

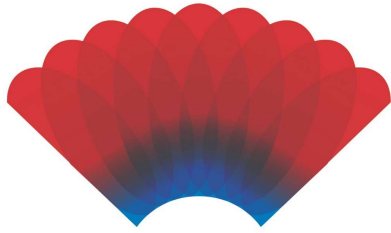
AGENDA

#	Agenda Item	Time Allocated	Planned End Time
	Procedural/Consent Items		
1	Call to Order: K. Morrison	3:30 pm	3:31 pm
2	Introductions and Welcome Remarks: K. Morrison	3:31 pm	3:32 pm
3	Approval of Board Agenda and Call for Other Business: K. Morrison	3:32 pm	3:33 pm
4	Declarations of Conflict of Interest: K. Morrison	3:33 pm	3:35 pm
	Discussion and Action Items		
5	Minutes of February 3, 2023, Board Meeting: K. Morrison <ul style="list-style-type: none"> • Motion to accept the minutes of February 3, 2023 	3:35 pm	3:37 pm
6	CPFF Reports <ul style="list-style-type: none"> ➤ CPFF Financials (January 2023): V. Pringle & S. Lee ➤ Executive Director Report: <ul style="list-style-type: none"> ▪ 2022-2023 Activity Update <ul style="list-style-type: none"> ○ November Board Meeting Follow Up <ul style="list-style-type: none"> • Mission/Vision Statements (see attached) • Procurement Policy (see attached) • Banking Policy (in progress) • Sharon's KPIs (see attached) • MAB Review and Succession: C. Fell ○ June 16/17, 2023 Board Retreat (Virtual) <ul style="list-style-type: none"> • Mar 3, 2023 – Strategic Plan (see attached) • Apr 14, 2023 - Changes to work plan • May 5, 2023 – Budget ▪ CPFF & Vaultt Database Revenue Generation Update: N. Hilliard, D. Mastin & S. Lee ➤ FY23-24 Plan: S. Lee 	3:37 pm	4:55 pm

#	Agenda Item	Time Allocated	Planned End Time
	<ul style="list-style-type: none"> ▪ Proposed Strategic Plan Updates (see attached) ➤ CPFF Committee Reports: <ul style="list-style-type: none"> ▪ Governance: T. Georgieff & S. Lee ▪ Advocacy & Support: M. Ashcroft, H. Smith & S. Lee <ul style="list-style-type: none"> ○ Pucker Up ○ Canadian Organization for Rare Disorders (CORD) <ul style="list-style-type: none"> • March 27 – 29, 2023 in Ottawa <ul style="list-style-type: none"> ▪ Parliament Hill Meeting with PM, and Ministers – Billion Dollars for Rare Diseases ▪ CORD Conference – Collective collaboration on policies • Canadian Thoracic Society <ul style="list-style-type: none"> • April 20 – 22, 2023 in Montreal <ul style="list-style-type: none"> ▪ Booth and registration for 3 ▪ ILD meeting participation • April 2024 in? <ul style="list-style-type: none"> ▪ Booth and registration for 3 ▪ ILD meeting participation ▪ CPFF patient conference for 1 day ○ JAMP Pharma meeting <ul style="list-style-type: none"> • April 19, 2023 in Montreal ▪ Communications & Fundraising: T. Hunter & S. Lee <ul style="list-style-type: none"> ○ DIY fundraisers & funds raised: S. Lee ○ 2022 Surveys: S. Lee <ul style="list-style-type: none"> • Patient & Caregiver survey (see attached) • Healthcare professionals survey (see attached) • Oxygen providers survey (see attached) ○ February – Rare Disease: S. Lee <ul style="list-style-type: none"> • Global Heroes – National Digital & Print Media in BC & ON • Pucker Up Challenge • Naming of the CPFF Mascot (formerly Bob the Blob) contest <ul style="list-style-type: none"> ▪ Hope and Oxygen ▪ Copyright of CPFF Mascot 		

#	Agenda Item	Time Allocated	Planned End Time
	<ul style="list-style-type: none"> ○ 2023 HBH: S. Lee <ul style="list-style-type: none"> ● Events <ol style="list-style-type: none"> 1. Tom Hunter, June 25, 2023 – Half Ironman – Mont-Tremblant 2. Queens Varsity Team (20 members) – Toronto Triathlon Event – July 23, 2023 <ul style="list-style-type: none"> ▪ Sent off with patient support group members, and invite government officials 3. Andre Moran-MacDonald, Half Ironman – July 30, 2023 - Calgary, BC 4. Clarke Walk – Sep 9, 2023 – Calgary, AB 5. In memory of Rob Garbutt - ? – Winnipeg, MN 6. Davidson Walk – Sep 16 – Markham, ON 7. Georgieff-Fenton/Khan Walk – Sep 23, 2023 – Montreal, QC ● Greetings (Premiers & Healthcare Ministers) ● Lighting of Buildings across Canada ● Paralympics 2024 <ul style="list-style-type: none"> ▪ Presentation of Hope & Courage in support of PF patients ● Pucker Up Challenge <ul style="list-style-type: none"> ▪ PF organizations from around the globe ▪ Medical Advisory Board (MAB): C. Fell <ul style="list-style-type: none"> ○ April 3, 2023 – Fellowship Reviews 		
7	<p>New Business</p> <ul style="list-style-type: none"> ● In Camera Session (if needed) 		

#	Agenda Item	Time Allocated	Planned End Time
8	<p>CPFF Board Meeting Dates for FY 22-23:</p> <p>Friday April 14, 2023 Friday May 5, 2023 Board Retreat: Friday June 16, & Saturday June 17, 2023 Friday July 7, 2023 Friday August 11, 2023 Friday September 8, 2023 Friday October 13, 2023 Friday November 3, 2023 Friday December 1, 2023 – CPFF Virtual Open House</p>	4:55 pm	4:58 pm
9	Adjournment	5:00 pm	



Canadian Pulmonary Fibrosis Foundation

Board Minutes

Held via ZOOM

On Friday February 3, 2023

Commencing at 3:30 pm EST

Present: Kirk Morrison, Chair
Verity Pringle, Treasurer
Todd Georgieff, Vice and Governance & Finance Chair
Sharon Lee, Executive Director
Tom Hunter, Communications & Fundraising Chair
Mark Ashcroft, Advocacy & Support Co-Chair (joined @ 3:07pm)
Dr. Holly Smith, Advocacy & Support Co-Chair
Nicole Hilliard
Ranjena Maloni
Derek Mastin
Ray Protti

Guest(s): None

Regrets: Dr. Charlene Fell

Minutes: Roberto Zapata

Call to Order

The meeting was called to order by K. Morrison.

Introductions and Welcome

K. Morrison welcomed everyone.

Approval of the Board Agenda

It was moved and seconded,
That the Board agenda be approved as amended.

Carried.

Declarations of Conflict of Interest

There were no declarations of conflict.

Minutes of January 13, 2022 Board Meetings

It was moved and seconded,
That the minutes of the January 13 meeting be approved.

CPFF Board Minutes of February 3, 2023

Carried.

CPFF Financials

V. Pringle presented the December 2022 financials and highlighted that donations are up by roughly \$16,000 year-to-year.

She pointed out that:

- There are still some expenses from the previous fiscal year that still require adjustment;
- \$60,000 have been received from Boehringer Ingelheim;
- Year-to-date income from donations and grants is so far pretty even.

Executive Director Report

It was mentioned that the mission and vision statements have been ironed out following the December 2nd Stakeholder meeting and that the feedback will be shared with the Board in the near future.

The procurement policy still needs some work and it was proposed that the banking and procurement policies be merged. The Governance & Finance committee will delve into the feasibility and details of that endeavor.

It was confirmed that:

- H. Davidson's contract has been drafted and signed.
- CPFF's KPIs have been approved by K. Morrison and results will be collected over the next month.

The 2023 Board Retreat will take place on June 16th and 17th. Notably, the Board will discuss the Innovation Fund and the mission and vision statements.

The proposed plan to approve the workplans for the 2023-2024 fiscal year goes as follow:

- Proposal for workplans to be provided by the April Board meeting;
- Quotes for workplan to be provided by the May Board meeting;
- Workplans and providers to be approved by the June Board meeting.

It was proposed that Board meetings ought to occasionally have guest speakers. The suggestion has been noted and S. Lee and K. Morrison will discuss the pros and cons offline.

Vaultt Database Revenue Generation Proposal

The Board discussed the Vaultt proposal, which seeks to turn the CPFF app into an income stream by selling data collected from it to interested companies. It was pointed out that:

- This would come at no cost to CPFF;
- Vaultt extracts value from this endeavor by doing a "trial run" with CPFF that can be marketed to other foundations in their future prospection;
- No one is keeping the data except the individual app users;
- Data collection is optional, as surveys are voluntary;
- No personal information collected;
- Each individual app user has to give permission for data collection;
- Data is packaged and anonymized before being transacted.

CPFF Board Minutes of February 3, 2023

It was pointed out that, from a legal perspective, accepting the letter of intent does not oblige CPFF to move forward past the testing phase.

Several Board members are concerned with the legal ramifications, security risks and community sentiment of the full implementation of this proposal.

N. Hilliard and D. Mastin will assist S. Lee in composing an appropriate response to Vaultt on the back of the concerns shared during the Board meeting, as reassurance is needed before the Board can unanimously agree on moving forward.

MAB Report

In the absence of C. Fell, S. Lee and T. Georgieff stepped in to offer an update on the MAB.

It was confirmed that the Robert Davidson Fellowship instructions and terms of reference have been updated. The documents will be uploaded onto the website on the business day following the Board meeting. The Board will be looking at having 2 fellow recommendations for the April Board meeting.

It was mentioned that confirmation has been received from all current MAB members that they are willing to renew for a new term, which is expected to be a 5-year term. Furthermore, C. Fell will check with fellows to see if any of them would be interested in joining the MAB. CPFF will also work with the Canadian Thoracic Society to prospect for community respirologists also interested in joining the MAB.

It was pointed out that the MAB currently has no Board representative following the departure of G. Vidyasankar. C. Fell has considered stepping into the role, in parallel with her Chair role, though the potential risks of that have yet to be fully examined and considered.

It was also pointed out that succession planning for the MAB Chair is being discussed, as there's currently no obvious successor.

It was reminded that patient and family member voices are important on that MAB. It was furthermore added that the intention would be to hopefully have more than one voice of each to rely on.

Governance & Finance Report

As the new Governance & Finance Chair, T. Georgieff will wait until after he chairs his first committee meeting before presenting a report.

Advocacy & Support Report

It was mentioned that Boehringer Ingelheim international divisions have been approached about doing the Pucker Up Challenge. So far, the Canada, South America and Global divisions have taken the challenge, while the Japan, China and USA divisions are expected to follow suit.

It was pointed out that:

- S. Lee, T. Georgieff and R. Zapata will take part in the Canadian Thoracic Society conference in Montreal from April 20th to 22nd.

CPFF Board Minutes of February 3, 2023

- S. Lee will meet with Jamp on April 19th.
- A new chair for the PMPRB has been appointed.

It was mentioned that there is currently a prejudice against MAID in support groups and that something ought to be done about it. The Board agrees that it is a politically charged subject and that further discussion is needed.

Communications & Fundraising Report

It was reminded that:

- The Rare Disease campaign has been shifted to the month of March in order to give enough rest to the donor base following the Holiday campaign;
- A print copy of the Global Heroes initiative will be available in British Columbia and Ontario – Directors living in those provinces were encouraged to get a copy;
- Boehringer Ingelheim will continue to support CPFF after OFEV goes off patent, though they will do so through a different department;
- There is currently one ongoing DIY Fundraiser.

Two other DIY Fundraisers are in the works, including:

- A. Moran-Macdonald's second year participating in an Ironman event;
- T. Hunter participating in the Mont-Tremblant Ironman event.

It was pointed out that a one-pager summary of their intentions ought to be requested from potential DIY Fundraisers for approval. The intent of this would be to avoid having any fundraising activities take place that do not resonate with CPFF's values.

The committee has been discussing the translation into French of the CPFF website. More information to come in the upcoming months

The committee agreed that the fundraising goal for FY 2022-2023 was \$350,000. On the back of that, it was pointed out that CPFF will be receiving a legacy gift of \$465,000.

It was pointed out that a name-picking for the CPFF mascot will take place during the month of February. Two to three rounds of votes are to be expected.

The Board were prompted to take part in the Pucker Up Challenge to help raise awareness.

The Board reaffirmed their decision of investing \$40,000 to produce 24 patient stories that are 2 to 3 minutes long videos.

It was moved and seconded,

That the budget of \$40,000 be approved to produce 24 patient stories.

Carried.

Adjournment

The meeting was adjourned at 4:52 pm EDT.

CPFF Board Minutes of February 3, 2023

Next CPFF Board meeting will be held March 3, 2023.

Certified correct,

SIGNATURE TO BE INCLUDED

Kirk Morrison
CPFF Board Chair

Canadian Pulmonary Fibrosis Foundation
Balance Sheet
As of January 31, 2023

	As of Jan. 31, 2023	Total As of Jan. 31, 2022 (PY)	Change
Assets			
Current Assets			
Cash and Cash Equivalent			
1021 Restricted Cash	130,000.00	130,000.00	0.00
1060 Chequing Bank Account	1,347,024.41	1,472,181.97	-125,157.56
1061 TD Investor Acct	15,288.77	15,130.76	158.01
1062 BMO High Interest Savings	509,449.89	452,018.10	57,431.79
Total Cash and Cash Equivalent	\$ 2,001,763.07	\$ 2,069,330.83	-\$ 67,567.76
1022 Internally Restricted Cash	6,027.00	6,027.00	0.00
1310 Inventory of Items for Resale	1,749.67	1,749.67	0.00
1320 Prepaid Expenses	1,621.00	1,621.00	0.00
2318 PSB Rebate Receivable	18,473.45	18,473.45	0.00
Total Current Assets	\$ 2,029,634.19	\$ 2,097,201.95	-\$ 67,567.76
Non-current Assets			
Property, plant and equipment			
1820 Furniture and Equipment	2,313.20	2,313.20	0.00
1825 Accum Depr - Furn and Equip	-2,313.20	-2,313.20	0.00
Total Property, plant and equipment	\$ 0.00	\$ 0.00	\$ 0.00
Total Non Current Assets	\$ 0.00	\$ 0.00	\$ 0.00
Total Assets	\$ 2,029,634.19	\$ 2,097,201.95	-\$ 67,567.76
Liabilities and Equity			
Liabilities			
Current Liabilities			
Accounts Payable (A/P)			
2100 Accounts Payable	377.13	619.05	-241.92
Total Accounts Payable (A/P)	\$ 377.13	\$ 619.05	-\$ 241.92
Credit Card			
1070 TD Visa 3392	2,761.05	429.54	2,331.51
Total Credit Card	\$ 2,761.05	\$ 429.54	\$ 2,331.51
2000 Current Liabilities			
2220 Vacation Payable	22,828.88	17,876.92	4,951.96
2315 GST/HST Paid on Purchases	-21,124.08	-1.17	-21,122.91
Total 2000 Current Liabilities	\$ 1,704.80	\$ 17,875.75	-\$ 16,170.95
Due to TD Bank	270.00	270.00	0.00
Total Current Liabilities	\$ 5,112.98	\$ 19,194.34	-\$ 14,081.36
Total Liabilities	\$ 5,112.98	\$ 19,194.34	-\$ 14,081.36
Equity			
3500 Retained Earnings	974,077.92	974,077.92	0.00
3561 Internatly Restricted Funds	6,027.00	6,027.00	0.00
Retained Earnings	1,222,497.68	561,032.24	661,465.44
Profit for the year	-178,081.39	536,870.45	-714,951.84
Total Equity	\$ 2,024,521.21	\$ 2,078,007.61	-\$ 53,486.40
Total Liabilities and Equity	\$ 2,029,634.19	\$ 2,097,201.95	-\$ 67,567.76

CPFF Fiscal July 31, 2023
August 2022 YTD

			6.00	100%	14%	16.00%	24%	23%	23%	
	July 2022 ACTUAL	2023 budget	YTD BUDGET	VARIANCE	2023 Actual	Admin	Advocay	Education Awariness	Patient Support	Research
Foundation Grants	882,667	475,000	237,500	(39,010)	198,490	198,490				
Donation and fundraising	332,695	160,000	80,000	142,904	222,904	222,904				
Regional Donations			-	-	-	-				
Interest income	18,566		-	130	130	130				
Miscellaneous Income	126									
Deferred Revenue										
	1,234,055	635,000	317,500	104,024	421,524	421,524	-	-	-	-
1 Grants to charities	80,000	180,000	90,000	(90,000)						
	-	40,000	20,000	194,753	214,753.46	30,065	34,361	51,541	49,393	49,393
2 Salaries & benefits	97,274	125,000	62,500	(7,867)	54,633	7,649	8,741	13,112	12,566	12,566
	64,650	53,000	26,500	8,044	34,544	4,836	5,527	8,291	7,945	7,945
3 Patient support	11,223	500	250	180	430	60	69	103	99	99
		5,000	2,500	(2,500)						
		25,000	12,500	(12,500)						
		27,000	13,500	(13,500)						
		17,500	8,750	(8,750)						
4 Communications/Support website costs	342	200,000	100,000	(100,000)						
5 Awareness and advocacy	42,639	10,000	5,000	3,240	8,240	1,154	1,318	1,978	1,895	1,895
		10,000								
		100,000								
		20,000								
6 Fundraising events costs		75,000	37,500	(37,458)	41.92	6	7	10	10	10
			-	-						
			-	-						
7 Program education and consulting	184,398		-	243,242	243,242	34,054	38,919	58,378	55,946	55,946
			-	-						
			-	-						
			-	-						
	480,528	888,000	379,000	176,885	555,885	77,824	88,942	133,412	127,853	127,853
8 Professional fees	16,950	51,000	25,500	(17,164)	8,336	1,167	1,334	2,001	1,917	1,917
9 office and general	64,433	5,300	2,650	18,280	20,930	2,930	3,349	5,023	4,814	4,814
10 Travel and meeting costs	36	4,000	2,000	7,231	9,231	1,292	1,477	2,215	2,123	2,123
11 Telephone/Internet	7,225	6,700	3,350	2,067	5,417	758	867	1,300	1,246	1,246
12 Insurance	3,813	4,000	2,000	(2,000)	-	-	-	-	-	-
13 Interest and bank charges	1,462		-	(193)	193	27	31	46	44	44
	93,920	71,000	35,500	8,221	43,721	6,121	6,995	10,493	10,056	10,056
	659,607	-324,000	-97,000	(81,081)	178,081	337,579	-95,937	-143,905	-137,909	-137,909

Notes:

Note 1

All expenses allocated under pillars have been proportioned in accordance with the percentage resources approved by organization

Note 2

Deferred Grant from BI of \$149,500 provided to be spent on Advocacy, Education and Research has not been taken in YTD income as of Feb/21

Canadian Pulmonary Fibrosis Foundation

Profit and Loss by Class

January 2023

	Admin/Fun d-14%	Advocacy- 16%	Ed & Aware 24%	Patient & Care-23%	Research- 23%	TOTAL
INCOME						
4000 Revenue						0.00
4010 Contributions						0.00
4020 Received Donations	6,318.92					6,318.92
4300 Donations Through Paypal	905.00					905.00
4301 Donations Through Canada Helps	18,695.00					18,695.00
4302 Donations Through CAF Canada	46.00					46.00
4303 Donations Through CDN Online Giving	3,503.30					3,503.30
4304 Donations Through My Tribute Gift	175.00					175.00
Total 4010 Contributions	\$ 29,643.22	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 29,643.22
4190 Grants Received	3,000.00					3,000.00
4440 Interest Income	29.81					29.81
Total 4000 Revenue	\$ 32,673.03	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 32,673.03
Total Income	\$ 32,673.03	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 32,673.03
GROSS PROFIT	\$ 32,673.03	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 32,673.03
EXPENSES						
02. Salaries & Benefits						0.00
5410 Wages & Salaries						0.00
5411 Executive Director Salary	978.25	1,118.00	1,677.00	1,607.13	1,607.13	6,987.51
5414 Project Coordinator	593.60	678.40	1,017.60	975.20	975.20	4,240.00
5415 Heather Davidson Payroll	26.04	29.76	44.64	42.78	42.78	186.00
Total 5410 Wages & Salaries	\$ 1,597.89	\$ 1,826.16	\$ 2,739.24	\$ 2,625.11	\$ 2,625.11	\$ 11,413.51
5420 EI Expense	35.82	40.93	61.40	58.84	58.84	255.83
5430 CPP Expense	89.04	101.76	152.64	146.28	146.28	636.00
5460 Vacation Accrual	149.59	170.96	256.44	245.75	245.75	1,068.49
5461 Payroll Admin Expense	47.65	54.46	81.69	78.29	78.29	340.38
5470 Employee Benefits - Sharon	69.54	79.48	119.22	114.25	114.25	496.74
5471 Employee Benefits - Roberto	40.63	46.44	69.66	66.75	66.75	290.23

Total 02. Salaries & Benefits	\$ 2,030.16	\$ 2,320.19	\$ 3,480.29	\$ 3,335.27	\$ 3,335.27	\$ 14,501.18
03. Patient Support	5.82	6.65	9.98	9.56	9.56	41.57
05. Awareness & Advocacy						0.00
5327 Newsletter Expense	28.41	32.47	48.71	46.68	46.68	202.95
5530 Awareness & Advocacy	191.38	218.72	328.08	314.41	314.41	1,367.00
5615 Advertising and Promotion	26.03	29.74	44.62	42.76	42.76	185.91
Total 05. Awareness & Advocacy	\$ 245.82	\$ 280.93	\$ 421.41	\$ 403.85	\$ 403.85	\$ 1,755.86
07. Program Education & Consulting						0.00
5511 Patient Education	2,943.82	3,364.33	5,046.49	4,836.22	4,836.22	21,027.08
Total 07. Program Education & Consulting	\$ 2,943.82	\$ 3,364.33	\$ 5,046.49	\$ 4,836.22	\$ 4,836.22	\$ 21,027.08
08. Professional Fees						0.00
5696 Bookkeeping	123.69	141.36	212.04	203.20	203.20	883.49
Total 08. Professional Fees	\$ 123.69	\$ 141.36	\$ 212.04	\$ 203.20	\$ 203.20	\$ 883.49
09. General & Administrative						0.00
5650 Staff Equipement - computers	18.38	21.01	31.51	30.20	30.20	131.30
5686 Governance	280.00	320.00	480.00	460.00	460.00	2,000.00
5700 Office Supplies	22.72	25.97	38.95	37.33	37.33	162.30
5770 Storage	44.09	50.39	75.57	72.43	72.43	314.91
5890 Credit Card fees	4.22	4.83	7.24	6.94	6.94	30.17
5891 Other Commissions	11.64	13.31	19.96	19.13	19.13	83.17
5895 Canada Helps fees	102.55	117.20	175.80	168.48	168.48	732.51
5896 PayPal fees	0.24	0.28	0.41	0.40	0.40	1.73
Total 09. General & Administrative	\$ 483.84	\$ 552.99	\$ 829.44	\$ 794.91	\$ 794.91	\$ 3,456.09
11. Telephone/Internet						0.00
5780 Telephone Expense	13.53	15.46	23.20	22.23	22.23	96.65
5781 Internet	22.64	25.87	38.81	37.19	37.19	161.70
Total 11. Telephone/Internet	\$ 36.17	\$ 41.33	\$ 62.01	\$ 59.42	\$ 59.42	\$ 258.35
13. Bank and Interest Charges						0.00
5690 Bank Service Charges	11.06	12.64	18.96	18.17	18.17	79.00
Total 13. Bank and Interest Charges	\$ 11.06	\$ 12.64	\$ 18.96	\$ 18.17	\$ 18.17	\$ 79.00
Total Expenses	\$ 5,880.38	\$ 6,720.42	\$ 10,080.62	\$ 9,660.60	\$ 9,660.60	\$ 42,002.62
PROFIT	\$ 26,792.65	-\$ 6,720.42	-\$ 10,080.62	-\$ 9,660.60	-\$ 9,660.60	-\$ 9,329.59

Canadian Pulmonary Fibrosis Foundation
Profit and Loss by Class
August 2022 - January 2023

	Admin/Fund- 14%	Advocacy- 16%	Ed & Aware 24%	Patient & Care- 23%	Research-23%	TOTAL
INCOME						
4000 Revenue						0.00
4010 Contributions						0.00
4020 Receipted Donations	52,352.25					52,352.25
4027 Rcptd Donations - September Awareness Walks	55,526.25					55,526.25
4030 Donations from Other Charities	1,890.00					1,890.00
4300 Donations Through Paypal	7,418.00					7,418.00
4301 Donations Through Canada Helps	92,689.99					92,689.99
4302 Donations Through CAF Canada	158.00					158.00
4303 Donations Through CDN Online Giving	7,029.73					7,029.73
4304 Donations Through My Tribute Gift	5,416.25					5,416.25
4305 Donations Through United Way	423.95					423.95
Total 4010 Contributions	\$ 222,904.42	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 222,904.42
4190 Grants Received	198,490.00					198,490.00
4440 Interest Income	129.54					129.54
Total 4000 Revenue	\$ 421,523.96	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 421,523.96
Total Income	\$ 421,523.96	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00	\$ 421,523.96
COST OF GOODS SOLD						
5000 Cost of Goods Sold						0.00
5190 Grants Made	29,400.00	33,600.00	50,400.00	48,300.00	48,300.00	210,000.00
5252 Clarke Family run - Expenses	385.48	440.55	660.83	633.30	633.30	2,753.46
5320 Sponsorship Costs	280.00	320.00	480.00	460.00	460.00	2,000.00
Total 5000 Cost of Goods Sold	\$ 30,065.48	\$ 34,360.55	\$ 51,540.83	\$ 49,393.30	\$ 49,393.30	\$ 214,753.46
Total Cost of Goods Sold	\$ 30,065.48	\$ 34,360.55	\$ 51,540.83	\$ 49,393.30	\$ 49,393.30	\$ 214,753.46
GROSS PROFIT	\$ 391,458.48	-\$ 34,360.55	-\$ 51,540.83	-\$ 49,393.30	-\$ 49,393.30	\$ 206,770.50
EXPENSES						
02. Salaries & Benefits						0.00
5410 Wages & Salaries						0.00

