary fibrosis patients often require higher litre flows than patients with other respiratory diseases."



OXYGEN PROVIDER

### 74% SAY PF PATIENTS REQUIRE MORE OXYGEN THAN COPD PATIENTS

*Q*: "How would you rank the oxygen needs of a pulmonary fibrosis patient compared to a COPD patient?"



### **PROVINCIAL GUIDELINES CREATE UNACCEPTABLE INEQUITY**



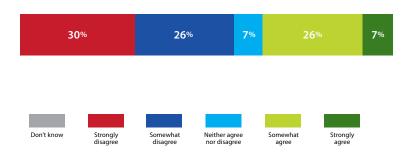
\*For adults, the normal range of SaO2 is 95 – 100%. A value <90% is considered low O2 saturation.

# **DELIVERING TO A VAST COUNTRY**

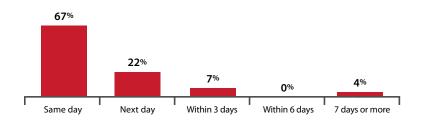
Once the hurdle of obtaining a prescription is overcome, a patient shouldn't need to wait days to receive the oxygen they need to breathe. While most do have same-day access, about one in ten wait three or more days. For rural Canadians the problem is exacerbated. Given the portable nature of oxygen systems, access to home oxygen should be universal, regardless of urban or rural locale. Canadians that require supplemental oxygen should be able to receive these services. This may require a dedicated strategy for rural communities, to ensure a dedicated and uninterrupted supply chain.

#### A MAJORITY SAY PATIENT LOCATION HAS AN ADVERSE EFFECT ON O2 DELIVERY

*Q*: "Where a patient lives does not affect access to timely oxygen deliveries–agree or disagree?"



### MORE THAN ONE IN THREE DO NOT RECEIVE SAME-DAY OXYGEN DELIVERY



"Rural NF is quite isolated from the rest of the province. Some O2 patients live 6+ hours from the nearest home oxygen provider. The further away you live, the longer it takes for you to receive supplies and the higher the bill."

#### NEWFOUNDLAND

"Patients in rural zones don't have great access to oxygen delivery"

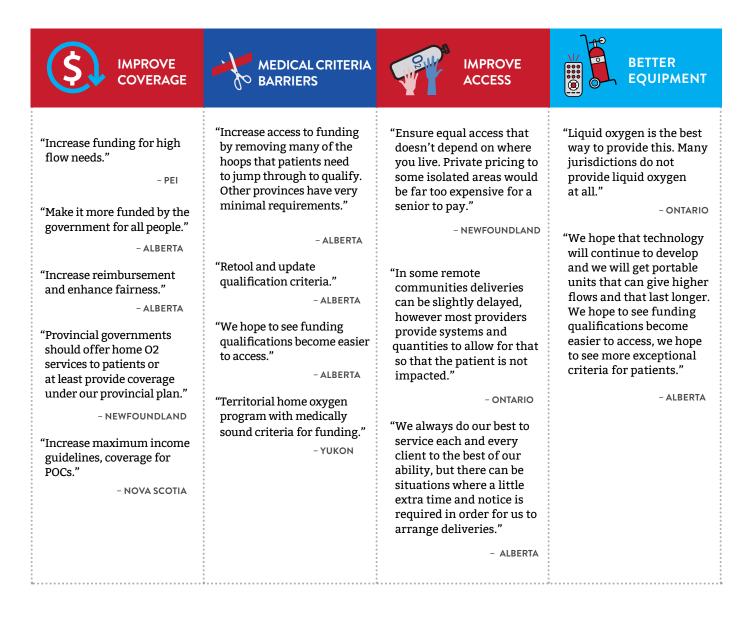
"Shipping costs are often not covered for community patients. Shipping companies dictate their own schedules."

YUKON

"Due to cost and staffing issues, providers cannot have oxygen in every community." ONTARIO

### OXYGEN PROVIDERS WEIGH IN ON HOW TO IMPROVE HOME OXYGEN THERAPY

Oxygen providers across Canada echoed common themes of affordability/ coverage, qualifying criteria, and better equipment mentioned by all surveyed groups. Their responses showed particular sensitivity to the difficulties of delivery to rural and isolated areas.





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:

### Disease-specific Qualifying Criteria

• 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 are based on unsuitable COPD data. Exertional needs specific to pulmonary fibrosis are not covered.

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

### **2** Reimbursement for All

• Misaligned provincial policies mean reimbursement for home oxygen therapy is inconsistent nationally. This is contrary to Canada's commitment 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.

• Patients are not always provided the equipment they need to maintain their oxygen levels outside the home. Without portable equipment, they may be housebound.

Patients, medical professionals, and oxygen providers 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 health system to provide the oxygen therapy patients 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:















For more information, please contact:

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# cpff.ca



Foundation

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