5411 Executive Director Salary	6,358.66	7,267.00	10,900.51	10,446.34	10,446.34	45,418.85
5414 Project Coordinator	3,858.40	4,409.60	6,614.40	6,338.79	6,338.79	27,559.98
5415 Heather Davidson Payroll	26.04	29.76	44.64	42.78	42.78	186.00
Total 5410 Wages & Salaries	\$ 10,243.10	\$ 11,706.36	\$ 17,559.55	\$ 16,827.91	\$ 16,827.91	\$ 73,164.83
5420 EI Expense	146.12	167.00	250.51	240.07	240.07	1,043.77
5430 CPP Expense	373.81	427.20	640.80	614.09	614.09	2,669.99
5460 Vacation Accrual	954.52	1,090.86	1,636.31	1,568.12	1,568.12	6,817.93
5461 Payroll Admin Expense	103.90	118.78	178.17	170.75	170.75	742.35
5470 Employee Benefits - Sharon	500.77	572.32	858.48	822.70	822.70	3,576.97
5471 Employee Benefits - Roberto	162.53	185.76	278.64	267.00	267.00	1,160.93
Total 02. Salaries & Benefits	\$ 12,484.75	\$ 14,268.28	\$ 21,402.46	\$ 20,510.64	\$ 20,510.64	\$ 89,176.77
03. Patient Support	60.19	68.75	103.13	98.83	98.83	429.73
05. Awareness & Advocacy						0.00
5327 Newsletter Expense	229.99	262.85	394.26	377.84	377.84	1,642.78
5530 Awareness & Advocacy	649.66	742.46	1,113.70	1,067.29	1,067.29	4,640.40
5615 Advertising and Promotion	274.03	313.15	469.74	450.19	450.19	1,957.30
Total 05. Awareness & Advocacy	\$ 1,153.68	\$ 1,318.46	\$ 1,977.70	\$ 1,895.32	\$ 1,895.32	\$ 8,240.48
06. Fundraising Events Costs	5.87	6.71	10.06	9.64	9.64	41.92
07. Program Education & Consulting						0.00
5511 Patient Education	33,900.37	38,743.24	58,114.86	55,693.40	55,693.40	242,145.27
5515 Consulting	153.57	175.51	263.26	252.29	252.29	1,096.92
Total 07. Program Education & Consulting	\$ 34,053.94	\$ 38,918.75	\$ 58,378.12	\$ 55,945.69	\$ 55,945.69	\$ 243,242.19
08. Professional Fees						0.00
5610 Accounting & Legal	217.99	249.13	373.70	358.13	358.13	1,557.08
5695 Professional Fees	83.67	95.62	143.43	137.46	137.46	597.64
5696 Bookkeeping	742.14	848.16	1,272.24	1,219.20	1,219.20	5,300.94
5705 Membership fees, dues, subscrip	123.25	140.84	211.26	202.46	202.46	880.27
Total 08. Professional Fees	\$ 1,167.05	\$ 1,333.75	\$ 2,000.63	\$ 1,917.25	\$ 1,917.25	\$ 8,335.93
09. General & Administrative						0.00
5500 General Administrative Expenses	1,118.05	1,277.78	1,916.64	1,836.81	1,836.81	7,986.09
5520 Education	45.64	52.17	78.27	74.99	74.99	326.06
5571 Website Hosting	31.65	36.20	54.29	52.03	52.03	226.20
5640 Courier & Postage	50.81	58.08	87.12	83.49	83.49	362.99
5650 Staff Equipement - computers	43.49	49.71	74.55	71.45	71.45	310.65

5686 Governance	1,031.31	1,178.64	1,767.96	1,694.30	1,694.30	7,366.51
5700 Office Supplies	115.99	132.57	198.86	190.57	190.57	828.56
5770 Storage	258.72	295.68	443.47	425.02	425.02	1,847.91
5890 Credit Card fees	27.97	31.98	47.98	45.98	45.98	199.89
5891 Other Commissions	19.23	21.98	32.97	31.61	31.61	137.40
5895 Canada Helps fees	187.37	214.15	321.21	307.83	307.83	1,338.39
5896 PayPal fees	-0.12	-0.12	-0.19	-0.17	-0.17	-0.77
Total 09. General & Administrative	\$ 2,930.11	\$ 3,348.82	\$ 5,023.13	\$ 4,813.91	\$ 4,813.91	\$ 20,929.88
10. Travel & Meeting Costs	259.31	112.73	169.09	162.04	162.04	865.21
5784 Travel	1,033.04	1,364.26	2,046.40	1,961.13	1,961.13	8,365.96
Total 10. Travel & Meeting Costs	\$ 1,292.35	\$ 1,476.99	\$ 2,215.49	\$ 2,123.17	\$ 2,123.17	\$ 9,231.17
11. Telephone/Internet						0.00
5780 Telephone Expense	155.18	177.34	266.04	254.95	254.95	1,108.46
5781 Internet	603.23	689.37	1,034.06	990.98	990.98	4,308.62
Total 11. Telephone/Internet	\$ 758.41	\$ 866.71	\$ 1,300.10	\$ 1,245.93	\$ 1,245.93	\$ 5,417.08
13. Bank and Interest Charges						0.00
5690 Bank Service Charges	-27.06	-30.92	-46.38	-44.45	-44.45	-193.26
Total 13. Bank and Interest Charges	-\$ 27.06	-\$ 30.92	-\$ 46.38	-\$ 44.45	-\$ 44.45	-\$ 193.26
Total Expenses	\$ 53,879.29	\$ 61,576.30	\$ 92,364.44	\$ 88,515.93	\$ 88,515.93	\$ 384,851.89
PROFIT	\$ 337,579.19	-\$ 95,936.85	-\$ 143,905.27	-\$ 137,909.23	-\$ 137,909.23	-\$ 178,081.39

Thursday, Feb. 23, 2023 08:11:21 p.m. GMT-8 - Accrual Basis

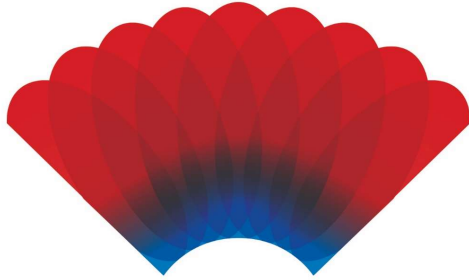
Canadian Pulmonary Fibrosis Foundation
Profit and Loss by Class
August 2022 - January 2023

	Aug. 2022 - Jan. 2023	Total Aug. 2021 - Jan. 2022 (PY)	Change
INCOME			
4000 Revenue			0.00
4010 Contributions			0.00
4020 Receipted Donations	52,352.25	20,342.03	32,010.22
4026 Receipted Donations- Clark Run		3,300.00	-3,300.00
4027 Rcptd Donations - September Awareness Walks	55,526.25		55,526.25
4030 Donations from Other Charities	1,890.00	285.31	1,604.69
4300 Donations Through Paypal	7,418.00	16,397.84	-8,979.84
4301 Donations Through Canada Helps	92,689.99	118,273.28	-25,583.29
4302 Donations Through CAF Canada	158.00	300.00	-142.00
4303 Donations Through CDN Online Giving	7,029.73	5,491.10	1,538.63
4304 Donations Through My Tribute Gift	5,416.25	4,410.00	1,006.25
4305 Donations Through United Way	423.95	557.18	-133.23
Total 4010 Contributions	\$ 222,904.42	\$ 169,356.74	\$ 53,547.68
4190 Grants Received	198,490.00	560,667.00	-362,177.00
4440 Interest Income	129.54	15.26	114.28
Total 4000 Revenue	\$ 421,523.96	\$ 730,039.00	-\$ 308,515.04
Total Income	\$ 421,523.96	\$ 730,039.00	-\$ 308,515.04
COST OF GOODS SOLD			
5000 Cost of Goods Sold			0.00
5190 Grants Made	210,000.00	20,000.00	190,000.00
5252 Clarke Family run - Expenses	2,753.46		2,753.46
5320 Sponsorship Costs	2,000.00		2,000.00
Total 5000 Cost of Goods Sold	\$ 214,753.46	\$ 20,000.00	\$ 194,753.46
Total Cost of Goods Sold	\$ 214,753.46	\$ 20,000.00	\$ 194,753.46
GROSS PROFIT	\$ 206,770.50	\$ 710,039.00	-\$ 503,268.50
EXPENSES			

02. Salaries & Benefits				0.00
5410 Wages & Salaries				0.00
5411 Executive Director Salary	45,418.85	39,882.18		5,536.67
5414 Project Coordinator	27,559.98	27,805.17		-245.19
5415 Heather Davidson Payroll	186.00			186.00
Total 5410 Wages & Salaries	\$ 73,164.83	\$ 67,687.35	\$	5,477.48
5420 EI Expense	1,043.77	547.36		496.41
5430 CPP Expense	2,669.99	1,303.77		1,366.22
5460 Vacation Accrual	6,817.93	3,441.16		3,376.77
5461 Payroll Admin Expense	742.35	598.10		144.25
5470 Employee Benefits - Sharon	3,576.97	3,273.72		303.25
5471 Employee Benefits - Roberto	1,160.93	294.73		866.20
Total 02. Salaries & Benefits	\$ 89,176.77	\$ 77,146.19	\$	12,030.58
03. Patient Support	429.73	5,132.61		-4,702.88
5321 Support Group Expenses	0.00	1,000.48		-1,000.48
Total 03. Patient Support	\$ 429.73	\$ 6,133.09	-\$	5,703.36
05. Awareness & Advocacy				0.00
5327 Newsletter Expense	1,642.78	4,998.97		-3,356.19
5530 Awareness & Advocacy	4,640.40	751.54		3,888.86
5615 Advertising and Promotion	1,957.30			1,957.30
Total 05. Awareness & Advocacy	\$ 8,240.48	\$ 5,750.51	\$	2,489.97
06. Fundraising Events Costs	41.92			41.92
07. Program Education & Consulting				0.00
5511 Patient Education	242,145.27	36,057.60		206,087.67
5515 Consulting	1,096.92			1,096.92
Total 07. Program Education & Consulting	\$ 243,242.19	\$ 36,057.60	\$	207,184.59
08. Professional Fees				0.00
5610 Accounting & Legal	1,557.08	9,832.68		-8,275.60
5695 Professional Fees	597.64	597.64		0.00
5696 Bookkeeping	5,300.94	883.49		4,417.45
5705 Membership fees, dues, subscrip	880.27	281.38		598.89
Total 08. Professional Fees	\$ 8,335.93	\$ 11,595.19	-\$	3,259.26
09. General & Administrative				0.00
5500 General Administrative Expenses	7,986.09	11,912.93		-3,926.84

5520 Education	326.06			326.06
5525 Conferences	0.00	56.51		-56.51
5571 Website Hosting	226.20			226.20
5640 Courier & Postage	362.99	974.30		-611.31
5650 Staff Equipement - computers	310.65			310.65
5686 Governance	7,366.51	10,394.00		-3,027.49
5700 Office Supplies	828.56	1,430.43		-601.87
5770 Storage	1,847.91	1,841.66		6.25
5890 Credit Card fees	199.89	205.95		-6.06
5891 Other Commissions	137.40	386.43		-249.03
5895 Canada Helps fees	1,338.39	4,168.26		-2,829.87
5896 PayPal fees	-0.77	605.90		-606.67
Total 09. General & Administrative	\$ 20,929.88	\$ 31,976.37	-\$	11,046.49
10. Travel & Meeting Costs	865.21			865.21
5784 Travel	8,365.96	10.44		8,355.52
Total 10. Travel & Meeting Costs	\$ 9,231.17	\$ 10.44	\$	9,220.73
11. Telephone/Internet				0.00
5780 Telephone Expense	1,108.46	698.54		409.92
5781 Internet	4,308.62	3,488.11		820.51
Total 11. Telephone/Internet	\$ 5,417.08	\$ 4,186.65	\$	1,230.43
13. Bank and Interest Charges				0.00
5690 Bank Service Charges	-193.26	312.51		-505.77
Total 13. Bank and Interest Charges	-\$ 193.26	\$ 312.51	-\$	505.77
Total Expenses	\$ 384,851.89	\$ 173,168.55	\$	211,683.34
PROFIT	-\$ 178,081.39	\$ 536,870.45	-\$	714,951.84

Thursday, Feb. 23, 2023 08:12:17 p.m. GMT-8 - Accrual Basis



Canadian Pulmonary Fibrosis Foundation

CPFF Vision & Mission Refresh Approach

CPFF's proposed new vision and mission statements have been developed in consultation with the CPFF Board of Directors and CPFF Community Stakeholders (patients & caregivers).

STEP 1: CPFF Board Member Vision & Mission Exercise

In March 2022, CPFF board members were asked to complete an interactive exercise intended to gather input on key themes and wording that matters for the CPFF vision and mission.

STEP 2: December 2022 Stakeholder Meeting Pre-Meeting Survey

In December 2022, Community stakeholders were asked to vote on mission statement options and provide their reasons why.

STEP 3: Final CPFF Vision and Mission Statement

In January 2023, CPFF's vision and mission statement have been revised to reflect input.

Vision Statement: "Inspires us to dream"

A guiding purpose. The ideal that your mission and values build toward. A vision statement is more of a visual of what the world would look like if you completed your mission, and not the steps you're going to take to get there. This should be something that has not yet happened.

Mission Statement: "Inspires us to take action"

The actions your organization will take to achieve its vision. (Note: this doesn't need to be ALL the actions... it should be short and easily memorized.)

Here's what we're proposing:

NEW CPFF VISION & MISSION STATEMENTS

OUR VISION

A world free of pulmonary fibrosis

OUR MISSION

We improve the lives of people living with pulmonary fibrosis by providing compassionate support, leading advocacy, raising awareness, funding research, and inspiring hope.

CPFF Policy

Authority to Commit and Approve Payment

Purpose

This policy describes the scope and limits to both commit CPFF to contracts and other commitments, and payment of CPFF expenses. It also describes requirements for procuring goods and services for CPFF.

Scope

This policy applies to all expenditures, commitments and contracts entered on behalf of Canadian Pulmonary Fibrosis Foundation (CPFF), including contracts that do not involved an exchange of payments such as non-disclosure agreements or confidentiality agreements. Employees may only approve an expenditure or sign either a contract, or other commitment agreement, on behalf of CPFF in compliance with this policy.

Policy Statement

Signing Authority

The Board Chair, Executive Director and Foundation Staff, Treasurer, Vice Chair, Governance Chair, and Directors are granted Signing Authority within their area of responsibility on behalf of CPFF.

Authority to Commit and Approve Payment

Authority to Commit and Approve Payment is granted to the positions within CPFF at the levels set out in the Authority to Commit and Approve Payment Limits Matrix within an individual's area of responsibility. Authorization Limits are per each transaction and the total cost of the transaction must be used to determine the position level holding the required Authority to approve the transaction. For greater clarity, transactions must not be divided or separated so as to appear as lesser amounts to avoid the Authority to Commit and Payment Authority limit that would otherwise apply to the transaction.

Delegations of Authority

Authority to Commit CPFF to contracts or other commitments, may not be delegated.

Authority to Approve Payment may be delegated to an employee within the Organizational for which he or she holds budget responsibility. For greater clarity, Authority to Approve Payment cannot be delegated to a Contractor. Nothing in this policy is intended to prevent Contractors from being given authority to create Purchase Requisitions.

Delegations of Authority to Approve Payment must be done in writing and must be time-limited. No delegation of Authority to Approve Payment may be for longer than 24 months.

Sub-delegation of a delegated Authority to Approve Payment is not permitted.

General Provisions

In an emergency, the Executive Director may exceed his/her Authority to Commit and Approve Payment Limit, subject to subsequent ratification by the Board. The Executive Director must seek Board ratification of emergency spending powers as soon as it is practicable.

Authority to Commit and Approve Payment is aligned with budget responsibility and cost centers. Employees with cost center responsibility have the obligation, on an ongoing basis, to manage and monitor expenditures to ensure expenditures remain within approved annual budget amounts.

Context

This policy sets out Authority to Commit and Payment Approval Authority for CPFF. The authorities set out in this policy are designed to meet strong governance practices, meet operational needs as well as ensures CPFF meets or exceeds government’s fiscal requirements while maintaining Canada Revenue Agency guidelines and a focus on cost containment throughout the organization.

Attachment

Authority to Commit and Approve Payment Limits Matrix

Authority to Commit Approve Payment Limits Matrix

Position	Contracts					Commitments	Payment (5)			
	Non-disclosure, Professional & Master Services Agreements (1)	Employment Contract (1) (2)	Budgeted Operating Expense (6) (8)	Unbudgeted Operating Expense (7) (8)	Capital Expenditure (7)	Guarantees, Loans, Joint Ventures, Letters of Credit & all other Undertakings (1)	Tax & Payroll Related (3)	Budgeted Operating Expense	Unbudgeted Operating Expense	Expense Accounts (4)
Board	All	>\$50,000	>\$30,000	>\$10,000	>\$10,000	All	>\$30,000	>\$30,000	>\$10,000	>\$10,000
Executive Director		\$50,000	\$30,000	\$10,000	\$10,000		\$30,000	\$30,000	\$10,000	\$10,000
Staff			\$1,000					\$1,000		

Notes

- (1) Require legal review
- (2) Limits apply to salaries per annum for employees two levels below the position indicated.
- (3) All payroll & tax related payments required Treasurer approval.
- (4) ED expense account to be approved by Board Chair. Board member expense accounts to be approved by Executive Director.
- (5) Board approval of payments requires approval by Treasurer and one of Board Chair, Vice-Chair or Committee Chair.
- (6) Budgeted operating expenses under \$30,000 can be sole-sourced to a qualified vendor. 2 proposals must be received for budgeted operating expenses greater than or equal to \$30,000.
- (7) 2 proposals from qualified vendors must be received for un-budgeted & capital expenses under \$30,000. 2 proposals must be received for un-budgeted operating & capital expenses greater than or equal to \$30,000.
- (8) Includes Master Service Agreement Purchase Orders & Work Orders

Sharon's KPIs for FY 2022-2023

Key Performance Indicator (KPI)	Objective	Results
<p><u>Communications</u></p> <ul style="list-style-type: none"> • Number of people are visiting CPFF website • Number of people using the CPFF app • Number of people signing up for webinars • Number of people participating in CPFF's call to action <ul style="list-style-type: none"> ○ Share stories ○ Volunteer at event, organizing proclamations, lighting up of buildings 	<ul style="list-style-type: none"> • To increase CPFF's visibility • To increase awareness of PF 	<ul style="list-style-type: none"> • Increased traffic to our website and followers from Canada • Traffic from around the Globe <ul style="list-style-type: none"> ○ Australia ○ China ○ Finland ○ Germany ○ India ○ Japan ○ United Kingdom ○ United States
<p><u>Advocacy & Support</u></p> <ul style="list-style-type: none"> • Increase number of support groups • Group leader training and support <ul style="list-style-type: none"> ○ Materials – what is needed • Community participation in CPFF events <ul style="list-style-type: none"> ○ Advocacy (i.e.: drug formulary, oxygen) ○ Surveys (CPFF will use responses to revise their strategic planning) • GR relations <ul style="list-style-type: none"> ○ Community to participate in the engage of bureaucrats and Health Ministers 	<ul style="list-style-type: none"> • Ensuring that there are support groups for everyone interested • Updating CPFF Patient Guidebook • Understanding oxygen from patients/healthcare professionals/oxygen providers point of view • Ensuring that government understands the needs of the PF community (patients, caregivers, healthcare and oxygen providers) 	<ul style="list-style-type: none"> • Launch of national patient support group • Launch of national caregiver support group • Completion of patient guidebook • Completion of 3 surveys (patients & caregivers, healthcare professionals & oxygen providers) • Greetings from Health Ministers and Premiers
<p><u>Fundraising</u></p> <ul style="list-style-type: none"> • Donor recognition • Donor Bill of Rights • DIY fundraisers and number of events hosted 	<ul style="list-style-type: none"> • Acknowledging donors • Increasing DIY events 	<ul style="list-style-type: none"> • Profile of DIY events • Acknowledgement of donors in newsletter

<ul style="list-style-type: none"> Targeted fundraisers (i.e.: February: rare disease month, September: PF month, November: lung month, December: Holiday Season) 	<ul style="list-style-type: none"> Ensuring targeted fundraisers are successful in raising awareness as well as funds 	<ul style="list-style-type: none"> Increased funds from targeted fundraisers <ul style="list-style-type: none"> Sep PF month = \$113,000 Dec 21 Days of Gratitude = \$47,000
<p><u>Governance & Finance</u></p> <ul style="list-style-type: none"> Continue work with John Dinner on CPFF policies and have them completed by December 31, 2022 Recruitment of Board Directors – 2 by the end of December 31, 2022 Recruitment of Committee Volunteers – 2 by the end of December 31, 2022 HR Consultant to complete Board evaluation and ED appraisal by Spring of 2023 Satisfaction ratings by Board, ED and employees. Use results as baseline data from the last 2 years and set future goals 	<ul style="list-style-type: none"> Ensuring CPFF policies are current Continued recruitment of volunteers for the Board, committees and CPFF events HR Consultant to support CPFF with HR needs, evaluation of Board and ED 	<ul style="list-style-type: none"> Completion of 15 policies Increased interests from volunteers in supporting CPFF for the Board, committees and CPFF events Two HR Consultants for RFP
<p><u>Medical Advisory Board (MAB), Research, Fellowship</u></p> <ul style="list-style-type: none"> MAB quarterly meeting <ul style="list-style-type: none"> Invite Fellows and Grant recipients to participate Acknowledgement by Fellows and Grant recipients in publications resulting from work funded by CPFF (abstracts, posters, publications, talks) September PF awareness month participation <ul style="list-style-type: none"> Presentation of webinars by MAB members 	<ul style="list-style-type: none"> Ensuring MAB supports and understands CPFF’s needs Engaging Fellows and Grant recipients to raise the profile of CPFF Soliciting presenters in giving updates on progress being made in PF Soliciting presenters in giving relevant information expressed by patients 	<ul style="list-style-type: none"> MAB have all confirmed their continued interest and support of CPFF Engaging Fellows and Grant recipients to join MAB and present webinars Top presenters were engaged in presenting on mental health, creating universal blood type lung donor

○ Presentation of webinars by Fellows and Grant recipients		



Canadian Pulmonary Fibrosis Foundation (CPFF)

2/22/2023

Strategic Plan FY23-24

The Canadian Pulmonary Fibrosis Foundation is a registered Canadian Charitable Foundation established to provide hope and support for people affected by pulmonary fibrosis. The CPFF is a not-for-profit charitable organization. The charitable registration # is 850554858RR0001.

47 Squire Baker's Lane
Markham, Ontario L3P 3G8

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sharon@cpff.ca
www.cpff.ca

Executive Summary

The Canadian Pulmonary Fibrosis Foundation (CPFF) provides support for all people affected by pulmonary fibrosis (PF), and is the voice of patients living with PF.

The CPFF works closely with the medical community and with support from Canadians, we hope to achieve our mission and vision.

The CPFF's logo is an open blue and red fan. The fan itself represents movement of air. The gradient colour symbolizes the oxygenation of blood that is necessary for survival. Bright red is the colour of oxygenated blood and blue is un-oxygenated blood.

Our four pillars of focus guide our strategy. They are:

1. Awareness: Educate and raise awareness about PF among Canadians;
2. Support: Support those affected by PF;
3. Research: Raise funds to finance research and;
4. Advocacy: Represent Canadians affected by PF to government, healthcare professionals, the media and the public.

Because of the growing needs of the PF community throughout Canada, CPFF intends to expand the services and programs that we deliver. As such a key focus of our short-term strategy is to expand our internal capabilities to deliver these services and programs. We call this "Building the Foundation for the Foundation".

Mission Statement

We improve the lives of people living with pulmonary fibrosis by providing compassionate support, leading advocacy, raising awareness, funding research, and inspiring hope.

Vision

A world free of pulmonary fibrosis

Pulmonary Fibrosis

Pulmonary fibrosis (PF) is an interstitial lung disease that affects an estimated 30,000 Canadians, with a projected 5,000 deaths each year. In patients with PF, the lung tissue becomes scarred and over time, thickens and becomes more widespread. In turn, the lungs lose their ability to transfer oxygen to the bloodstream, resulting in shortness of breath and vital organs being deprived of the necessary oxygen to survive.

Symptoms of pulmonary fibrosis usually have a gradual onset and may include:

- Shortness of breath, particularly during or after physical activity
- Spasmodic, dry cough
- Gradual, unintended weight loss or weight gain
- Fatigue and weakness
- Chest discomfort

- Clubbing, or enlargement, of the ends of the fingers (or sometimes the toes) due to a buildup of tissue

PF can be linked to particular causes, such as environmental exposures, chemotherapy or radiation therapy, residual infection, or autoimmune diseases such as scleroderma or rheumatoid arthritis. In the majority of cases of pulmonary fibrosis, the cause is uncertain or unknown and as such is termed idiopathic.

Unfortunately, there is currently no cure for pulmonary fibrosis and there is limited treatment available. Using an oxygen tank can help manage the strain of Pulmonary Fibrosis, however this varies from case to case and you should consult your doctor to learn more.

Key Elements of our Strategy

Key elements of our strategy are as follows:

- 1. Educate Canadians to increase awareness about both PF and the Canadian Pulmonary Fibrosis Foundation (CPFF)**
 - Utilize state of the art communications (including social media) to most effectively reach our community and communicate our story
 - Continue to run a national September campaign annually to recognize PF Awareness month. This campaign will include, but is not limited, to the following events:
 - Lighting up of buildings and structures in blue and red
 - Obtaining proclamations from all levels of government
 - Hosting of online and/or in person Patient Forums
 - Encouraging bubble blowing across the country
 - Clarke Walk for Pulmonary Fibrosis (national event)
 - Create opportunities for interested parties to become involved in the Foundation
 - Leverage and further develop grassroots relationships
- 2. Strengthen the focus on people affected by PF and strengthen the services we provide to them**
 - Build the numbers of people affiliated with the Foundation, using our network of Patient Support Groups as a platform.
 - Expand access to our Patient Support Groups by both increasing the number of Patient Support Groups, and using technology to allow virtual access to Support Group meetings and events.
 - Continue with our practice of conducting regular surveys of the PF community to identify needs, issues and priorities.
- 3. Invest in world-class research to slow and prevent Pulmonary Fibrosis (PF)**
 - Support and promote our Medical Advisory Board, as a national body of excellence in PF diagnosis, treatment and research.
 - Continue to build a critical mass of researchers in Canada that will lead to treatments for PF, while encouraging global collaborations and knowledge transfer.
 - Enhance clinical research in Canada
 - Continue to forge strong connections to individuals and families living with PF to ensure a strong base for potential clinical trial participation
 - Continue to award Robert Davidson fellowships and research grants on an annual basis

4. Advocate for Canadians living with PF and enhance the services we provide to them

- Maximize our connections with families and individuals living with PF
- Lead efforts to bring earlier diagnoses, and access to treatment (drugs and oxygen)
- Continue our federal and provincial advocacy efforts to earlier diagnoses and access to treatment (drugs and oxygen) and create a safe environment for people to tell their story
- Collaborate with other organizations to promote efficiency and communicate a coordinated message.

5. Demonstrate local, provincial and national leadership

- Develop and support Regional Committees, formally connected to the Foundation, to engage our local communities. These committees will:
 - Be the local source of information on PF for PF patients, their families and caregivers.
 - Liaise with local health authorities, municipalities and provincial ministries of health, and advocate for services and support for the local PF Community.
 - Develop new Patient Support Groups and assist existing, local Patient Support Groups with operational issues to allow them to expand and flourish.
 - Expand local volunteer base.
 - Develop and run local events for raising awareness, and fund raising.
 - Manage local components of national events (eg. Local proclamations, building lighting, and bubble blowing for September celebrations)
- Maintain relationships with global PF service providers and organizations, to ensure that we are aware of activities and developments outside of Canada which could benefit the Canadian PF community.
- Inspire engagement and collaboration with internal and external stakeholders
- Set the example for organizational stability, effectiveness and excellence
- Investigate opportunities for joint projects with other service providers

6. Build the foundation for the Foundation

- As previously noted, using our Patient Support Groups as a platform, Develop Regional Committees throughout the country.
- Operate efficiently.
 - Ensure that greater than 90% of revenues are used for Charitable Expenses, specifically for projects aligned with our 4 pillars.
- Operate transparently:
 - Board to approved annual Business Plans including 3-year Profit & Loss, Balance Sheet and Cash Flow forecasts.
 - All Charitable Expenses projects to have a Board approved scope of work, budget and schedule.
 - Report to Board of Directors quarterly on Charitable project progress relative to approved scope of work, budget and schedule.
 - Prepare an annual report for our PF Community.
 - Develop, nurture and retain a high-performing team.
 - Carry out annual performance reviews for Management and the Board of Directors.
 - Develop and maintain succession plans for all Board and key Management positions.
 - Support personal development for Board and Management positions.

7. Build the fundraising capacity of the Foundation

▪ **Create CPF Innovation Fund**

- Support fund with earned income for continued growth
- Annual review of funds by Board for alignment with strategic goals
- Internal restrictions as determined by Board for disbursement of interest earned
- Maintain strong relationships with existing corporate donors.
- Develop fundraising plan which will include but not be limited to:
 - Acknowledgement of contributions of current and historical donors and nurturing relationships.
 - Development of donor data base and management plan.
 - Specific plans for individual calendar events (e.g.: Giving Tuesday, Pay it Forward etc.)
 - Strategy for attracting bequests.

Draft - Harmonization of Oxygen White Paper

Introduction

- Summary and scope of paper

Literature Review

The first key study to evaluate the benefits of domiciliary oxygen use in respiratory disease was published in 1980, comparing nocturnal only vs continuous home oxygen use in patients with severe COPD (Nocturnal Oxygen Therapy Trial Group *Ann Intern Med.* 1980;93:391–398). These 203 patients met the criteria for severe hypoxemia, with a $pO_2 \leq 55$ mmHg or ≤ 59 mmHg and findings of polycythemia or right heart failure. Average duration of daily oxygen use was 12 vs 17.7 hrs/day in the nocturnal vs continuous group, respectively. Over an average period of nineteen months, 41 patients in the nocturnal group died vs 23 in the continuous group, with a relative risk of death of 1.94 for those in the nocturnal group. Shortly after this publication, the Medical Research Council from the U.K. published a trial involving 87 patients with severe COPD, chronic hypoxemia/hypercapnia, and cor pulmonale (Medical Research Council Working Party *Lancet* 1981 Mar 28;1(8222):681-6). Patients were randomized to continuous supplemental oxygen (minimum 15hrs/day) vs no oxygen, and followed for five years of followup. In this time, 19 vs 30 patients died in the treatment and control groups, respectively. These two fairly small landmark trials set the landscape for home oxygen therapy over the subsequent four decades, and the benefits of home oxygen for severe resting hypoxemia has not been re-evaluated since, given the lack of clinical equipoise in this patient population.

Since the 1980s, several other studies have been published to help clarify the benefits of home oxygen therapy, and to refine which individuals benefit the most from this treatment. In 2002, Eaton et al published a double-blind crossover study involving patients with severe COPD and documented severe exertional desaturation ($SpO_2 \leq 88\%$ during activity). Over 12 weeks, those randomized to supplemental oxygen demonstrated an improvement in 6-minute walk distance, as well as improvements in their Chronic Respiratory Questionnaire (CRQ) and Hospital Anxiety and Depression (HAD) questionnaire scores (Eaton et al *ERJ* 2002 20:306-312). Moore et al (*Thorax* 2011;66:32e37.) performed a placebo-controlled, double-blinded trial of supplemental air vs oxygen at a flow rate of 6L/min in 143 patients with COPD and a $pO_2 > 55$ mmHg. Documented exertional desaturation was not mandatory for participation, therefore only a third of participants had desaturation during activity $\leq 88\%$ on room air. This trial did not demonstrate a clinically significant improvement in dyspnea, between study groups, however a statistically but not clinically significant difference in 6 minute walk distance was observed favoring the supplemental oxygen group. In 2016, a much larger trial was completed in the United States by the Long-Term Oxygen Treatment Trial (LOTT Research Group *N Engl J Med* 2016;375:1617-27) to again evaluate the benefits of supplemental oxygen in stable COPD patients with moderate resting desaturation (resting SpO_2 89-93%) or exertional desaturation ($SpO_2 < 90\%$ for ≥ 10 s during a 6 minute walk test). This unblinded trial assessed nasal cannula oxygen (either continuous, or during exertion/nocturnally in the exertional desaturation group) vs no oxygen over up to six years, with a composite primary endpoint of

time to death or all-cause hospitalization. This trial overall did not show any difference between treatment and control groups in mortality, hospitalizations, or other quality of life measures.

The American Thoracic Society also published an updated guideline on the use of home oxygen in chronic lung disease. Defining severe hypoxemia as a PaO₂ ≤ 55mmHg or SpO₂ ≤ 88%, strong recommendations were made supporting the use of supplemental oxygen in patients with COPD or ILD with severe resting hypoxemia, citing the established mortality benefit in this population. For those with isolated severe exertional desaturation (SpO₂ ≤ 88% during activity), a conditional recommendation was made in support of ambulatory oxygen for this population. This was based on review of data supporting improvement in functional exercise capacity, and small improvements in patient-reported outcomes.

The majority of studies investigating home oxygen therapy are in those with COPD, and this data is often extrapolated to other respiratory diseases. Interstitial Lung Disease (ILD) is a group of heterogeneous disorders that typically involve progressive fibrosis and/or inflammation of the lung parenchyma. The physiology and effects of ILD are quite different than COPD, and affected patients often have marked desaturations during low workloads. As a result, the amount of oxygen required to normalize oxygen saturations can be significantly higher than in COPD. The AmbOx trial in 2016 was the first prospective RCT designed to evaluate the effects of supplemental oxygen during exertion alone in patients with ILD. The primary endpoint was an improvement in quality of life as determined by the King's brief ILD questionnaire (KBILD). In this crossover study, participants received supplemental oxygen vs. air via canister for two weeks, after which they were changed over to the alternative arm. A significant improvement in KBILD score was noted in the oxygen arm (increase by 3.7 points), with largest increases in the "breathlessness and activity" and "chest symptom" domains. In addition, there was a significant improvement in recovery time post-activity, with a slight improvement in 6-minute walk distance (Visca et al AmbOx Trial Lancet Respir Med 2018 Oct;6(10):759-770).

A systematic review in 2016 by colleagues in Australia of 13 articles summarized data around the benefits of short and long-term oxygen therapy in patients with ILD (Bell et al, Eur Respir Rev 2017; 26: 160080). This article identified that the impact of oxygen on dyspnea, exercise capacity, and mortality in this population is inconsistent, although non-randomized data did show potential benefits in endurance on 6 minute walk test. As identified by Johannson et al, there is a paucity of good quality evidence for supplemental oxygen in Interstitial Lung Disease, leading to inconsistencies in practice from one region to the next (Johannson et al Ann Am Thorac Soc Vol 14, No 9, pp 1373–1377, Sep 2017).

?ADD AMBOX TRIAL DATA

Current international guidelines continue to support the use of supplemental oxygen in lung disease, acknowledging the gaps in data for moderate hypoxemia. The American Thoracic Society published a recent guideline in 2020, highlighting the evidence of supplemental oxygen in lung disease. They concluded that for both COPD and ILD, home oxygen should be prescribed for patients with severe resting hypoxemia and severe exertional desaturation

(Jacobs, SA et al. Am J Respir Crit Care Med Vol 202, Iss 10, pp e121–e141, Nov 15, 2020). The guideline committee also gave a conditional recommendation against home oxygen for moderate resting hypoxemia alone in COPD. The paucity of strong data specifically for ILD was acknowledged.

Focusing specifically on Interstitial Lung Disease, an international Delphi study was completed in 2019, where an international panel of experts weighed in on the use of home oxygen in this disease population (Johansson et al Eur Respir J 2019; 54: 1900421). All survey participants recommended use of long-term oxygen in those with ILD and severe resting hypoxemia ($pO_2 < 55\text{mmHg}$ or $< 59\text{mmHg}$ and findings of polycythemia or right heart failure). Objective testing for nocturnal hypoxemia was recommended before prescribing for this indication alone. There was consensus for the use of oxygen in isolated symptomatic exertional hypoxemia, however the desaturation threshold to initiate this therapy varied amongst participants (majority suggest oxygen for exertional $SpO_2 < 89\%$).

Overall, the evidence for supplemental oxygen in severe resting hypoxemia remains consistent, with strong recommendations to prescribe domiciliary oxygen in these patients. There is also a general consensus to provide oxygen for those with exertional desaturation only, with improvements in patient-reported outcomes (PROs) and exercise tolerance. Finally, a paucity of data is noted for patients with Interstitial Lung Disease, with further research required to identify the unique needs of this population.

Canadian Overview

Reimbursement comparison

Currently home oxygen funding in Canada is regulated at the provincial/territorial level, which results in significant variability across the country. Although some regions reimburse up to 100% of costs, others have variable funding models based on the financial income of the recipient. Unfortunately the latter model can lead to large out-of-pocket costs for some, often thousands of dollars per year. This variation across the country creates significant inequities, placing significant financial strain on many Canadians.

British Columbia

Residents of British Columbia that have a valid health card, residing in the province for greater than six months of each calendar year, are eligible for home oxygen funding. Providing that medical criteria is met, residents will be reimbursed 100% for oxygen costs, irrespective of their income status. For those with private insurance, the Home Oxygen Program (HOP) will cover residual costs that the insurer does not. Funding is not contingent on the underlying medical condition. Periodic renewals are required as part of the HOP.

Alberta

The Alberta Aids to Daily Living (AADL) Respiratory Benefits Program provides reimbursement for oxygen costs up to 100% for residents that meet medical criteria (exempting some

disposable supplies). Financial income of the individual is not considered. Funding is not disease-specific, and will be provided as long as medical criteria is met. Periodic renewals are required to ensure that the patient remains medically eligible for home oxygen.

Saskatchewan

The Saskatchewan Aids to Independent Living (SAIL) program provides funding for home oxygen to all residents of the province, providing that medical criteria are met. There may be a monthly maximum that can be reimbursed, after which recipients may incur additional costs. Periodic renewals are required as per SAIL guidelines.

Manitoba

Home oxygen reimbursement in Manitoba is supplied via Home Care Services in the form of the Home Oxygen Concentrator Program (HOCP). Eligible residents of the province can avail of 100% reimbursement of oxygen costs, if deemed medically appropriate. As per other provinces, periodic renewals to confirm long-term eligibility are built into the program. No monthly maximum is cited in the application form.

Ontario

The province of Ontario funds home oxygen therapy via the Assistive Devices Program (ADP). At a minimum, this program will cover 75% of expenses associated with home oxygen, regardless of financial income. For those above the age of 65, residents of a long-term care facility, or those receiving social assistance benefits, ADP will cover 100% of costs. Period renewals are required.

Quebec

Quebec's National Program for Home Oxygen Therapy (NPHOT) provides 100% reimbursement of oxygen costs for patrons who meet medical criteria. No financial assessment is included in the application. Annual renewals are required. Of note, individuals who continue to smoke and fail a tobacco screening test are ineligible to receive funding for home oxygen.

New Brunswick

The Extra-Mural Program (EMP) in New Brunswick provides oxygen funding to residents of the province. However, the amount provided is based on a financial assessment by the Social Development department of the government. Periodic renewals may be required.

Newfoundland & Labrador

The Special Assistance Program (SAP) in the province provides funding for home oxygen and supplies, however this is based on a financial assessment. This support is not disease-specific, and a formal renewal process is not required.

Nova Scotia

The Home Oxygen Services Program in Nova Scotia is available to residents of the province through the Department of Health and Wellness. Candidates must be referred by a designated physician in the province, and may avail of reimbursement for home oxygen equipment if

financial criteria is met. Patrons of this service must remain non-smokers, and periodic renewals are required.

Prince Edward Island

The Home Oxygen Program in PEI covers home oxygen equipment for those who meet medical criteria. This therapy must be prescribed by an appropriate specialist. Universal funding is provided for up to 50% of costs, up to a maximum of \$200.00/month. Confirmation of persistent hypoxemia is required for long-term renewal.

Yukon

Reimbursement criteria was not available.

Northwest Territories

Through Extended Health Benefits, home oxygen equipment may be reimbursed. However, an application for specified disease conditions is required, which currently includes chronic obstructive pulmonary disease (COPD) and pulmonary hypertension, but not interstitial lung disease (ILD).

Non-insured Health Benefits (NIHB)

For those that are eligible recipients of the NIHB program (registered First Nations, recognized Inuit coverage), universal reimbursement is available for home oxygen equipment. Confirmation of persistent hypoxemia is required after three months of initial request, and annual renewals are required.

Canadian Overview

Medical Criteria Comparison

Akin to the reimbursement situation, medical criteria for the prescription of home oxygen also varies considerably across Canada. The threshold for severe hypoxemia is fairly consistent, i.e. a resting $pO_2 \leq 55\text{mmHg}$ or $<60\text{mmHg}$ with features of cor pulmonale, pulmonary hypertension or polycythemia. As noted in <isolated exertional desaturation table> however, the criteria for isolated exertional desaturation is more variable from one region to the next. Most jurisdictions require objective improvement in endurance with supplemental oxygen in order for individuals to qualify, which is typically done via paired exercise tests (i.e. 6 minute walk test). Provinces including Quebec and PEI do not fund oxygen for exertional desaturation alone. Canada's three territories, along with Newfoundland and Labrador, do not have officially published medical criteria for home oxygen, despite providing reimbursement.

Isolated Exertional Desaturation Table

Province/Territory	Exertional O ₂ covered?	Criteria
Newfoundland & Labrador	Yes	Criteria not specified
Nova Scotia		Qualifies if desaturation <86% on 6MWT with evidence of pulmonary hypertension or cor pulmonale
New Brunswick	Yes	Qualifies if desaturation <89% while performing activities of daily living (ADLs)
PEI	?not funded	---
Quebec	?not funded	---
Ontario	Yes	Qualifies if (1) Desaturation during activity to <80% for >1minute (2) 25% improvement in walk time, along with improvement in BORG score by >= 1 unit if able to walk >5min (3) Increase of >= 2 minute in walk time, along with improvement in BORG score >= 1 unit if walk time <5min
Saskatchewan	Yes	Qualifies if desaturation <87% on exertion, and demonstration of >20% improvement in exercise capacity with supplemental O ₂
Alberta, British Columbia, Manitoba, Veteran's	Yes	Qualifies if (1) Desaturation during activity to <80% for >1minute OR (2) Sustained desaturation <88% during 6MWT for >1minute, with a >25% AND >30m increase in 6MWT distance while using O ₂
Yukon	Criteria not specified	---
Northwest Territories	Criteria not specified	---
NIHB	Yes	Qualifies if (1) Desaturation during activity to <80% for >1minute OR

		<p>(2) Sustained desaturation <89% during 6MWT for >2minutes, with a >25% AND >30m increase in 6MWT distance on O₂</p> <p>(3) Sustained desaturation <89% during 6MWT for >2minutes, with a >25% and 2minute increase in walk time on O₂</p>
Veterans		

Criteria for reimbursement of oxygen for nocturnal hypoxemia is even more variable, with several provinces not funding this indication. Provinces such as BC specify that nocturnal oxygen will only be covered in the setting of concurrent resting or exertional hypoxemia during the day. Many jurisdictions including Alberta, along with Veteran’s affairs and NIHB, require that sleep apnea is ruled out first.

Patient perspective

Given the variation in oxygen criteria and reimbursement across Canada, the Canadian Pulmonary Fibrosis Foundation recently commissioned a patient and caregiver survey to determine the current state of affairs for those with pulmonary fibrosis. Although the participants did not include those with other chronic lung diseases, this survey provided valuable insight into the real-life issues around home oxygen delivery.

Of the 640 respondents, approximately 14% paid out-of-pocket costs for their oxygen supplies. This cost ranged from <25% of total expenses, to >50%. Based on the individual’s financial situation and geography, this could amount to several hundred dollars per month.

- Indigenous perspective

- Other special populations

NEEDS FURTHER SURVEY DATA

Proposed standard of care

Although healthcare delivery varies considerably across Canada, the need for domiciliary oxygen does not. Accordingly, access and funding for home oxygen therapy should not be dependent on one’s province or territory of residence. Medical gases are formally classified as

drugs in Canada, however in many aspects they are managed and funded as medical devices. As a result, access to a provincially-funded drug plan does not guarantee access to funding for home oxygen equipment. The primary aim of this paper is to develop consistency across the country, and to propose universal medical and reimbursement criteria for those that require long-term oxygen therapy.

Proposed Medical Criteria

- (1) Resting hypoxemia - Given the identified mortality benefit associated with treatment in this situation, it is proposed that the following is an indication for long-term home oxygen in those with resting hypoxemia:
 - a. Room air arterial blood gas testing demonstrating a $pAO_2 \leq 55$ mmHg
 - b. Room air arterial blood gas testing demonstrating a ≤ 60 mmHg with clinical sequelae of chronic hypoxemia (pulmonary hypertension, cor pulmonale, polycythemia)
 - c. Resting SpO₂ on room air of $\leq 88\%$ in cases where arterial blood gas testing is not obtainable

It is reasonable for a reassessment to be required after initial approval to confirm the need for ongoing oxygen therapy (e.g. for those recovering from an acute admission) with long-term approval thereafter if criteria is still met.

- (2) Isolated exertional hypoxemia - Based on current expert recommendations and current practices across Canada, the following is proposed as an indication for isolated exertional hypoxemia:
 - a. Sustained SpO₂ $\leq 88\%$ during a standard six minute walk test (6MWT) with associated dyspnea

Blinded or unblinded 6-minute walk tests are resource-intensive and not available in all regions. Furthermore, they tend to focus on an improvement in endurance, with less focus on an individual's quality of life. As a result, mandating such outcomes is overly restrictive, and may limit access to oxygen for those who could benefit from it. It is also important to highlight that patients with Interstitial Lung Disease have a greater potential for exertional desaturation due to numerous mechanisms (i.e. impaired gas exchange, reduced lung volumes) and may require higher flow rates of supplemental oxygen when active.

Proposed Reimbursement Criteria

- (1) Severe resting hypoxemia - It is our recommendation that all costs be reimbursed for those with severe resting hypoxemia, including the following:
 - (a) Stationary home concentrator for placement in residence
 - (b) Oxygen tubing, masks, and other disposable items

- (c) Options for exertional and out-of-home usage. This may include portable canisters for those who are minimally active or who require higher oxygen flow rates, or portable oxygen concentrators for those who seek higher levels of activity and independence

For disease states that require higher flow-rates of oxygen (e.g. Interstitial Lung Disease, pulmonary hypertension), access to liquid rather than compressed oxygen should be considered, if available in the area. Liquid oxygen canisters are lighter and have a greater lifespan than compressed oxygen, which can provide greater freedom for these patients.

- (2) Isolated exertional hypoxemia - For those who have demonstrated exertional desaturation during a 6MWT, we recommend reimbursement for the following:
 - a. A portable oxygen system for ambulatory activities. Typical options are portable tanks of oxygen that are supplied monthly, or a portable oxygen concentrator.
 - b. Oxygen tubing, masks, and other disposable items

Special Considerations

- (1) Geographic access - Given the portable nature of oxygen systems, access to home oxygen should be universal, regardless of urban or rural locale. We feel that all Canadians that require supplemental oxygen should be able to avail of these services. This may require a dedicated strategy for rural communities, to ensure a dedicated and uninterrupted supply chain.
- (2) Disease-specific approval - As noted throughout this paper, the majority of evidence around home oxygen is drawn from the COPD population. However, other chronic respiratory diseases such as interstitial lung disease, pulmonary hypertension, and neuromuscular disease can also lead to chronic, potentially severe hypoxemia. Most jurisdictions in Canada do not restrict oxygen funding and access to specific disease, and the recommendation is to provide home oxygen for those that require it, regardless of the underlying cause.

Summary

References



Canadian
Pulmonary
Fibrosis
Foundation

Canadian Pulmonary Fibrosis Foundation

Patient & Caregiver Survey Report

Pearl Strategy and Innovation Design

July 2022

Agenda

1. Objectives & Learning Goals	3
2. Methodology	4
3. Executive Summary	5
4. Patient & Caregiver Profile	11
5. Patient & Caregiver Journey	16
6. Oxygen & Support	42
7. CPFF & Support	58
8. Appendix	73

Objectives & Learning Goals

Objectives

- Provide insights and compare with 2020 findings to help CPFF understand how to advocate for better support, treatments and access to care that will make a difference for patients and caregivers living with PF/IPF.

Learning Goals

- Understand patient and caregiver experiences as it relates to the disease and its impact on daily lives
 - Disease experience, experience with currently available treatments, desired improved outcomes with new treatments
- Key areas that CPFF should prioritize to make the biggest impact on the lives of PF/IPF patients and caregivers
- Types of support patients and caregivers are looking for
- Patient and caregiver awareness and relationship with CPFF
- Uncover experiences for under-represented communities and determine how they can be better served
- Understand patient experiences with oxygen

Methodology

- Patients and caregivers were recruited through CPFF's database and network (newsletter, social media, associations) and asked to complete an online survey.
- Respondent Breakdown: **N=640 Total Respondents**
 - Patients living with pulmonary fibrosis (N=506)
 - Main caregiver of someone with pulmonary fibrosis (N=79)
 - Answering on behalf of patient who passed away from pulmonary fibrosis (N=39)
 - Not the primary caregiver but answering on behalf of loved one with pulmonary fibrosis (N=16)
- Sources Used To Access Survey:
 - CPFF Newsletter (N=217)
 - CPFF Website (N=206)
 - CPFF Social Media: Facebook (N=92), Twitter (N=2)
 - Lung Associations (N=35)
 - Scleroderma Canada (N=3)
 - Other Sources (e.g., Support Groups, Doctors, Emails) (N=85)

Executive Summary

Executive Summary – Key Findings

Key Findings

Key Findings

- Majority of patients waited a year or more to receive their diagnosis – for one-third, it took over 3 years.
- About two in ten patients do not feel their current treatment/routine can manage their pulmonary fibrosis.
- Among patients and caregivers who don't feel treatment is managing PF, top reasons were lack of improvement/condition getting worse, not enough access to information, and not enough support from or access to doctors.
- 1 in 5 are in need of, yet do not receive counselling/emotional support. About 1 in 6 are in need of, yet do not receive physiotherapy and palliative care.

Visible Minorities

- Demographically, the sample of Indigenous patients was in line with the Canadian population for total representation, while visible minority patients under-indexed versus the Canadian population.
- Directionally, visible minorities show a greater need for all treatments, especially anti-fibrotic drugs, counselling/emotional support, and physiotherapy.
- More than half of visible minority patients do not feel their current treatment/routine can manage their pulmonary fibrosis.

Oxygen

- About 1 in 5 of patients were unable to receive an oxygen therapy prescription when needed.
- Three-quarters of patients did not receive their oxygen the same day as prescribed, and over half had to wait a week or more
- Over one-third do not have a backup system in case of power outage. About 1 in 5 are not fully confident they know when and/how much to use.
- Access to oxygen at home is high, however it drops significantly when travelling.
- About six-in-ten feel their reliance on supplemental oxygen has a large impact on their quality of life.
- Improving unit portability was the top area for improvement for oxygen therapy.
- Over one-third said knowing when or how to get changes to their oxygen therapy is their biggest challenge.
- Close to 1 in 5 do not have their oxygen costs covered or reimbursed by their government health plan.

Executive Summary – Key Findings

Key Findings

What's the Same – 2022 vs. 2020

- Top patient daily activities impacted: ability to work, participation in leisure activities, and activities needed to take care of family/themselves.
- Top physical symptoms impacting quality of life are shortness of breath/difficulty catching breath and general weakness/feeling tired.
- The top caregiver challenge is the impact on their physical and mental wellbeing.
- Anti-fibrotic drugs and oxygen continue to be the most popular treatments being received. Most treatments received are covered by insurance/benefits.
- CPFF awareness has remained stable from 2020 to 2022. About 1 in 4 would like to learn more about CPFF or become more involved.
- Top CPFF priorities: Help ensure that new drugs and treatments are available and affordable, raise awareness of PF, Local support groups, and help raise awareness of treatment options
- Top information needs: Research & New Treatments, Current Treatments, Exercise, Nutrition & Supplements

What's Changed – 2022 vs. 2020

- Patient daily activities impacted: ability to do leisure activities, general weakness, fear/anger/embarrassment/depression, and fear of losing balance/falling down all increased from 2020 to 2022.
- Caregivers increase their time spent caregiving per day while experiencing a decline in their ability to work and do activities.
- Need for all treatments increased from 2020 to 2022, with palliative care showing the strongest gain.
- Participation in support groups, specifically among patients dropped.

Executive Summary – Opportunities

Opportunities

Disease Experience

- Connect patients and caregivers with resources to help answer their questions about what to expect as the disease progresses
- Build awareness among other doctors and medical specialists (i.e. Rheumatologists)

Treatments

- Continue to advocate for the patients and caregivers who feel their current treatment and routine is not enough to help them manage their pulmonary fibrosis
- Prioritize ensuring new drugs and treatments are available and affordable, raise awareness of clinical trials and treatments, and raise awareness of PF/ILD among the public

Information

- Provide patients with information about research and new treatments, current treatments and exercise
- Provide caregivers with information about research and new treatments, current treatments and oxygen therapy

Support

- Provide caregivers with resources to address concerns for their own physical and mental well being – including local support groups and self-care/support materials

CPFF Relationship

- Offer patients and caregivers opportunities to learn more about CPFF and get involved through the CPFF website and newsletter
- Continue to leverage the CPFF website as a top source of information for both patients and caregivers

Executive Summary – Overall Learnings

Overall Learnings

Diagnosis	Time from symptoms to diagnosis continues to be 1+ year – with 1 in 3 taking 3 years or longer to be diagnosed. Increase in final diagnosis made by a respirologist/lung doctor (81% to 85%) and a family doctor (3% to 7%)
Primary Doctor	Most patients see a respirologist/lung doctor or family doctor for their primary care. Respirologists/Lung Doctors show an increase in being the primary doctor from (40% to 48%), while Family Doctors declined (55% to 47%).
Treatments	Anti-fibrotic drugs and oxygen continue to be the most popular treatments. Need for all treatments increased from 2020 to 2022 - 1 in 5 need counselling or emotional support, and 1 in 6 need physiotherapy or palliative care. Over one-third of patients continue to feel their current treatment/routine is not effective at helping them manage their pulmonary fibrosis.
Oxygen	About 1 in 5 of patients were unable to receive an oxygen therapy prescription when needed, and three-quarters did not receive their oxygen the same day as prescribed. Access to oxygen therapy at home is rated highly and while travelling is poor. About 6 in 10 feel their reliance on supplemental oxygen has a large negative impact on their quality of life.
Impact on Patient Life	Top activities impacted remain the same: ability to work, participate in leisure activities, and activities needed to take care of family/themselves. Top physical symptoms impacting quality of life are shortness of breath/difficulty catching breath and general weakness/feeling tired. Ability to do leisure activities, general weakness, fear/anger/embarrassment/depression, and fear of losing balance/falling down all increased from 2020 to 2022.
Impact on Caregiver Life	Their top challenges continues to be the impact on their physical and mental wellbeing. Caregivers experienced a decline in their ability to work and do activities along with an increase in time spent caregiving per day. About 2 in 3 caregivers do not feel that they are able to work and do all their activities.
CPFF Awareness	CPFF awareness has remained stable from 2020 to 2022. About 1 in 4 would like to learn more about CPFF or become more involved.
CPFF Priority	Top priority areas remain the same: Help ensure that new drugs and treatments are available and affordable, raise awareness of PF, Local support groups, and help raise awareness of treatment options. Local support groups and education materials saw an increase in 2022 vs. 2020.
Support Groups	Caregivers continue to show higher interest in learning more about support groups or programs. Participation in support groups, specifically among patients, has dropped by 12ppts.
Information Needs	Top areas of information needs remain the same: Research & New Treatments, Current Treatments, Exercise, Nutrition & Supplements
Under-Represented Communities	Visible minorities show a strong need for better/or more access to other treatment plans and options – particularly for counselling and support groups.

Patient & Caregiver Journey Overview

The patient and caregiver journey shows an opportunity for CPFF to build a relationship with patients and caregivers and help them access information and resources across many areas of managing pulmonary fibrosis.

DIAGNOSIS

Timeline:

- 69% diagnosed within the past 5 years
- About 2 in 3 were diagnosed within 2 years of experiencing lung problems

Doctor:

- 85% were diagnosed by a respirologist/lung doctor

Sources of Information:

- Top source of information at time of diagnosis was respirologist/lung doctor, followed by the CPFF website

TREATMENTS

Effectiveness:

- 39% do not feel their current treatment/routine is effective in helping them manage pulmonary fibrosis

Primary Doctor:

- 48% see a respirologist/lung doctor – about 8 in 10 see them as knowledgeable
- 47% see a family doctor – about 6 in 10 see them as knowledgeable

Popular Treatments:

- Anti-fibrotic Drugs
- Oxygen

IMPACT ON LIFE

Patient Life:

- Top **symptoms** impacting **patient** life:
- Ability to work like before
- Ability to do leisure activities
- Shortness of breath/difficulty catching breath

Caregiver Life:

- Top **challenges** impacting **caregiver** life:
- Ability to do leisure activities
- Physical well being
- Feelings of hopelessness and depression

ROLE OF CPFF

Awareness:

- No growth from 2020
- Majority are somewhat aware of CPFF
- About 1 in 4 patients/caregivers would like to learn more about CPFF

Source of Information:

- CPFF is an important source of information to over half of patients and caregivers since diagnosis

FUTURE AREAS OF NEED

Priority Areas of Focus:

- Help ensure new drugs & treatments are available & affordable
- Raise awareness of PF/ILD among the public
- Local support groups

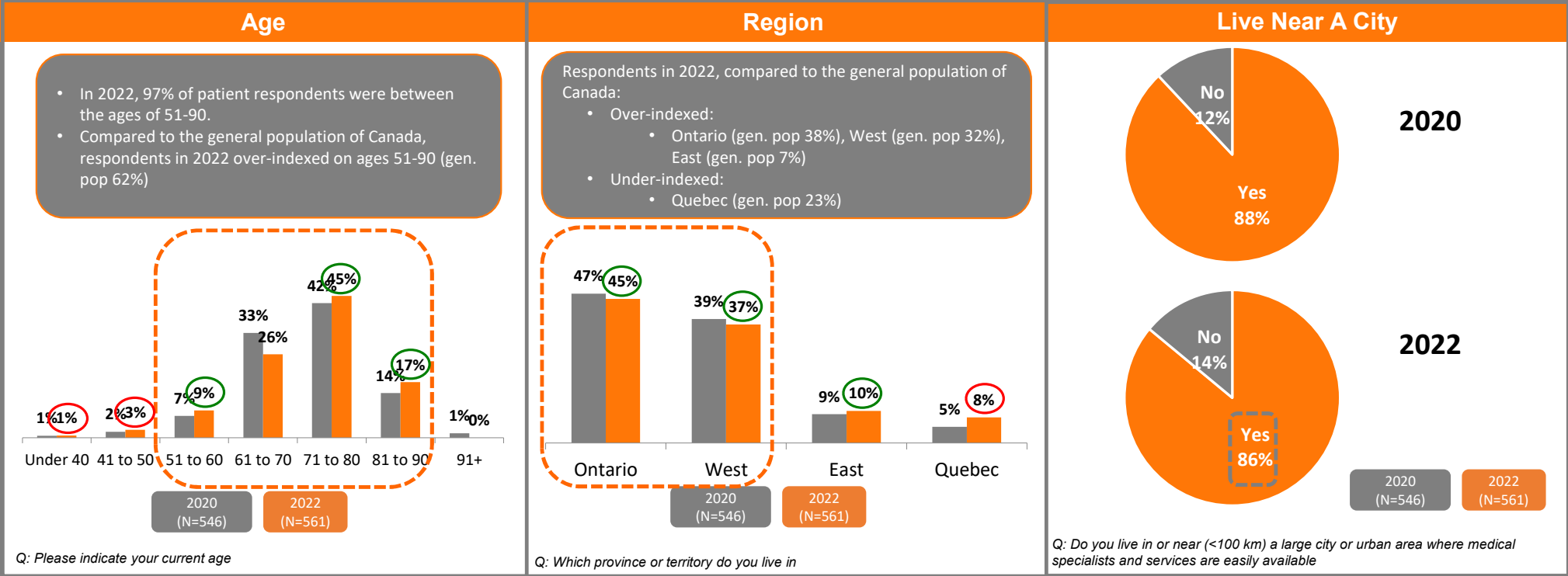
Additional Information Needs:

- Patients are looking for information on research & new treatments, current treatments, and exercise.
- Caregivers are looking for information on research & new treatments, current treatments, and oxygen therapy.

Patient & Caregiver Profile

Patient Demographics

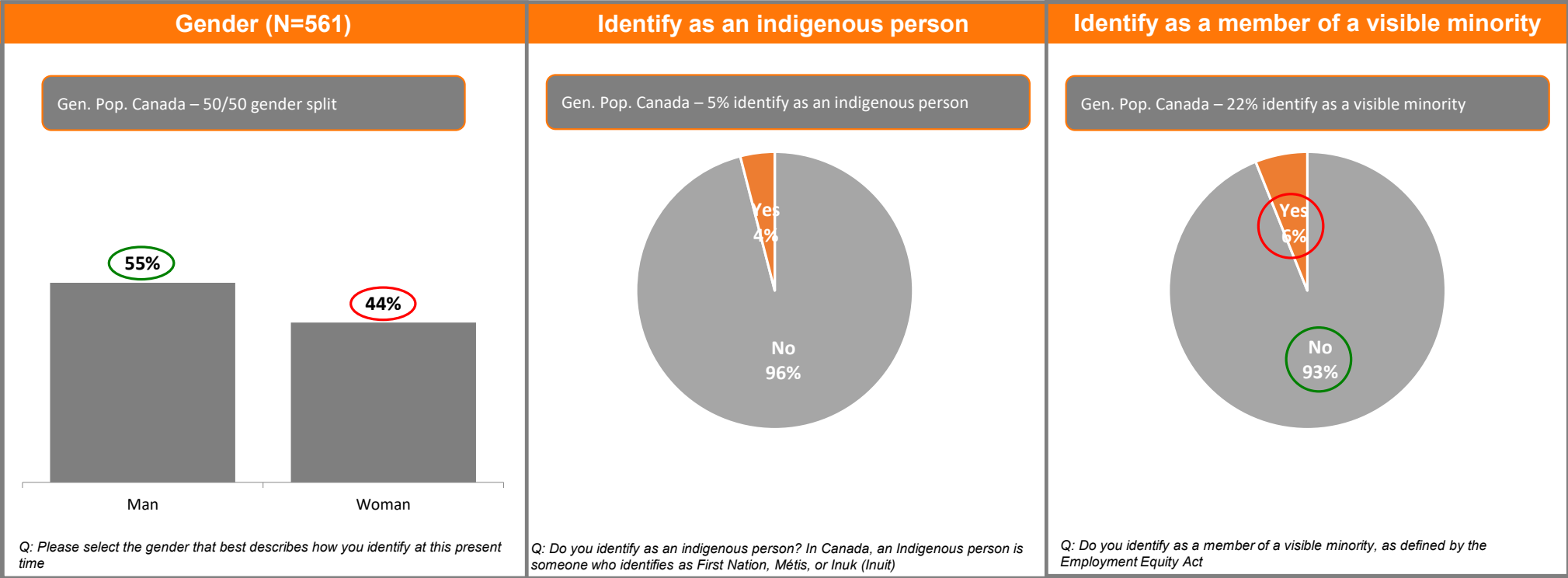
Majority of patient respondents were over the age of 60, from Ontario and the West, and live near a major city. Compared to 2020, there has been an increase in respondents between 71-90 years of age.



○ Indicates 2022 over-indexed vs. Canada's general population ○ Indicates 2022 under-indexed vs. Canada's general population

Patient Demographics

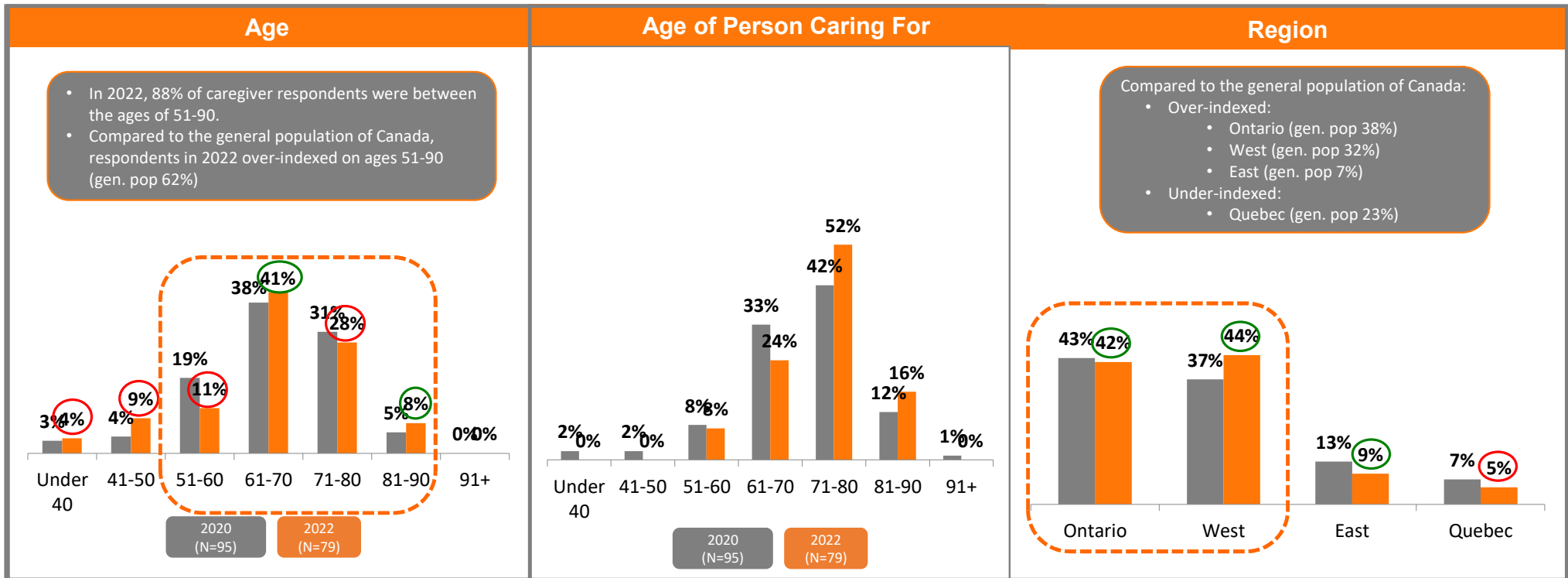
Gender mix was close to the general population mix of 50/50, and so was indigenous representation. Visible minority patients under-indexed versus the Canadian population.



○ Indicates 2022 over-indexed vs. Canada's general population
 ○ Indicates 2022 under-indexed vs. Canada's general population

Caregiver Demographics

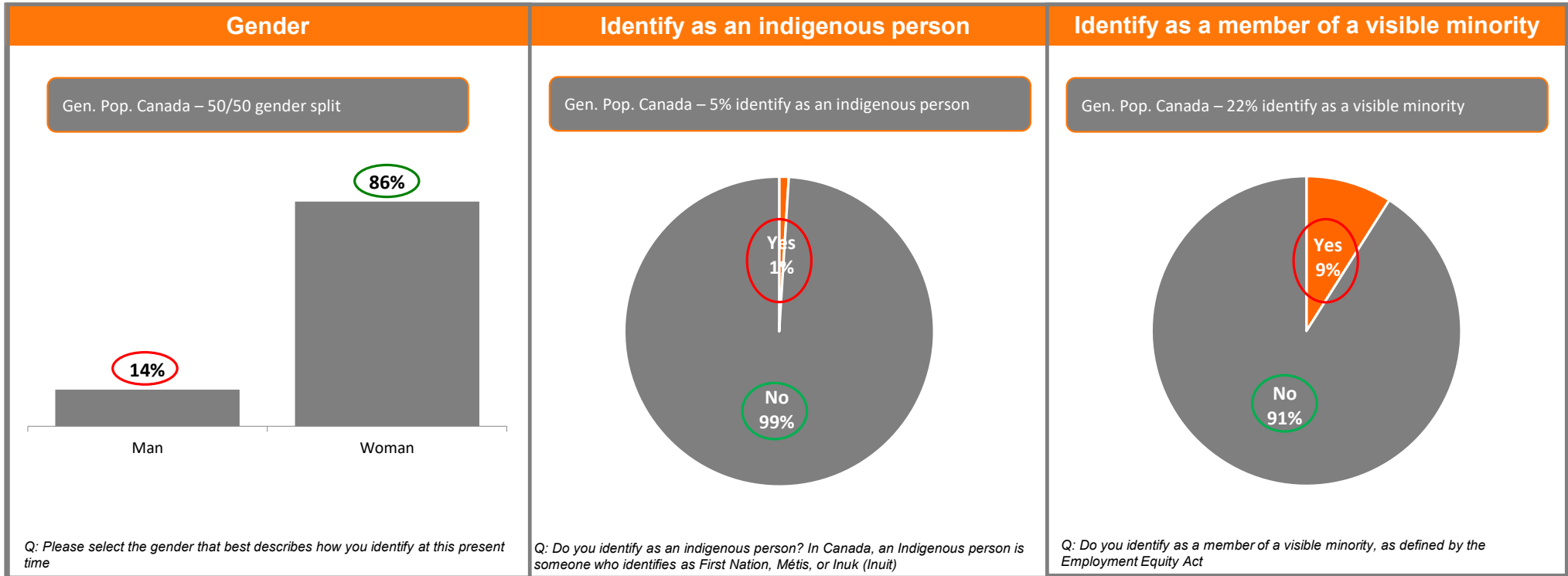
Caregiver respondents were mostly over the age of 60 and were also caring for someone over the age of 60. A majority are from Ontario and the West.



○ Indicates 2022 over-indexed vs. Canada's general population ○ Indicates 2022 under-indexed vs. Canada's general population

Caregiver Demographics 2022

Majority of caregiver respondents were women. Representation of those who identify as an indigenous person or visible minorities under-indexed versus the Canadian population.

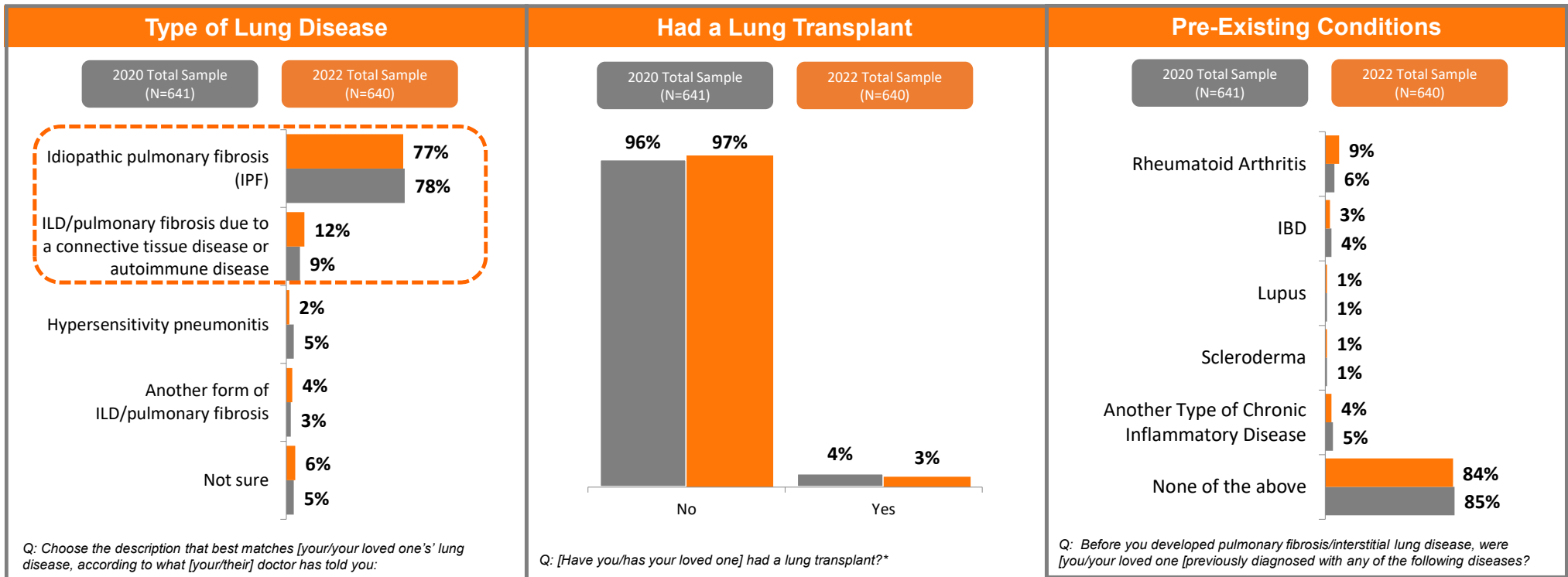


○ Indicates 2022 over-indexed vs. Canada's general population
 ○ Indicates 2022 under-indexed vs. Canada's general population

Patient & Caregiver Journey

Patient Health Overview

IPF remains the top type of lung disease among patients. ILD has seen a small increase (+3ppt) from 2020 to 2022.



Q: Choose the description that best matches [your/your loved one's] lung disease, according to what [your/their] doctor has told you:

Q: [Have you/has your loved one] had a lung transplant?*

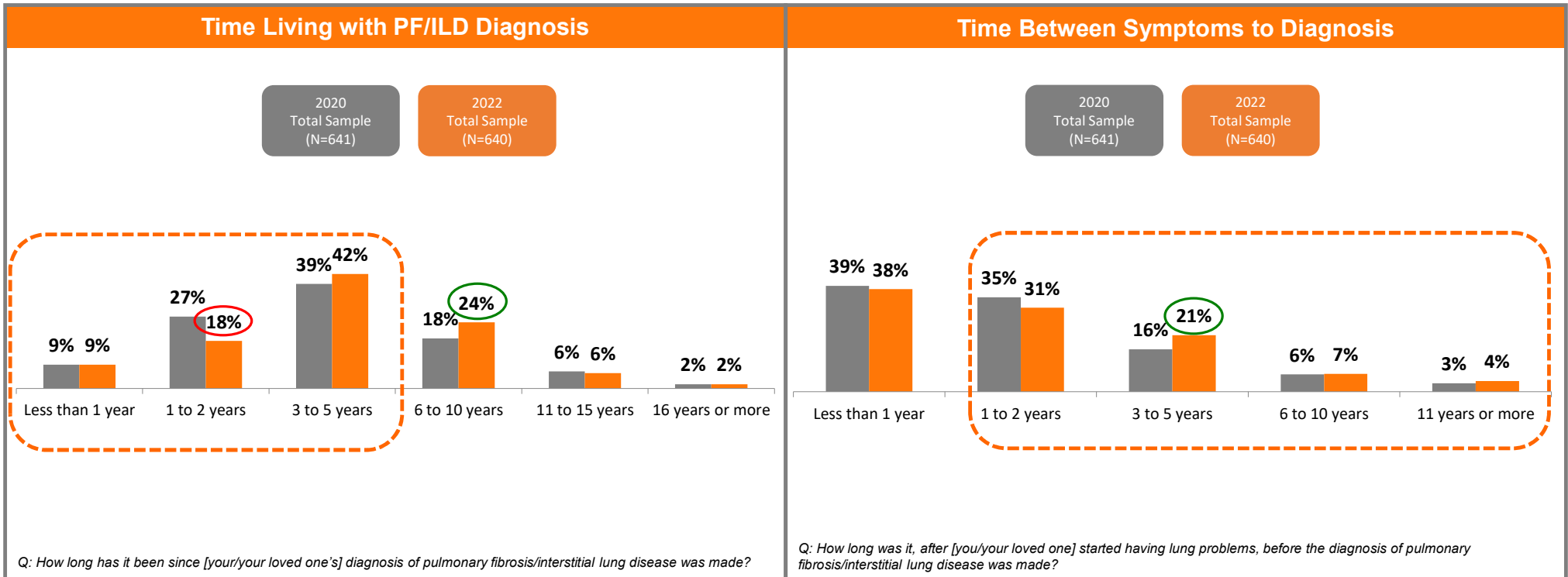
Q: Before you developed pulmonary fibrosis/interstitial lung disease, were [you/your loved one] [previously diagnosed with any of the following diseases?]

Indicates significantly higher vs. 2020

Indicates significantly lower vs. 2020

Diagnosis – Timeline

On average, patients have been living with their diagnosis for less than 5 years. Majority of patients waited a year or more to receive their diagnosis – for one-third, it took over 3 years.

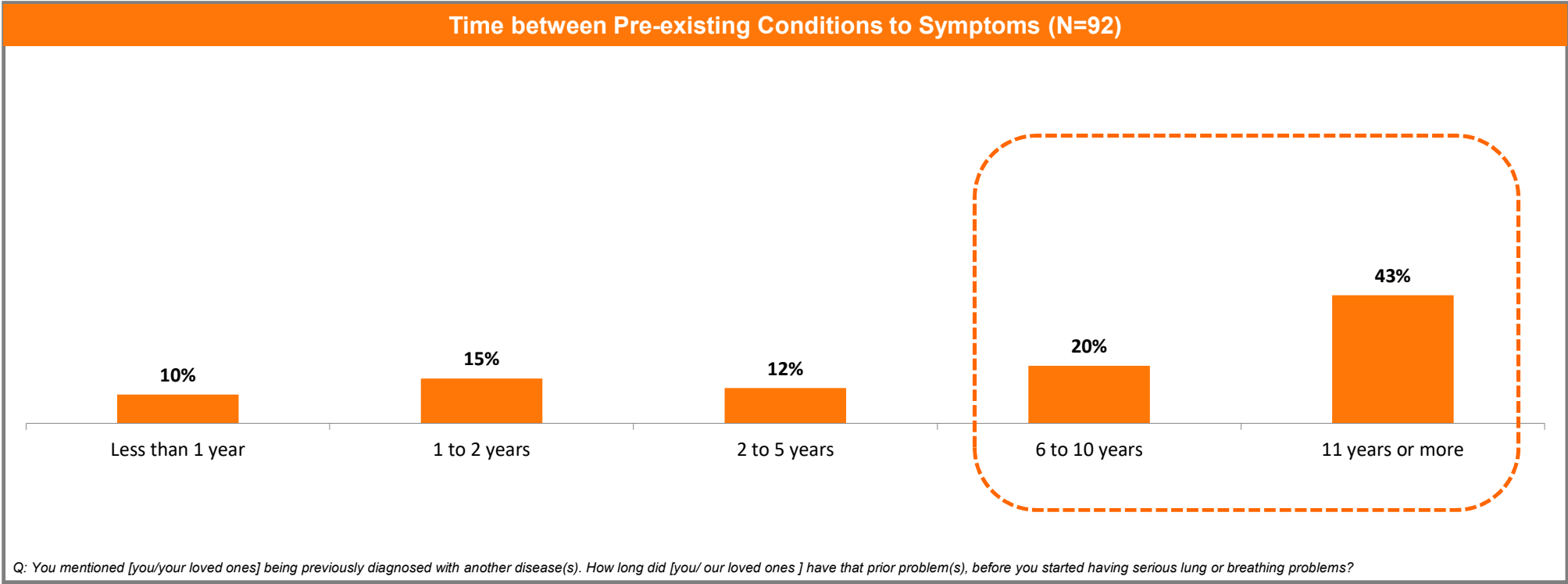


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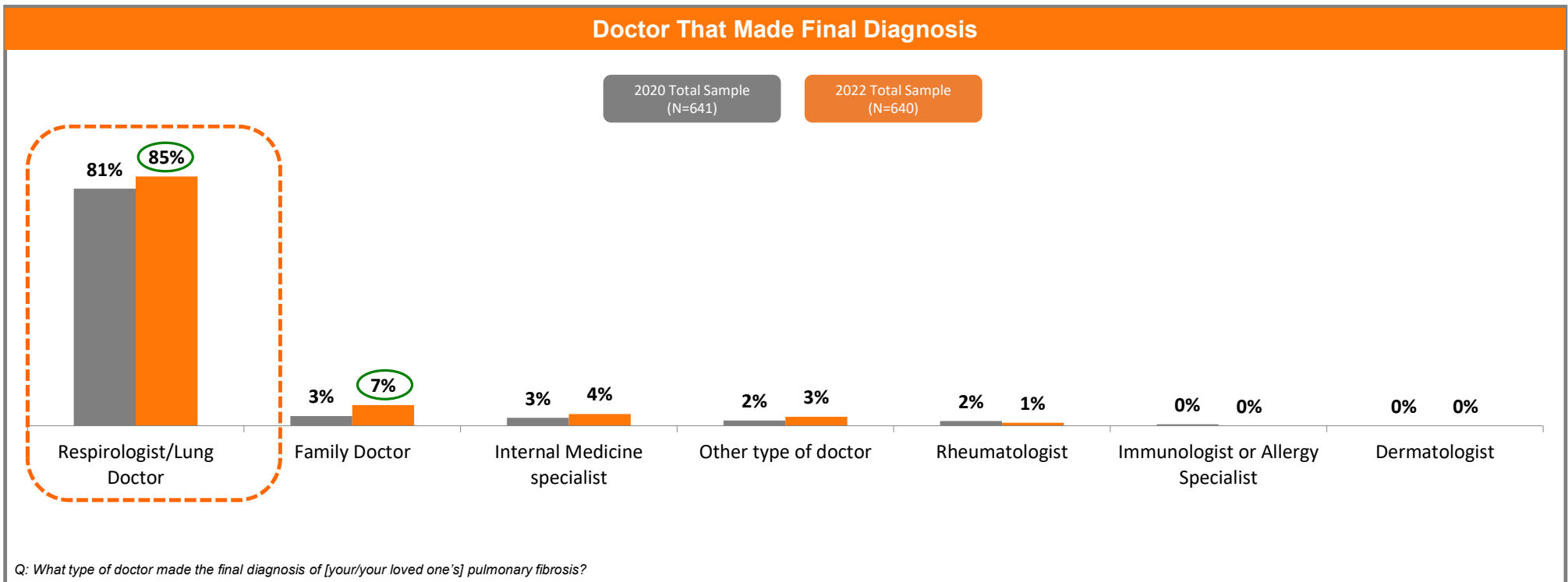
Diagnosis – Timeline

Almost two-thirds of patients had pre-existing conditions for 6 or more years before experiencing serious lung or breathing problems.



Diagnosis – Doctor Type

Respirologists/lung doctors remain the top doctor diagnosing pulmonary fibrosis.

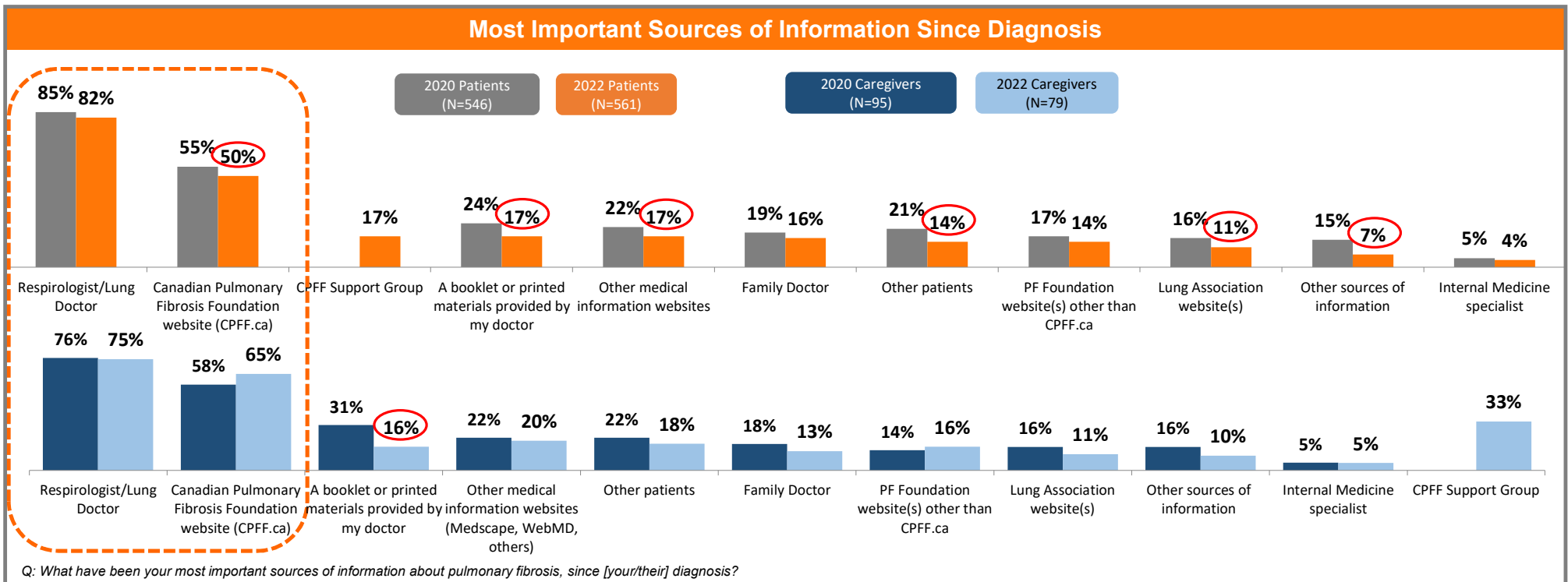


○ Indicates significantly higher vs. 2020

○ Indicates significantly lower vs. 2020

Most Important Sources of Information in 2020 vs 2022

Respirologist/Lung Doctors and the CPFF website remain the most important sources of information for both patients and caregivers.

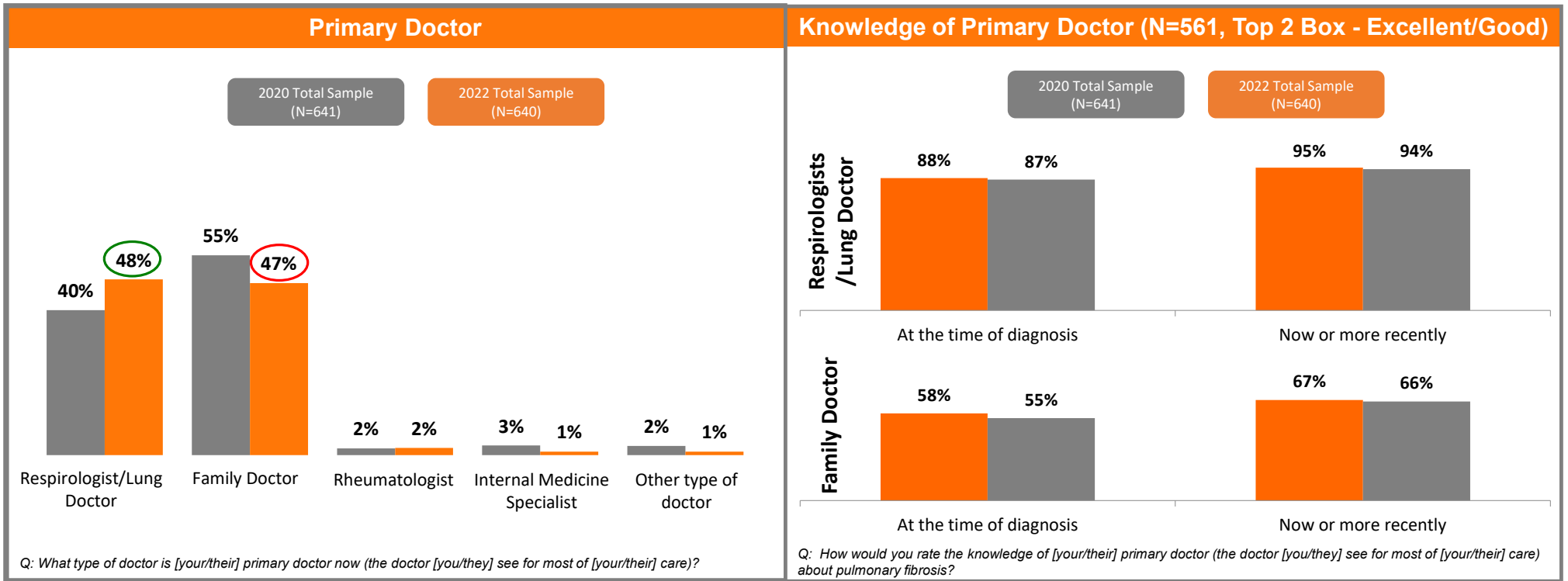


○ Indicates significantly higher vs. 2020

○ Indicates significantly lower vs. 2020

Treatments – Primary Doctor Experience

Respirologists/Lung Doctors show an increase of +8ppts in being the primary doctor from 2020 to 2022, while Family Doctors declined by -8ppts. Respirologists/Lung Doctors continue to be seen as more knowledgeable than Family Doctors.



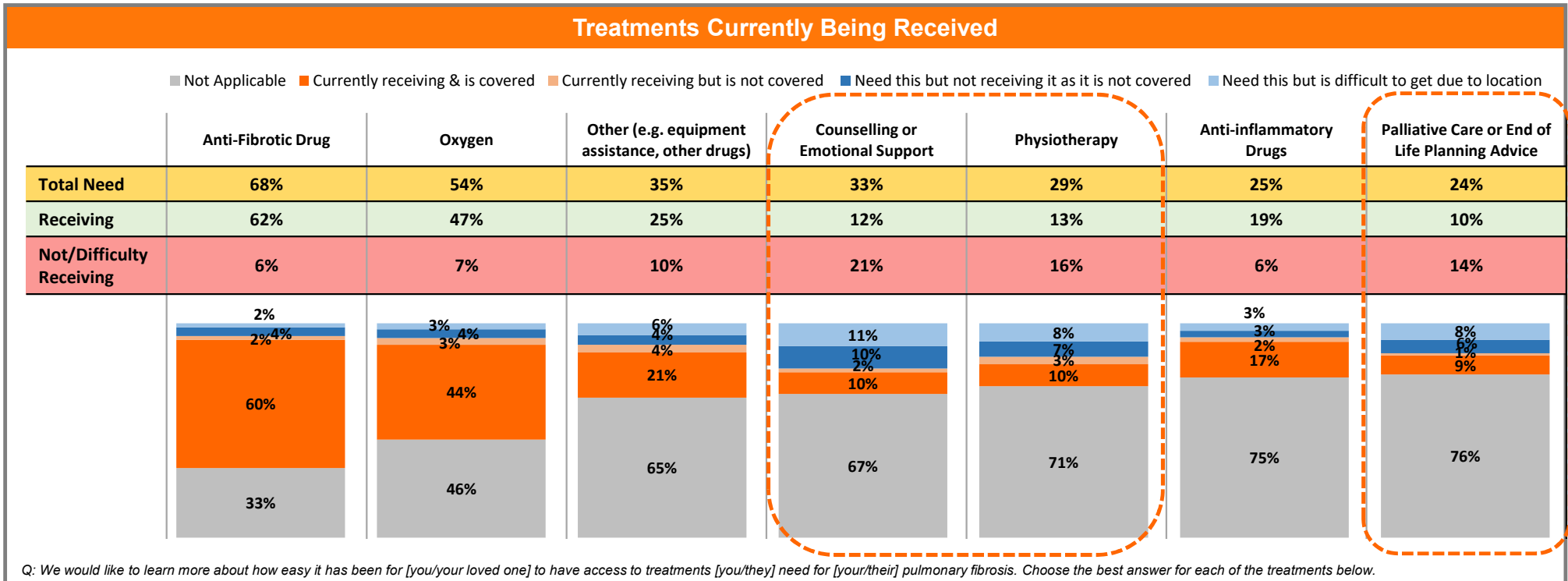
○ Indicates significantly higher vs. 2020

○ Indicates significantly lower vs. 2020

Treatments – Currently Being Received (Total Sample)

Anti-fibrotic drugs and oxygen remain the most needed treatments.

1 in 5 are in need, yet do not receive counselling/emotional support. About 1 in 6 are in need, yet do not receive physiotherapy and palliative care.



Treatments – Visible Minority & Indigenous Persons

Directionally, visible minorities show a greater need for all treatments, especially anti-fibrotic drugs, counselling/emotional support, and physiotherapy. Less than half of visible minority patients feel their current treatment/routine can manage their pulmonary fibrosis.

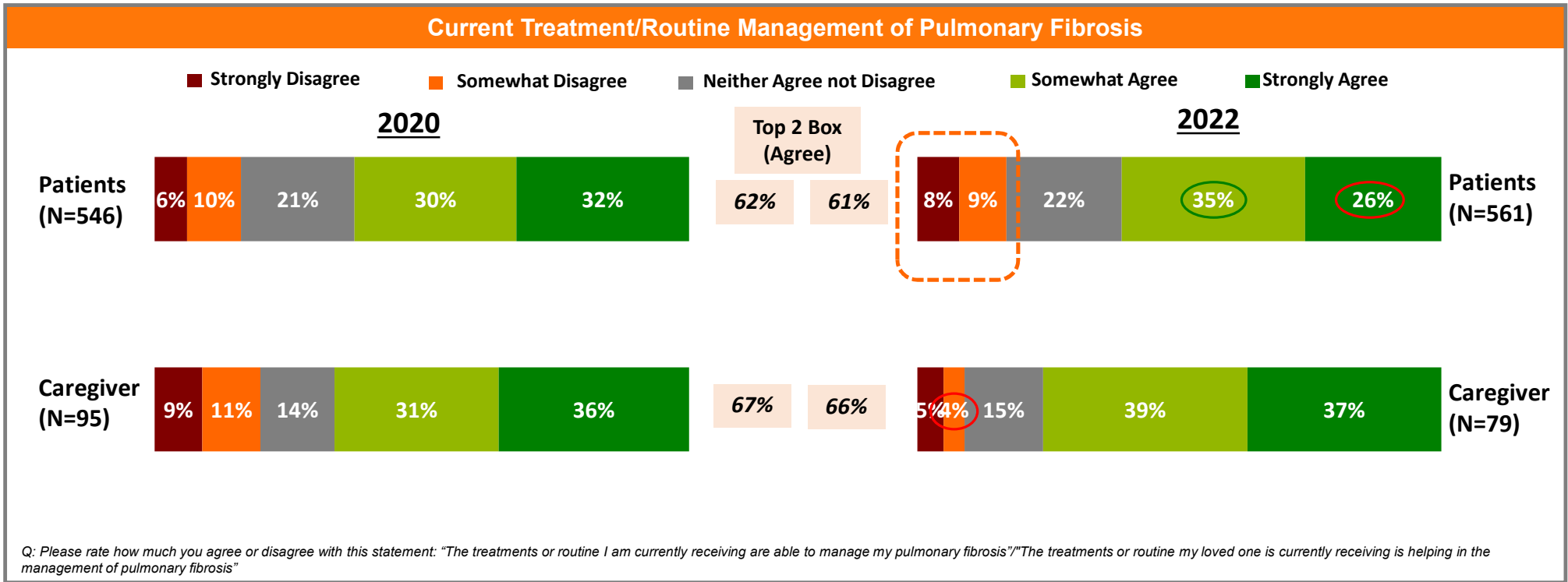
Treatments In Need Of	Total Sample (N=640)	Identify as a Visible Minority (N=39*)	Identify as an Indigenous Person (N=24*)
Anti-Fibrotic Drug	6%	18%	8%
Oxygen	7%	10%	4%
Other (e.g. equipment, assistance, other dugs)	10%	15%	4%
Counselling or Emotional Support	21%	31%	21%
Physiotherapy	16%	26%	25%
Anti-inflammatory	6%	10%	4%
Palliative Care or End of Life Planning Advice	14%	15%	4%
Effectiveness of current treatments/routine (% agree)	62%	46%	63%

** Caution: Small sample size, interpret data with caution*

Q: We would like to learn more about how easy it has been for [you/your loved one] to have access to treatments [you/they] need for [your/their] pulmonary fibrosis. Choose the best answer for each of the treatments below.

Treatments – Effectiveness

About two in ten patients do not feel their current treatment/routine can help them manage their pulmonary fibrosis.



 Indicates significantly higher vs. 2020

 Indicates significantly lower vs. 2020

Treatments – Effectiveness (Disagree)

Among respondents who don't feel their treatment is managing PF, top reasons were lack of improvement/condition getting worse, and not enough support/access to information and doctors.

Respondents who DISAGREE with the statement “The treatments or routine I/my loved one am/is currently receiving are able to manage my/their pulmonary fibrosis”



Popular Themes Mentioned:

- Lack Of Improvement/Not Stable/Getting Worse
- Not Enough Support Or Access To Information/Doctors/Specialists
- Side Effects
- Not Treated Soon Enough
- Oxygen Was The Only Helpful/Effective Treatment
- Lack Of Access/Not Prescribed

Word cloud includes words with 3+ mentions

Treatments – Effectiveness (Disagree)

Respondents who DISAGREE with the statement “The treatments or routine I/my loved one am/is currently receiving are able to manage my/their pulmonary fibrosis”

Not Enough Support Or Access To Information/Doctors/Specialists

- *“I am not managing the disease. I feel like I have to find solutions as the specialists aren't providing any information beside medication and waiting to get testing done is very discouraging.”*
- *“My Dr is not giving me any information about my condition of course”*
- *“Still waiting to see a Pulmonary Fibrosis Dr to find out what it's from and how to manage My lung Dr just said there's nothing could be done with it”*
- *“Not enough rehab support nor emotional support”*
- *“I just feel more could be done, I just feel I'm left on the wayside to struggle on my own.”*
- *“I haven't seen the right specialist for my pulmonary fibrosis”*
- *“The doctor told me there is no treatment of my diseases.”*
- *“So far there has been no support emotionally. Also I requested lung physiotherapy a year ago”*
- *“Believe I am in decline and have no idea of “what's Next”. Ongoing support is very sketchy. Little or no contact between 6 month check ups.”*

Lack Of Improvement/Not Stable/Getting Worse

- *“The oxygen therapy was helpful but no drug treatments were effective.”*
- *“Medication and oxygen supply do not have a big positive impact as expected”*
- *“Atropine is not very effective, cellcept stopped being effective.”*
- *“I'm only on Sybicort at the moment not helping to well and was not able to see my specialist for a year due to testing waiting”*
- *“I am not able to manage my PF it is worsening and I am in hospital and I want to be put in palliative care.”*

Side Effects

- *“All available treatments have been tried and the side affects are worse than the disease itself.”*
- *“My digestive system cannot handle the harder drugs. I would be on the toilet and in digestive agony 24/7”*
- *“Side effects are debilitating”*
- *“OFEV side effects have left me unable to try new therapies, and I cannot take anti-inflammatory meds because of OFEV's damage to my kidneys”*

Treatments – Effectiveness (Disagree)

Respondents who DISAGREE with the statement “The treatments or routine I/my loved one am/is currently receiving are able to manage my/their pulmonary fibrosis”

Not Treated Soon Enough

- *“treatment didn't come soon enough. My husband slipped through the cracks because of COVID”*
- *“I scored low on this because by the time we found out that my father had IPF it was too late. His earlier diagnosis was overlooked.”*

Oxygen Was The Only Helpful/Effective Treatment

- *“The oxygen therapy was helpful but no drug treatments were effective”*
- *“medications did not help except for oxygen”*

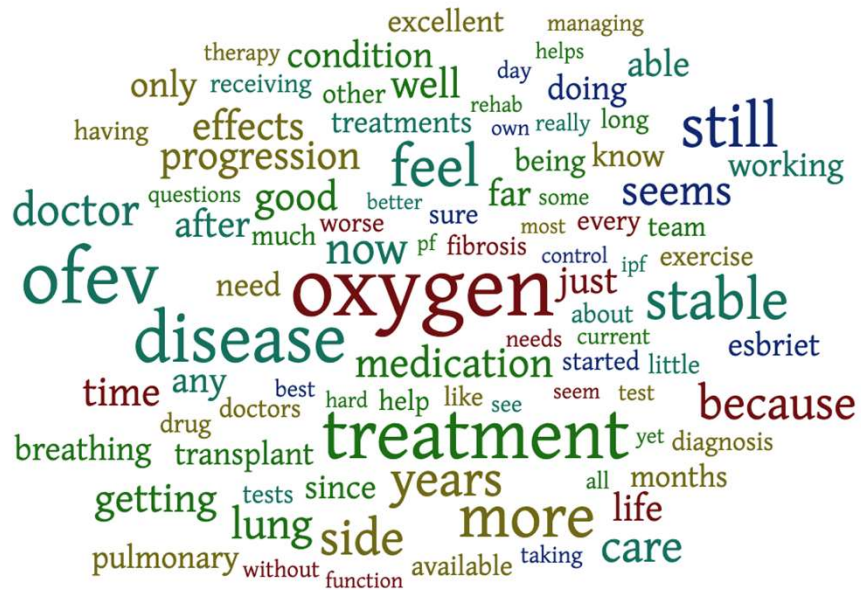
Lack Of Access/Not Prescribed

- *“My local respirologist wrote me a prescription for Oxygen this morning but it is not in place yet.”*
- *“I have tried to advocate for more oxygen cylinders (5 more biweekly)”*
- *“I have not yet been prescribed OFEV or Espreit”*
- *“I am on prednisone and waiting to start OFEV”*
- *“I have not received the drug (ofev) yet.”*
- *“I do not receive treatment or medication”*

Treatments – Effectiveness (Agree)

Among respondents who feel their treatment is managing their PF top reasons were good support/confidence in their healthcare team, felt their symptoms were being managed or that their PF was improving or slowing.

Respondents who AGREE with the statement “The treatments or routine I/my loved one am/is currently receiving are able to manage my/their pulmonary fibrosis”



Popular Themes Mentioned:

- Good Support/Confidence In Healthcare Team
- Controlling/Managing Symptoms/Improving Life
- PF Improving or Disease Not Progressing
- Oxygen Is Accessible And Helpful
- Specific Medications/Treatments Being Used (e.g. OFEV, Esbriet)

Word cloud includes words with 8+ mentions

Treatments – Effectiveness (Agree)

Respondents who AGREE with the statement “The treatments or routine I/my loved one am/is currently receiving are able to manage my/their pulmonary fibrosis”

Good Support/Confidence In Healthcare Team

- *“When we were followed before transplant the pneumologist the was amazing. He helped us understand treatment options and would answer our calls when it was more difficult, even called post transplant to see how we were managing.”*
- *“Excellent palliative care team. Regular follow-up visits with physician and team. Regular assessment by both health care providers and supplementary oxygen provider.”*
- *“The Respirologist, who is looking after me is very conscientious and constantly monitors my situation. As well, I am confident that I can call him at any time if I have any concerns.”*
- *“We feel our Lung Specialist is exceptional and is on top of every aspect of this insidious disease”*
- *“I have a very good doctor and with the program I am on feel I am very well looked after”*
- *“The Drs involved in care are open to questions and discussions whenever we need them. Also the patient support group helps with understanding and coping with management. I anticipate additional resources as things progress will also be available.”*
- *“He is getting the best care possible”*

Controlling/Managing Symptoms/Improving Life

- *“Oxygen enables him to continue doing some physical work to allow him to feel as normal as possible”*
- *“Without oxygen my husband wouldn’t be able to cope ”*
- *“the oxygen and exercise rehab has made such a difference into the quality of life. “*
- *“I’m able to do most things without a problem although I tire doing anything strenuous.”*
- *“I can now sleep through the night”*

PF Improving or Disease Not Progressing

- *“Because the treatments are helping and strongly agree that is what is needed or appropriate.”*
- *“Esbriet seems to be effective in slowing progression of my IPF.”*
- *“He is presently taking Ofev and upon diagnosis was given a life expectancy of 3-5 years and so far it has been 4 1/2 years since diagnosis and he still has not required any oxygen. He sees his pulmonologist on a regular basis and usually has PPF tests and 6 minute walk test every 6 months.”*
- *“Ofev has helped delay PF hugely, despite its side affects”*
- *“OFEV seems to be slowing the IPF progression”*

Treatments – Effectiveness (Agree)

Respondents who AGREE with the statement “The treatments or routine I/my loved one am/is currently receiving are able to manage my/their pulmonary fibrosis”

Oxygen Is Accessible And Helpful

- *“I am well supported by my Doctors and the oxygen supplier”*
- *“I was previously below 30% lung capacity and ;on exertional oxygen but am up to 45%and don't need oxy any more”*
- *“The oxygen therapy I am currently on does allow me to do a number of activities and have a relative normal lifestyle”*
- *“My only "treatment" is the occasional use of oxygen for activities such as longer walks and cutting of grass-and the mobile equipment I have handles that.”*
- *“Oxygen enables him to continue doing some physical work to allow him to feel as normal as possible”*

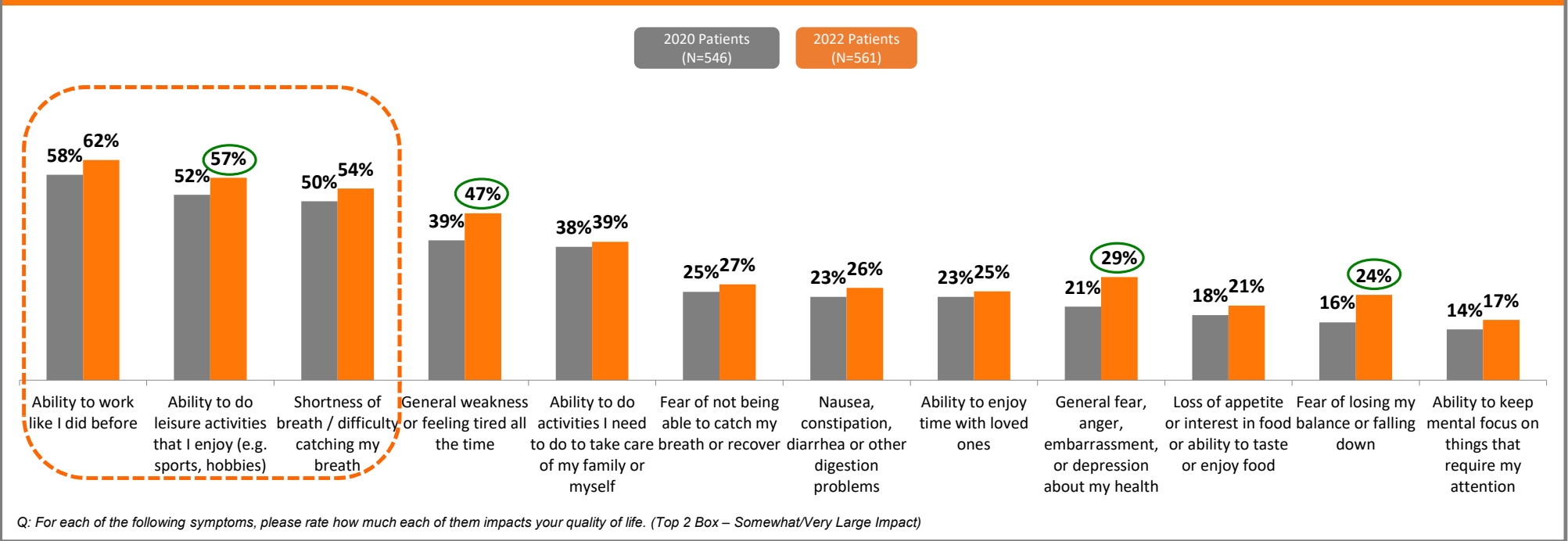
Specific Medications/Treatments Being Used (e.g. OFEV, Esbriet)

- *“Ofev has helped delay PF hugely, despite its side affects”*
- *“OFEV seems to be slowing the IPF progression”*
- *“We believe the medication while awful for side affects is working.”*
- *“I have been really stable on Ofev 150 in the morning and 100 in the evening. Actually my pulmonary function test has slightly improved. Really feel quite healthy.”*
- *“I am receiving Esbriet and there has been little downwards progression of my disease over the last 3 years”*
- *“My IFP has been stable since being on pirfenidone and my respirologist reviews current test results to previous years. I am to let her know immediately if there any sudden changes.”*
- *“Using Esbriet, am stable for 5 years, not on oxygen”*
- *“The medication I am taking has reduced the rate of deterioration of my breathing capability.”*
- *“Teva- Mycophenolate appears to be slowing the progression.”*
- *“My mom is too frail to receive OFEV or Esbriet because of their side effects. Taking chemo like drug that has halted the progression (which is great) but puts her at risk for cancers which she’s had 2 tumors removed in the last few years.”*
- *“Has been on mycophenolate for a year and has had a slight improvement.”*

Impact on Life – Patient Symptoms

Ability to work like before and do leisure activities remain the top areas impacted by symptoms. Ability to do leisure activities, general weakness, fear/anger/embarrassment/depression, and fear of losing balance/falling down all increased from 2020 to 2022.

Symptom Impact on Quality of Life (Top 2 Box – Somewhat/Very Large Impact)

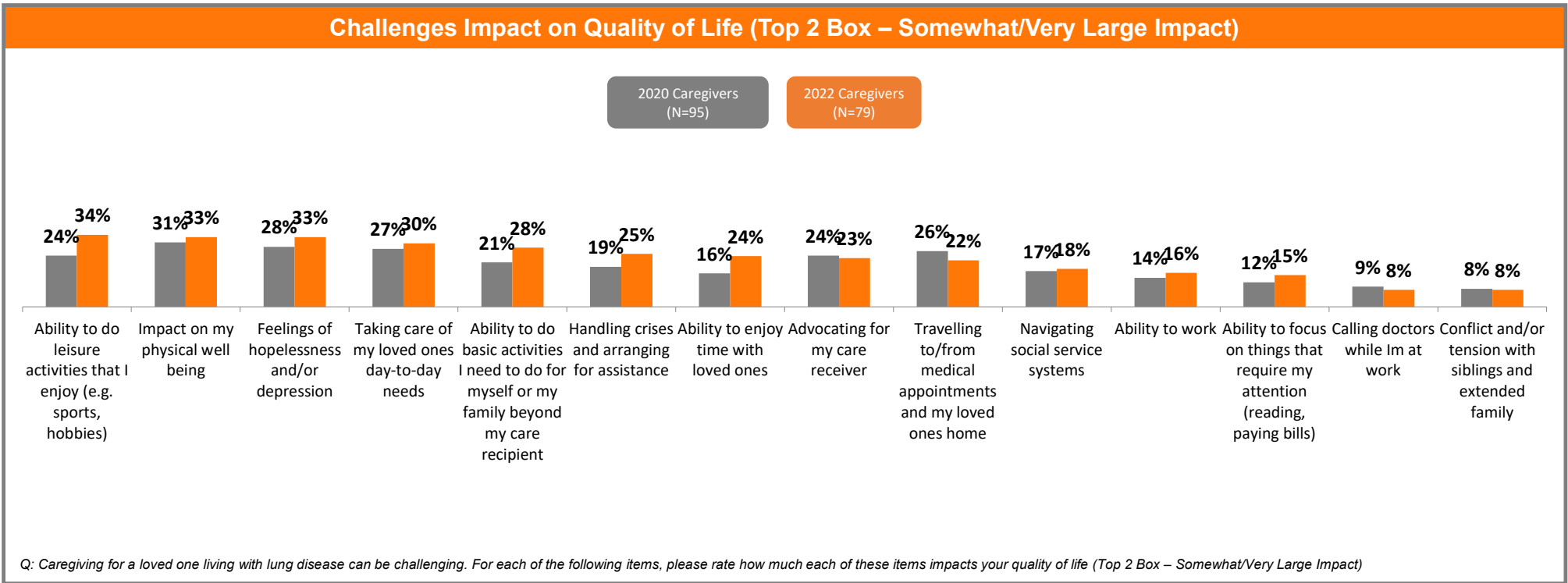


○ Indicates significantly higher vs. 2020

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Impact on Life – Caregiver Challenges

Top caregiver challenges include ability to do leisure activities, physical well being, feeling hopeless and/or depression, and taking care of her/his loved one daily needs.

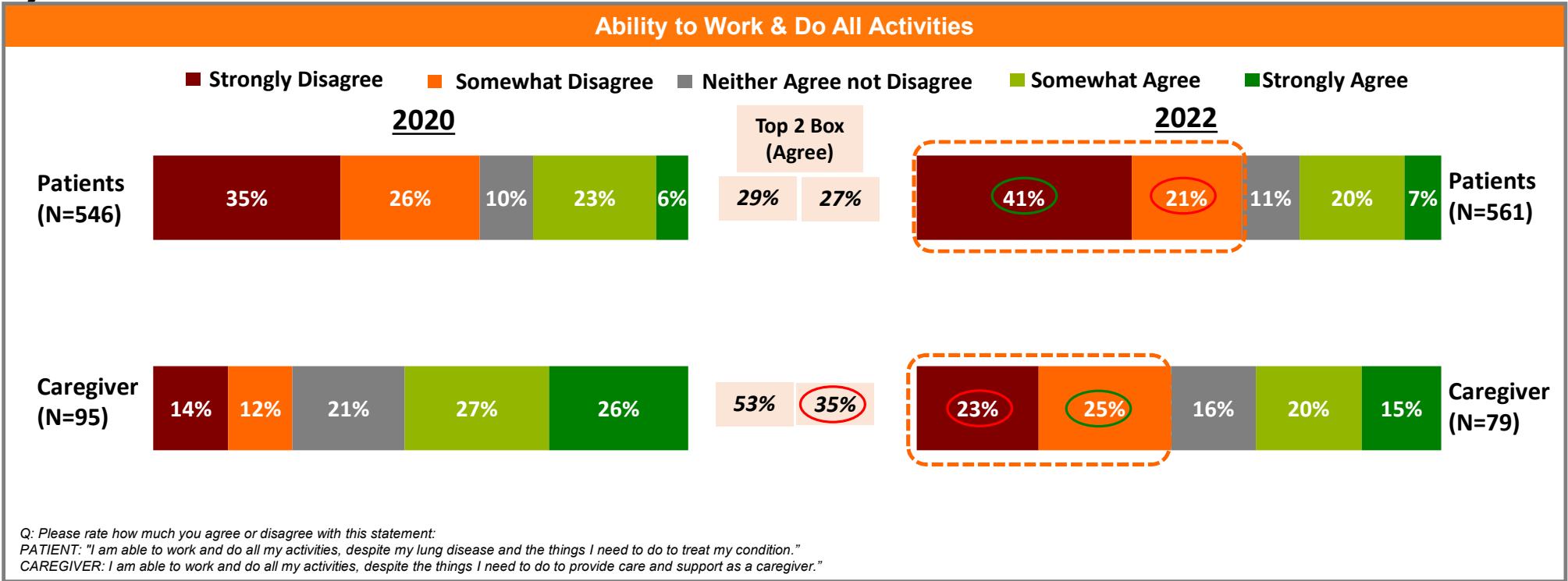


○ Indicates significantly higher vs. 2020

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Impact on Life – Work & Activities

Caregivers experienced a decline in their ability to work and do activities – about half do not feel that they are able to work and do all their activities. About 6 in 10 patients also do not feel that they are able to do all of their activities and work.

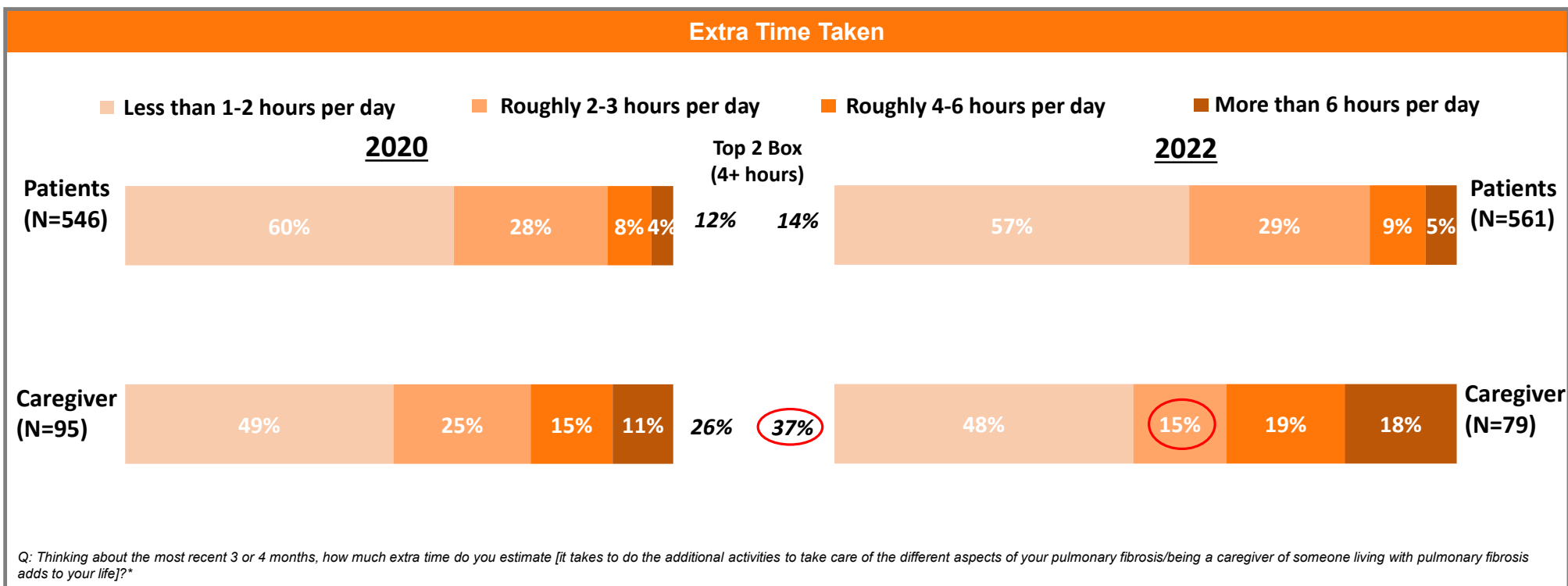


 Indicates significantly higher vs. 2020

 Indicates significantly lower vs. 2020

Impact on Life – Extra Time

Four in ten patients take 2+ hours per day to care for their PF, while that increases to about half of caregivers who take 2+ hours per day. The number of caregivers who spend 4+ hours per day has increased by +11ppts.

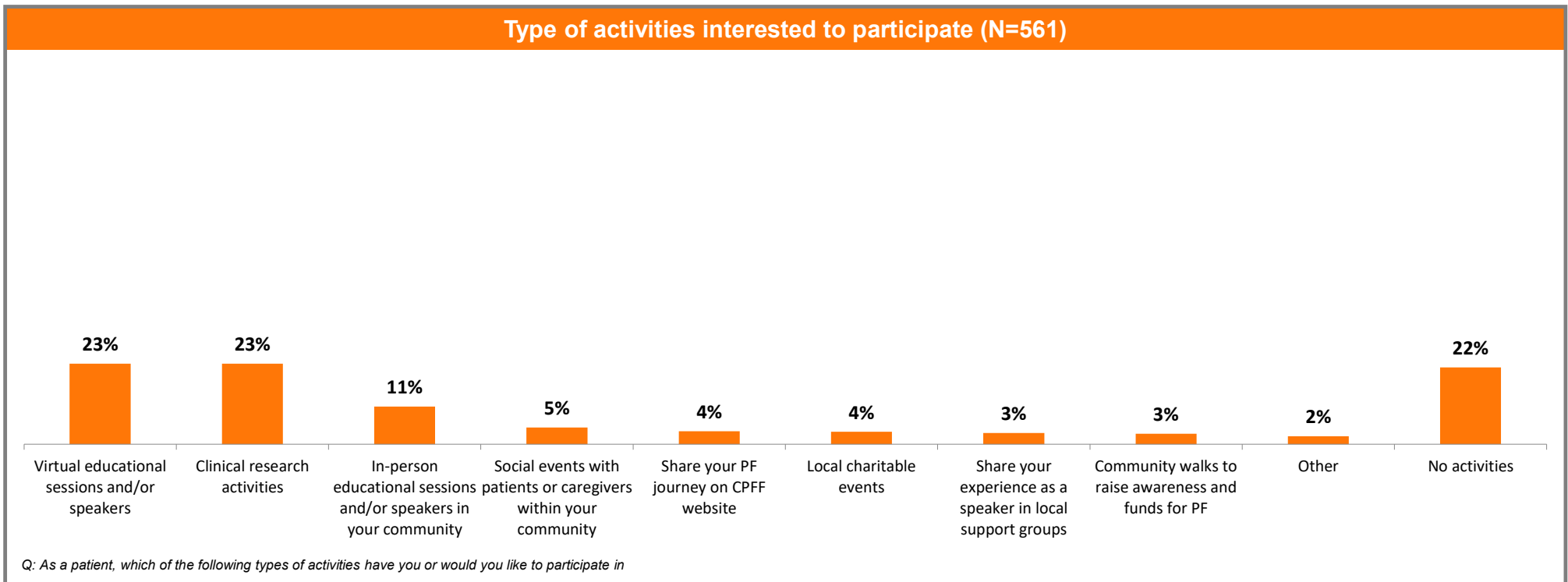


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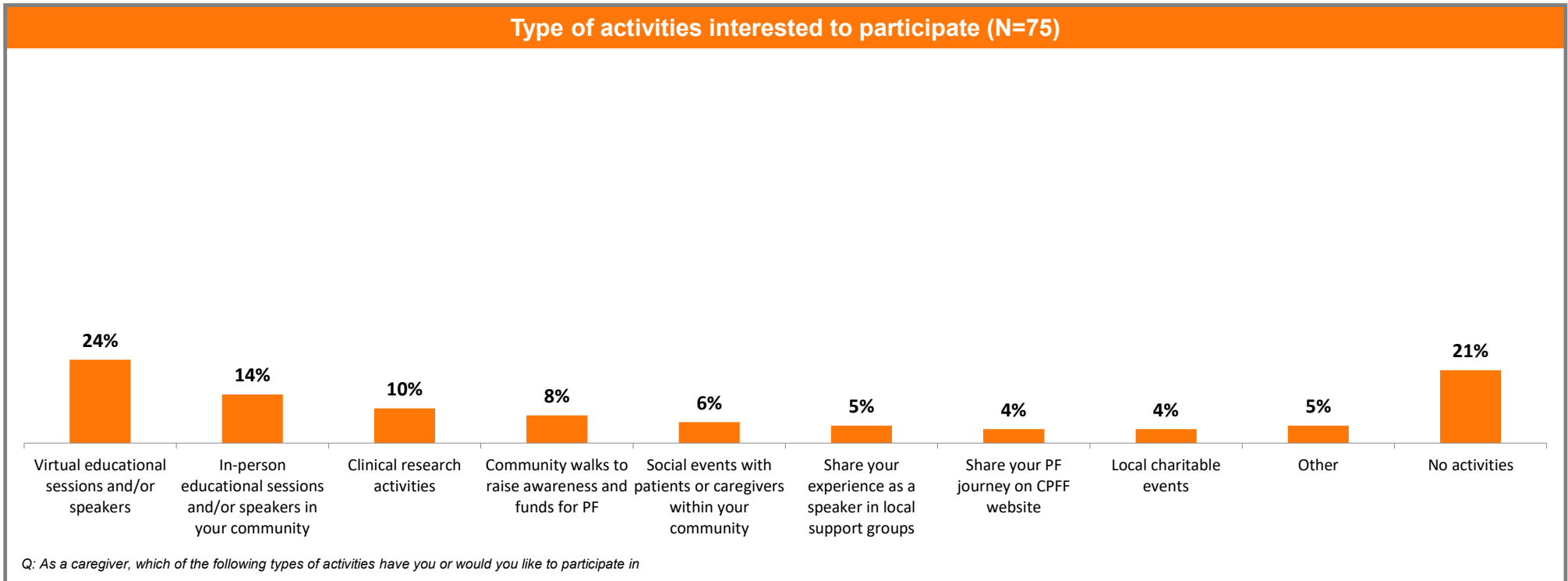
Patients Interest in Activities

About 4 in 5 patients are interested in participating in an activity. Virtual education sessions/speakers and clinical research activities are their top choices.



Caregiver Interest in Activities

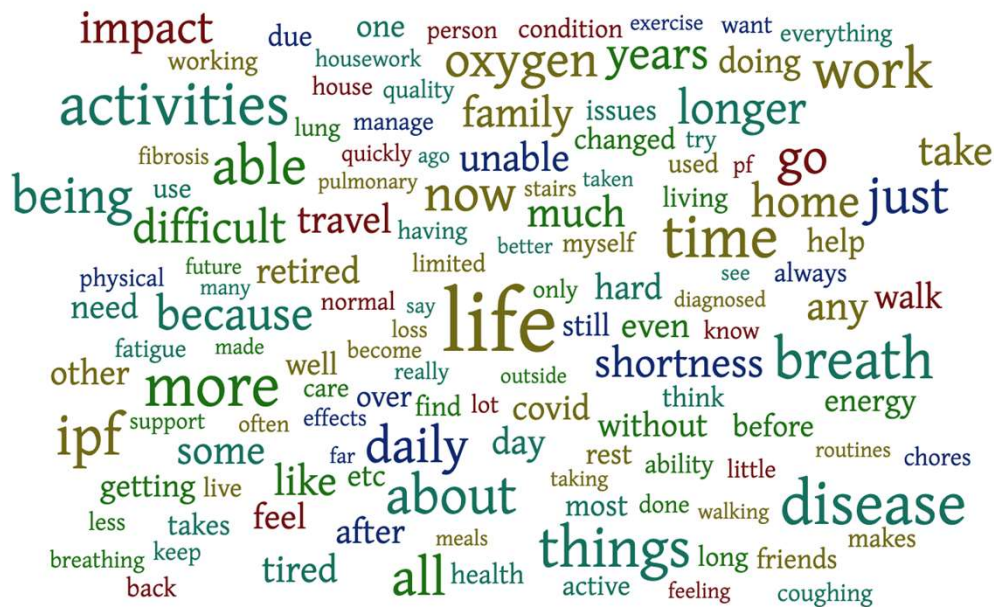
About 4 in 5 caregivers are interested in participating in an activity. Virtual education sessions/speakers are their top choices.



Patient Life Impact

Top life areas impacted by PF were limited activities, staying at home, and physical impact of symptoms.

Q: Are there other comments about your pulmonary fibrosis that you would like to add about how living with this disease has impacted your life and daily routines, both at work and at home?



Popular Themes Mentioned:

- Doing Limited Activities/Taking More Time To Do A Task/Less Active Overall
- Having To Stay At Home/Miss Out
- Impact of Symptoms (i.e. Loss of Strength, Shortness Of Breath, Tired Easily, Constant Coughing)

Word cloud includes words with 9+ mentions

Patient Life Impact

Q: Are there other comments about your pulmonary fibrosis that you would like to add about how living with this disease has impacted your life and daily routines, both at work and at home?

Doing Limited Activities/Taking More Time To Do A Task/Less Active Overall

- *"Lack of energy, limited to very small list of activities, unable to do household chores like cut the grass."*
- *"PF has restricted me to my home. I have very limited energy. I went from working, playing tennis, doing all daily activities to barely being able to walk to my back yard or even taking a shower without gasping for air. I am very limited."*
- *"It has taken away any spontaneous activities. All need to be planned..."*
- *"This is a cruel disease. I loved to go on long walks etc. I was quite active. Now I can't make the bed or vacuum with out being out of breath. I can't go places with my grandkids. I can do art and anything that doesn't require much movement. I worry about my oxygen when we do go out. We can go for drives and out to eat."*

Having To Stay At Home/Miss Out

- *"I am limited to do activities outside my home as I am dependent on my oxygen. I have 1 hour a day. If I go food shopping that's my 1 hour. I also have to rush as I need oxygen to get from my vehicle to my condo."*
- *"I miss frequent social activities with family and friends although I so far am seeing as often as possible"*
- *"I am not able to do any house or yard work, tired and depressed that I mostly have to stay in my home and am not able to function as I did before this disease"*

Impact of Symptoms (i.e. Loss of Strength, Shortness Of Breath, Tired Easily, Constant Coughing)

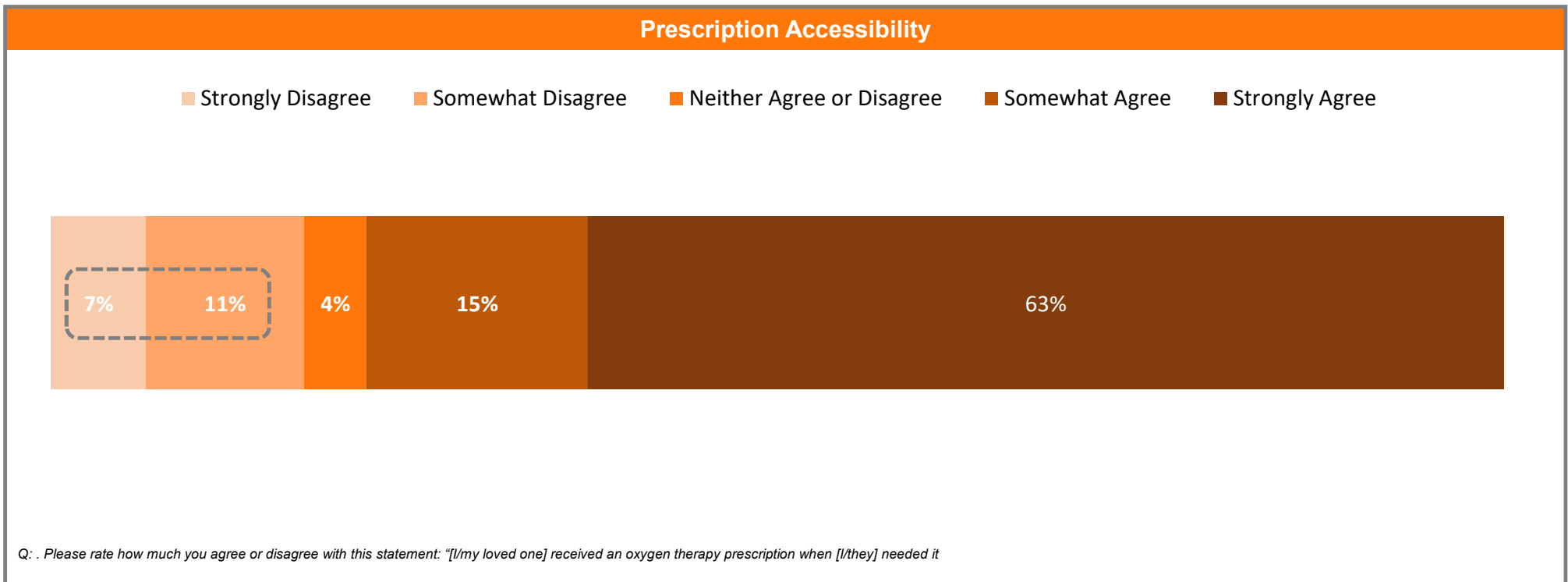
- *"It has left me feeling useless. I have no strength to do things."*
- *"I cannot do anything that takes energy or is strenuous."*
- *"Shortness of breath has resulted in being unable to do some heavy or brisk activities. I have also started feeling weak and also losing muscle and weight. These do affect my mental state at times."*
- *"The biggest impact of my NSIP has been the decrease in my breathing capacity which has significantly reduced my ability for physical activities."*
- *"I have now resigned (Retired) from my work (Employment) because of the in-ability to communicate without breaking into uncontrollable coughing and not enough strength to do the daily tasks required by my daily work."*
- *"The cough and shortness of breath make for social anxiety in mixing with others in social circumstance."*

Word cloud includes words with 9+ mentions

Oxygen & Support

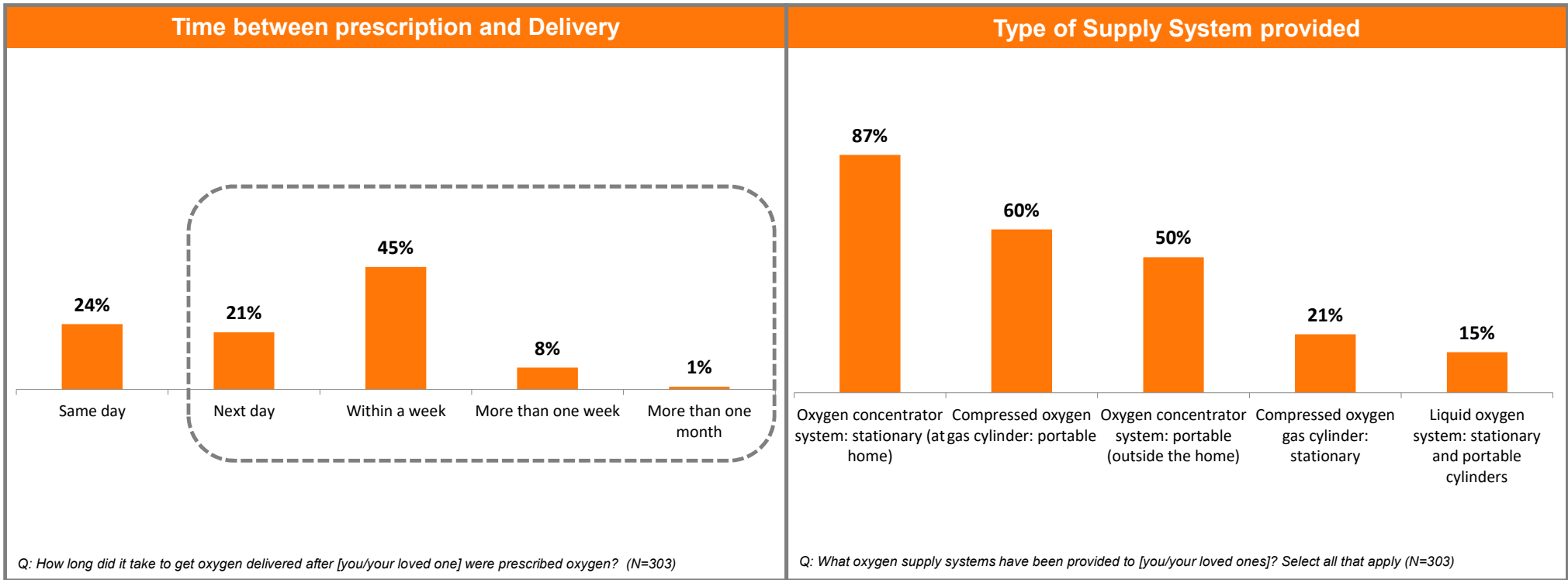
Oxygen Therapy – Prescription Availability

About 1 in 5 of patients were unable to receive an oxygen therapy prescription when needed.



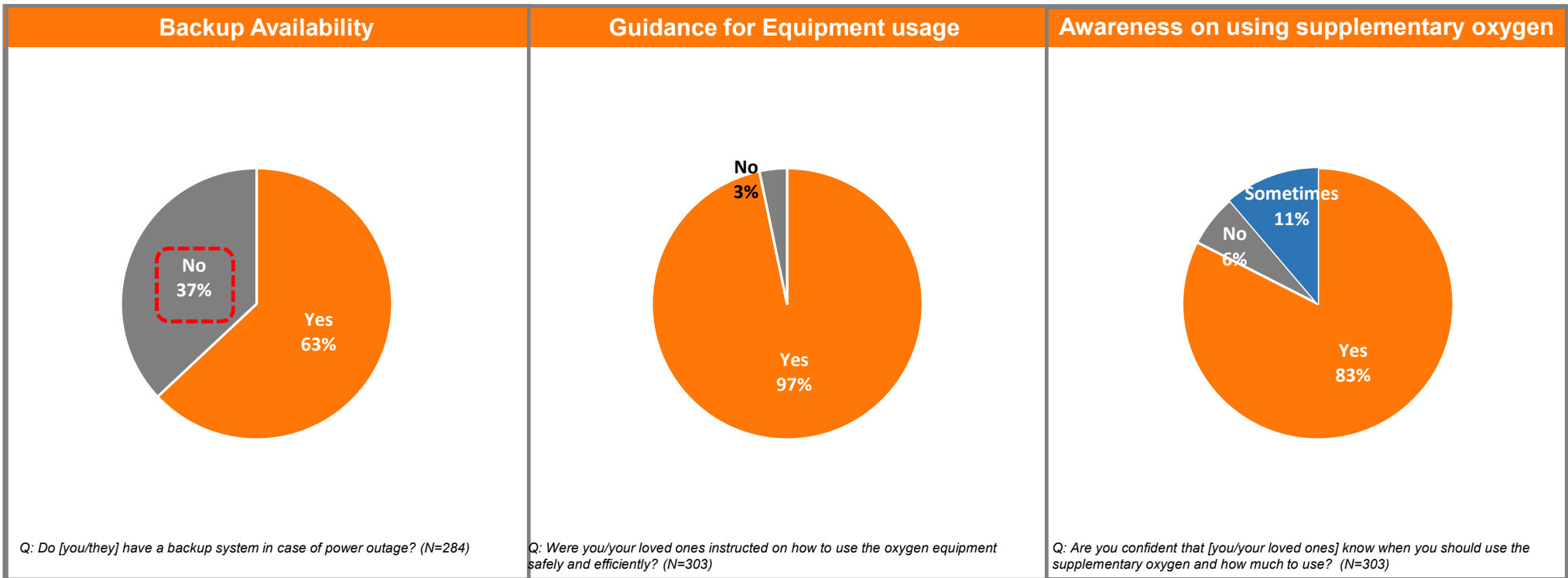
Oxygen Support – Delivery and Supply System

Three-quarters of patients did not receive their oxygen the same day as prescribed, and over half had to wait a week or more. Most were provided a stationary oxygen concentrator system.



Oxygen – Backup and Usage Awareness

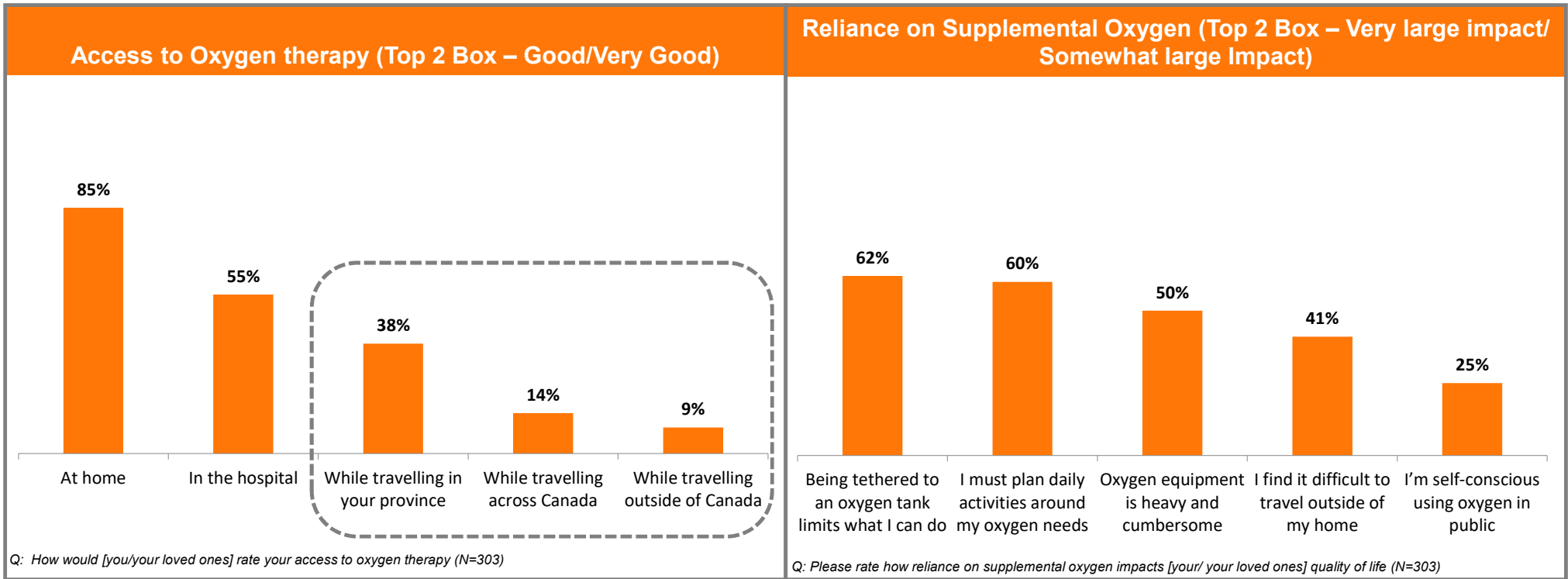
Over one-third do not have a backup system in case of power outage. Almost all were instructed on how to use the oxygen equipment. About 1 in 5 are not fully confident they know when and/how much to use.



Oxygen Needs – Access and Reliability

Access to oxygen at home is high, however it drops significantly when travelling.

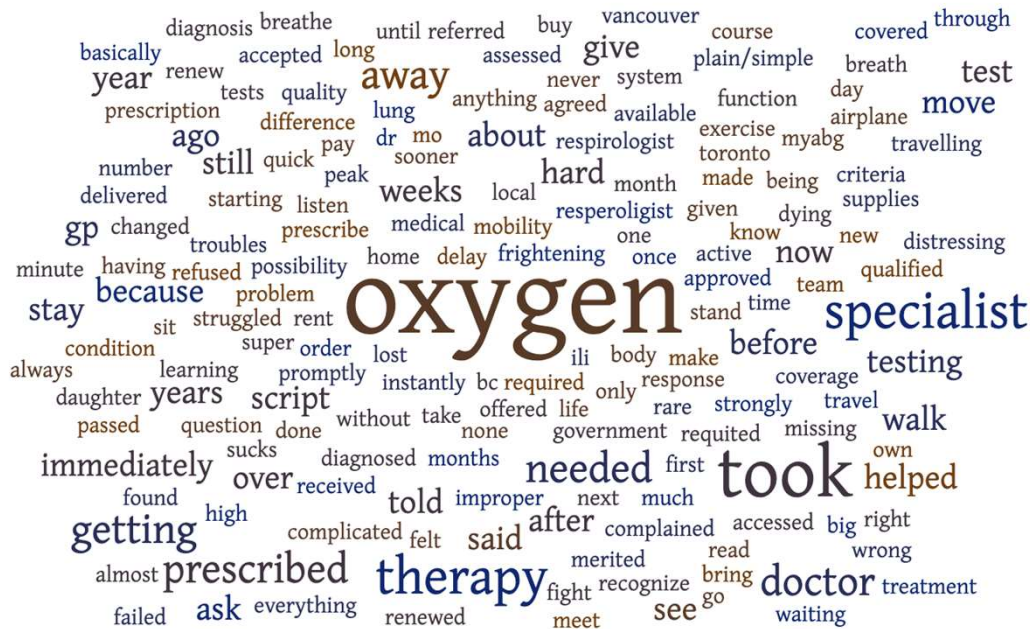
About six-in-ten feel their reliance on supplemental oxygen has a large impact on their quality of life.



Access To Oxygen Therapy – Disagree

Among those who did not receive oxygen therapy when needed, top reasons were because it took too much time/effort, difficulty qualifying, or the need was not recognized by their doctor.

Respondents who DISAGREE with the statement “I received an oxygen therapy prescription when I needed it”



Popular Themes Mentioned:

- Took Too Much Time/Effort To Access Due To Testing And/or Medical System Delays
- Difficulty Qualifying
- Severity Of Need Not Recognized By Doctor

Access To Oxygen Therapy – Disagree

Respondents who DISAGREE with the statement “I received an oxygen therapy prescription when I needed it”

Took Too Much Time/Effort To Access Due To Appointment, Testing And/or Medical System Delays

- *“It took a year for it to go through”*
- *“I had to fight to get oxygen supplies.”*
- *“Had to ask the specialist but only prescribed for travelling now waiting to get a prescription but won't give until lung function test.”*
- *“It took the medical system one year to get the testing done so I could get oxygen”*
- *“Delay getting in to see respirologist”*

Difficulty Qualifying/Not Covered By Insurance

- *“Couldn't do anything, body was missing oxygen and when you see the doctor they ask not to move and stay home because it's not covered.... Basically if you're not dying they don't give it to you..... To get it and pay was also super complicated.....”*
- *“Dr. said I needed oxygen government said no.”*
- *“had a hard time getting qualified for oxygen because of improper testing”*

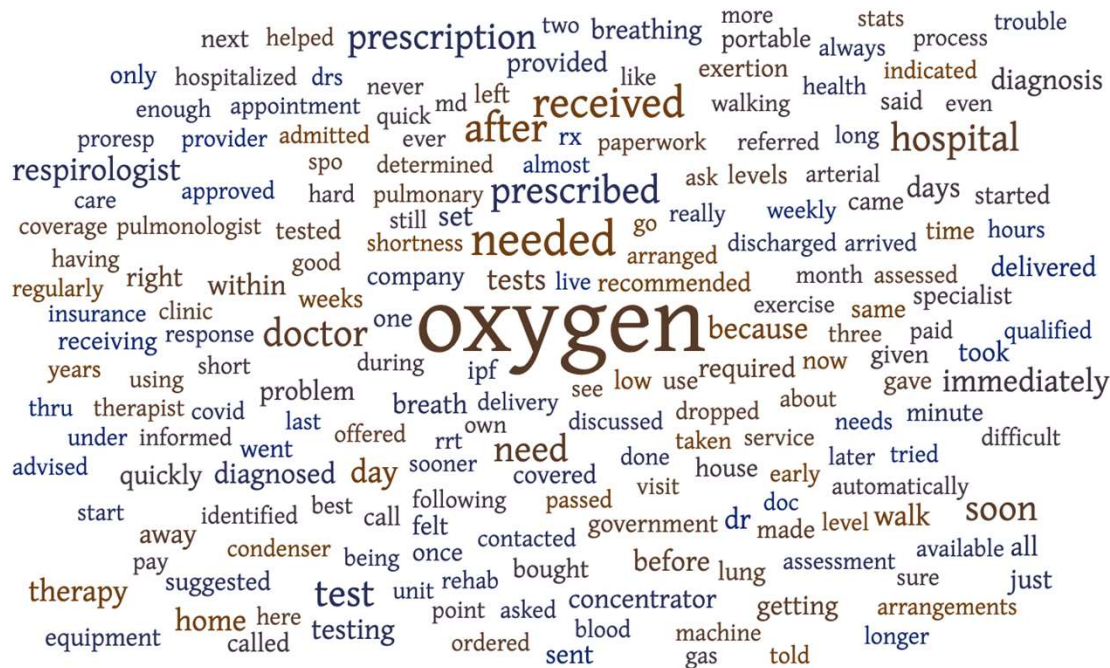
Severity Of Need Not Recognized By Doctor

- *“I didn't get a 6 minute walk test when I complained about being out of breath. I had to bring up the possibility of oxygen.”*
- *“Local respirologist refused to renew my script. Almost lost coverage. Took over a month to get script renewed.”*
- *“My first GP didn't recognize how ill I was so I changed GP and I was then referred to my now specialist.”*

Access To Oxygen Therapy – Agree

Among those who received oxygen therapy when needed, top reasons are they received it promptly, the medical system worked quickly, and payment was covered.

Respondents who AGREE with the statement “I received an oxygen therapy prescription when I needed it”



Popular Themes Mentioned:

- Received It Promptly/When I Needed It
- Medical System Worked Together/Quickly
- Payment Coverage

Word cloud includes words with 2+ mentions

Access To Oxygen Therapy – Agree

Respondents who AGREE with the statement “I received an oxygen therapy prescription when I needed it”

Received It Promptly/When I Needed It

- *“Came home it was there after 4 days in hospital”*
- *“I was given my RX for oxygen as soon as the 6 minute walk indicated I needed it .” After been diagnostic I get the oxygen in 3 days”*
- *“The oxygen service was provided the next day after I came home from the hospital”*
- *“Was given oxygen therapy as soon as my stats dropped into danger zone.”*
- *“Went for a breathing test and they set me up within a few days”*
- *“Called my doctor and three hours later I had the oxygen delivered to my house.”*

Medical System Worked Together/Quickly

- *“Pulmonologist and health region RT identified need and med system set in motion (testing for breathing capacity) then enrolled and received. Move to 24/7 O2 also required testing, which was hard to manage - just getting to & getting. Good now”*
- *“I had a breathing & walking test at our hospital & received oxygen in a couple of days. They were right on the ball.”*
- *“My SpO2 level dropped significantly in my last 6MWT. Then, with Oxygen, my level was maintained at 95%+ on a shortened test so RRT recommended Oxygen to my Respirologist and he wrote the Rx and sent it back to the RRT who forwarded it to Oxygen.”*

Payment Coverage

- *“I was prepared to pay for it but only paid one month before test verified coverage criteria”*
- *“When the Firestone Clinic specified my need for oxygen, it was immediately available at no out-of-pocket cost.”*
- *“When the lung Dr said I needed o² I got it right away and it has always been covered”*
- *“It is fully covered under Saskatchewan health authority”*

Improve Oxygen Therapy

“In your opinion, what should be done to improve oxygen therapy?”

Improve Unit Portability (Smaller, Lighter, Easier to Move, Quieter)

- *“A small cylinder lighter and easily accessible would make going out less difficult.”*
- *“A small portable oxygen concentrator would be much better than the compressed oxygen tanks. I cannot fly with a tank. At 4LPM, which is what I currently need on exertion, a tank lasts for less than two hours which limits my time out of the house.”*
- *“portable options that are lighter and easier to travel with”*

Remote Adjusting/Monitoring

- *“Remote monitoring and adjustment of oxygen equipment”*
- *“While using my home system, it would be beneficial to have a remote control to adjust amount of oxygen.”*

Accessibility/Easier to Qualify

- *“Be more lenient on oxygen therapy... When a patient have a hard time breathing provide oxygen! For portability offer new and different tools to help mobility”*
- *“Easier access to other suppliers, comprehensive listing of provincial/national suppliers with contact listings, uniform pricing, in Ontario change regulations to allow personal purchase of portable concentrators,”*
- *“The level of qualification should be lowered so people can get the oxygen they need”*

Affordability/Coverage

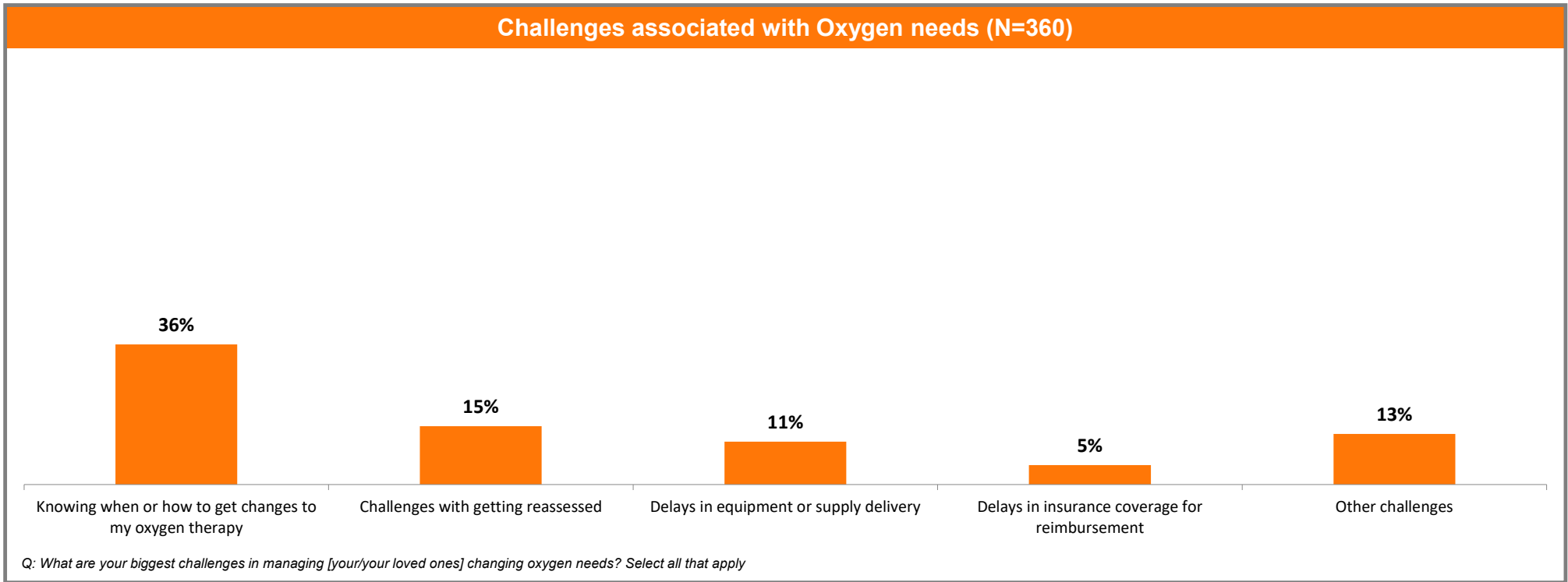
- *“Covered completely by govt and easier to do things out of the house”*
- *“There’s lot of patients that can’t afford oxygen for inside home or oxygen for outside. The government needs to lower the percentage to be able to approve to get oxygen”*
- *“My coverage for portable tanks is only three tanks per month which amounts to six hours out of the home. Any extra I need to pay out of pocket. A smaller POC would be much easier to manage and not have to worry about running out.”*
- *“Getting it regulated I go out lots as I try to keep active the government only pays for 10 tanks small or lg in total & after that I have to pay & this will limit my outings as I can not afford it so I will have to cut my outside activity off”*
- *“I was prepared to pay for it but only paid one month before test verified coverage criteria”*
- *“When the Firestone Clinic specified my need for oxygen, it was immediately available at no out-of-pocket cost.”*
- *“It is fully covered under Saskatchewan health authority”*

Support/Information

- *“There is no counselling on "oxygen therapy", other than if your level falls below 90 you should use oxygen. Other than that I have had no contact to "oxygen therapy " treatment.”*
- *“I was not informed that I could increase the oxygen allowed. Initially I was told 8 every 2 weeks. Then when my husband pushed how important my oxygen is for exercise they increased the amount. I worry I will run out if oxygen bottles.”*

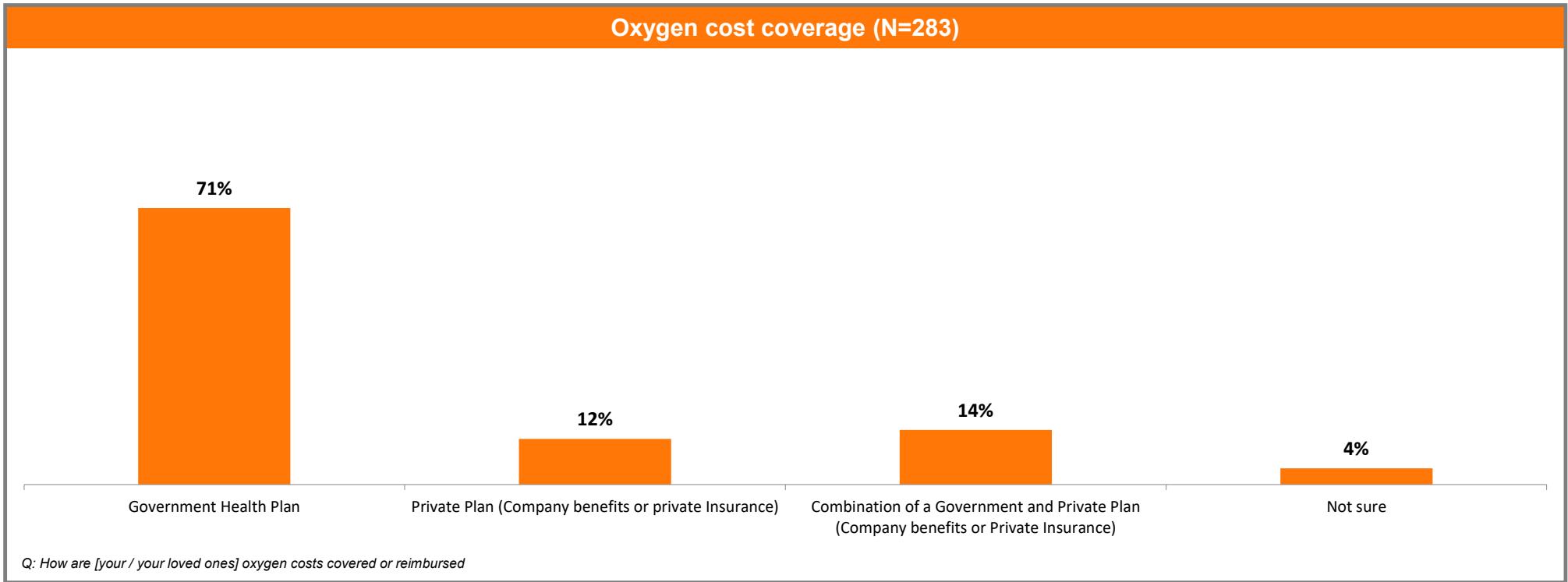
Oxygen Need Challenges

Over one-third said knowing when or how to get changes to their oxygen therapy is their biggest challenge.



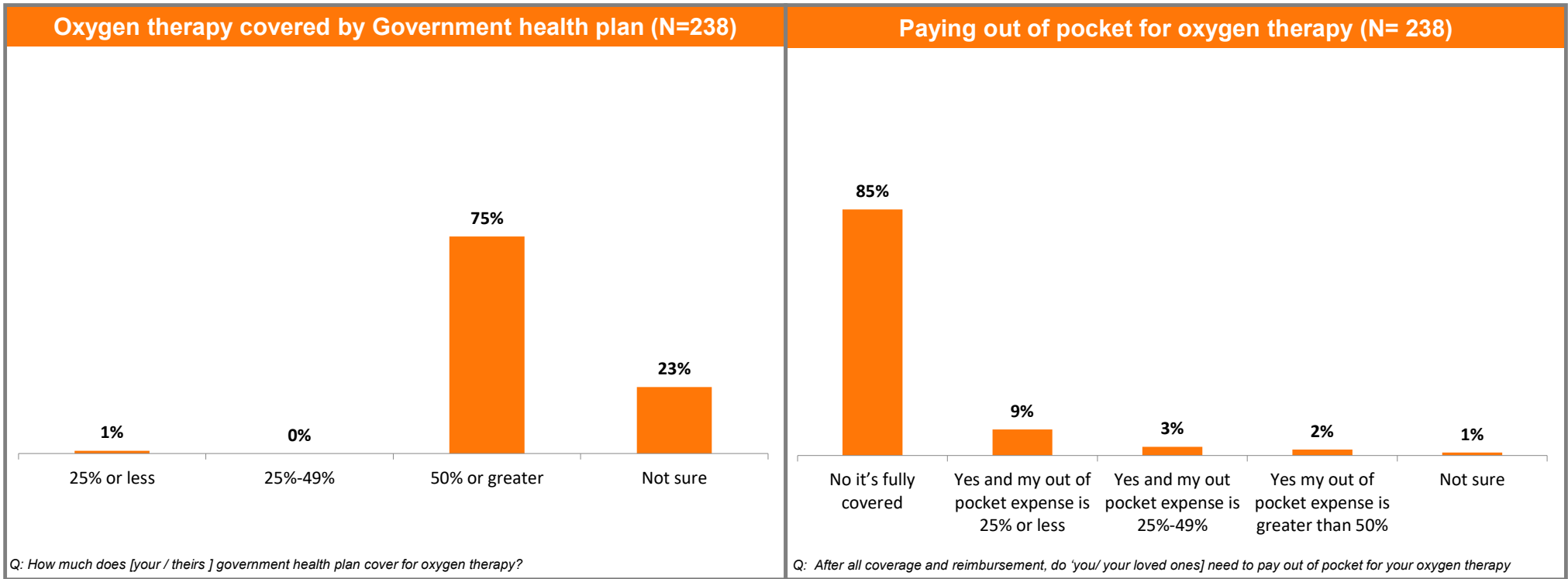
Oxygen Therapy – Cost Coverage

Close to 1 in 5 do not have their oxygen costs covered or reimbursed by their government health plan.



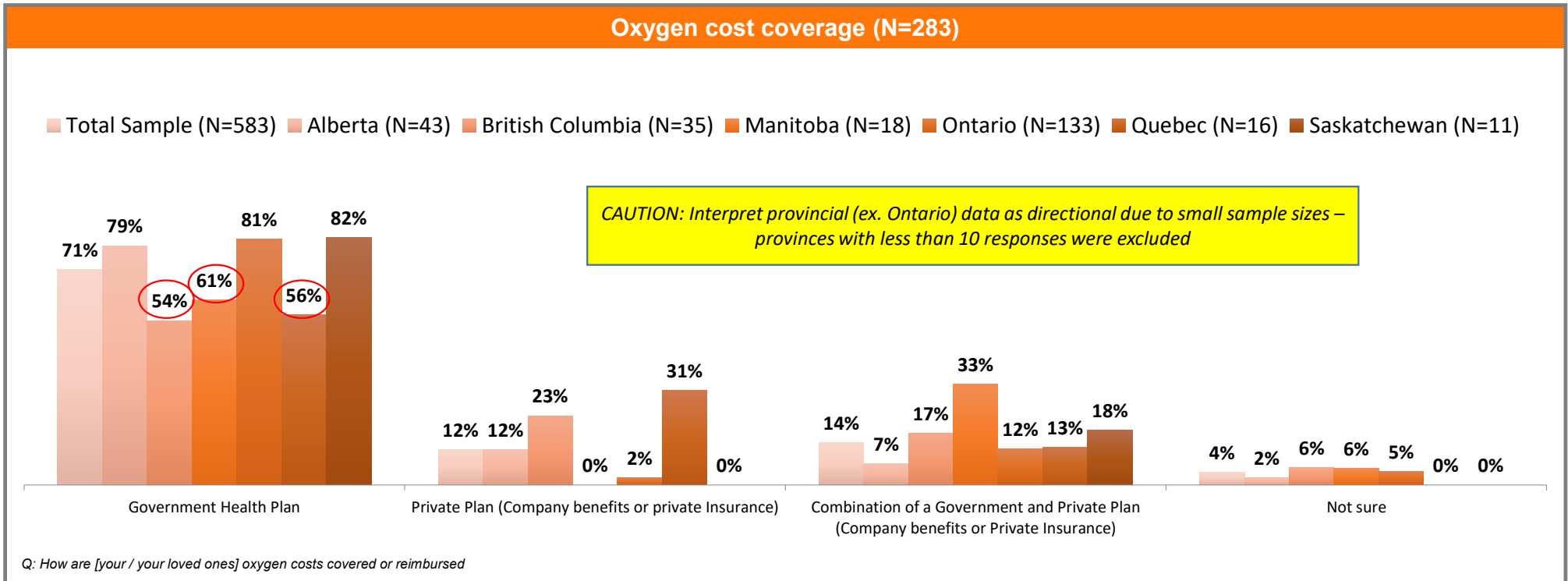
Oxygen Therapy – Insurance Coverage

Government health plans cover 50% or greater of their oxygen therapy. About 1 in 8 pay out of pocket.



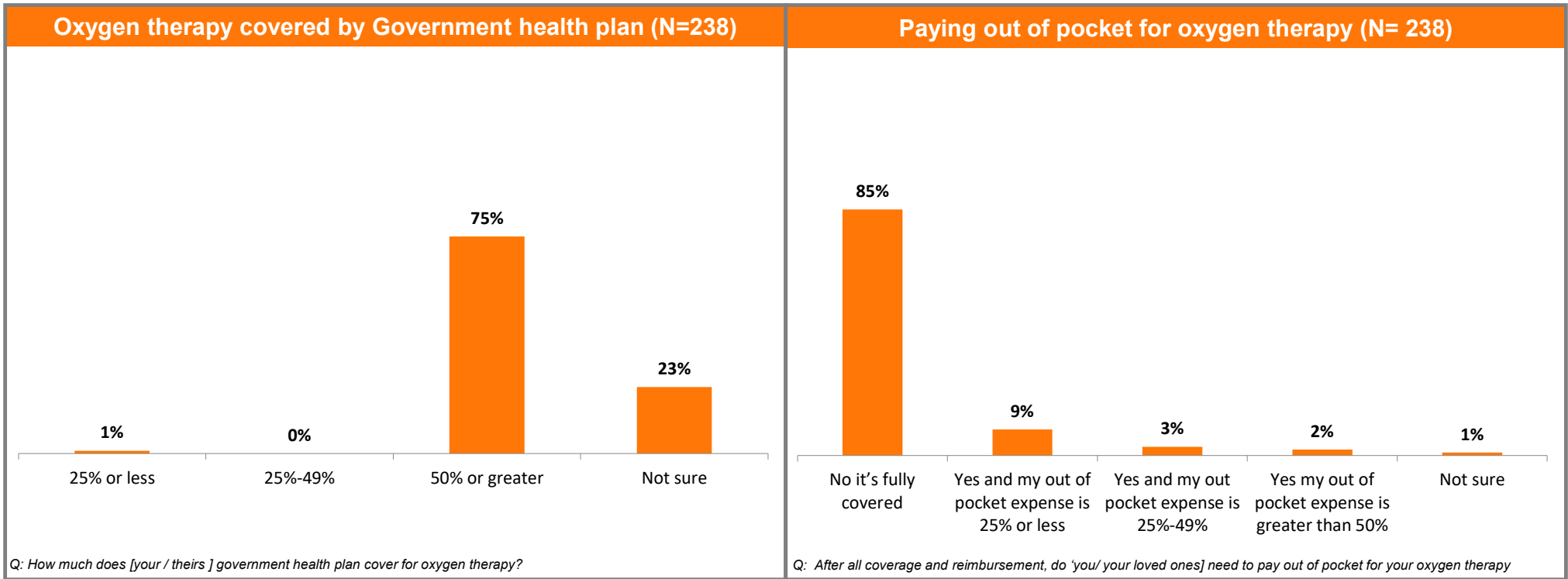
Oxygen Therapy – Cost Coverage by Province

Directionally, British Columbia, Manitoba and Quebec residents are less likely to have oxygen costs covered by a government health plan.



Oxygen Therapy – Insurance Coverage

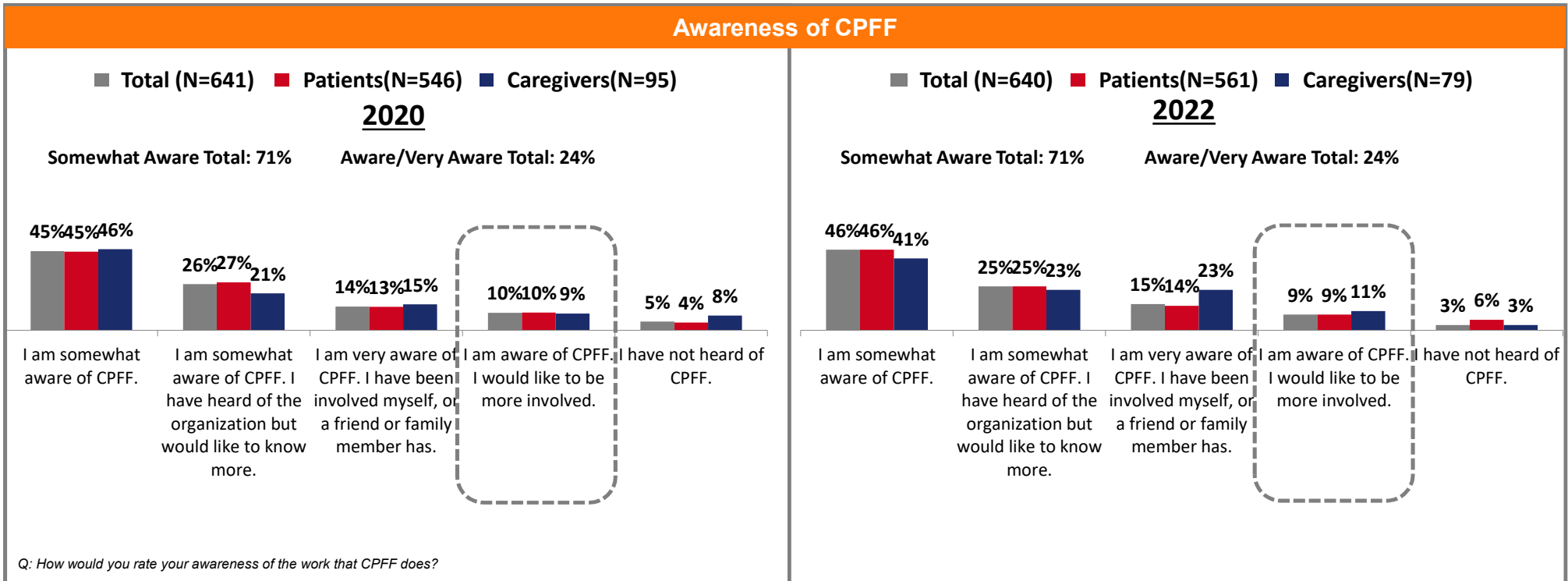
Government health plans cover 50% or greater of their oxygen therapy. About 1 in 8 pay out of pocket.



CPFF & Support

CPFF – Awareness

CPFF awareness has remained stable from 2020 to 2022 with about one-quarter being aware/very aware. About one-tenth who are aware would like to be more involved.

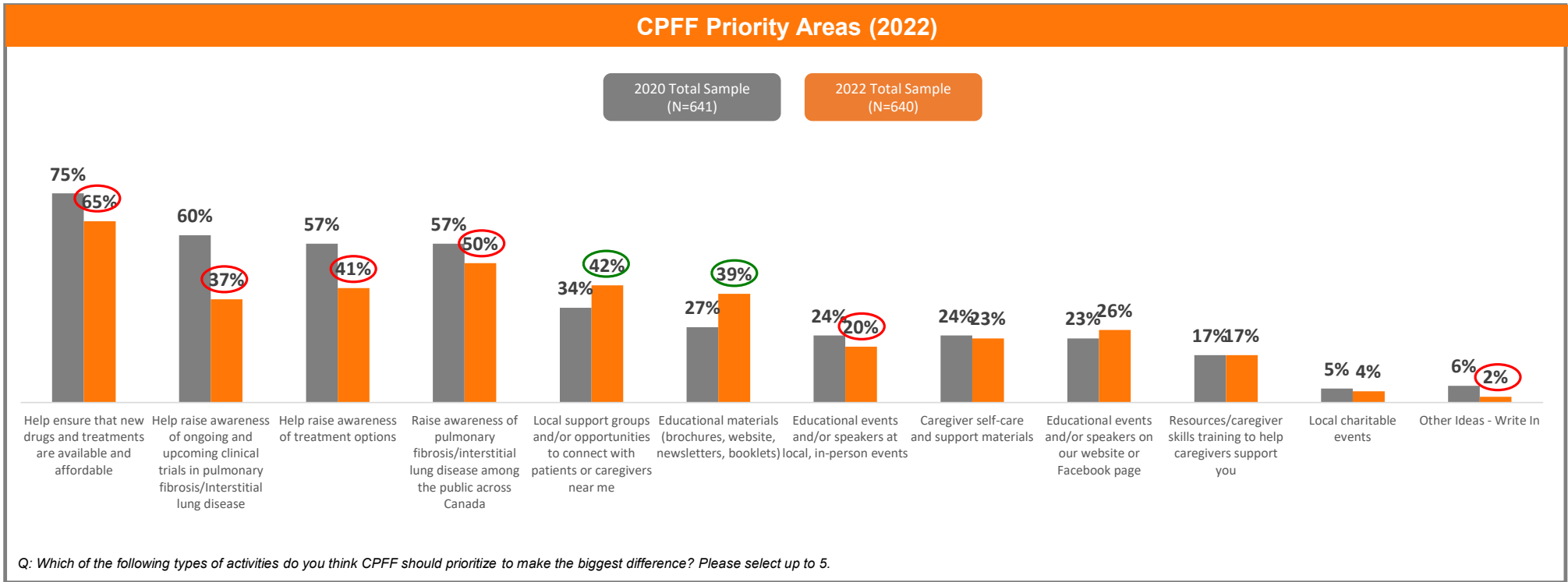


○ Indicates significantly higher vs. 2020

○ Indicates significantly lower vs. 2020

CPFF – Priority Areas of Focus in 2022

Ensuring new drugs and treatments are available and affordable remains the top priority. Local support groups and education materials saw an increase in 2022 vs. 2020.

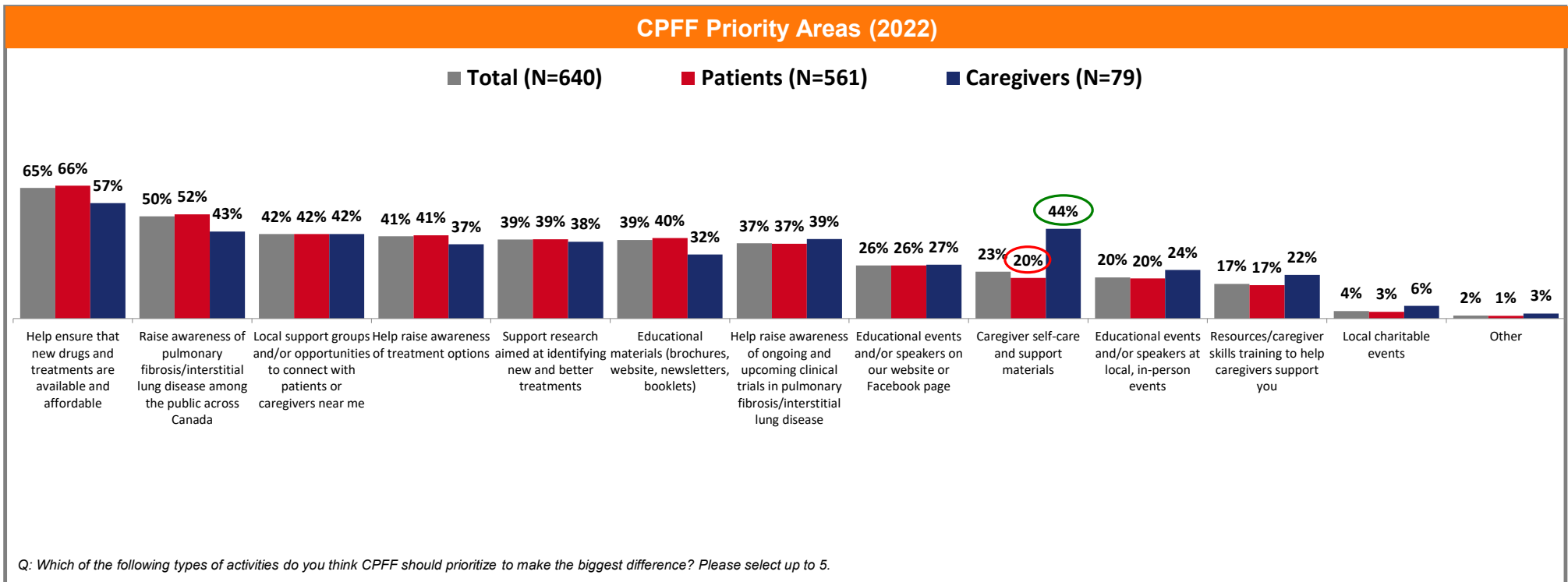


○ Indicates significantly higher vs. 2020

○ Indicates significantly lower vs. 2020

CPFF – Priority Areas of Focus in 2022

Over half of patients and caregivers want CPFF to prioritize helping to ensure new drugs & treatments are available & affordable, and to raise awareness among the Canadian public. Caregivers also rated caregiver self-care and support materials to be a high priority.

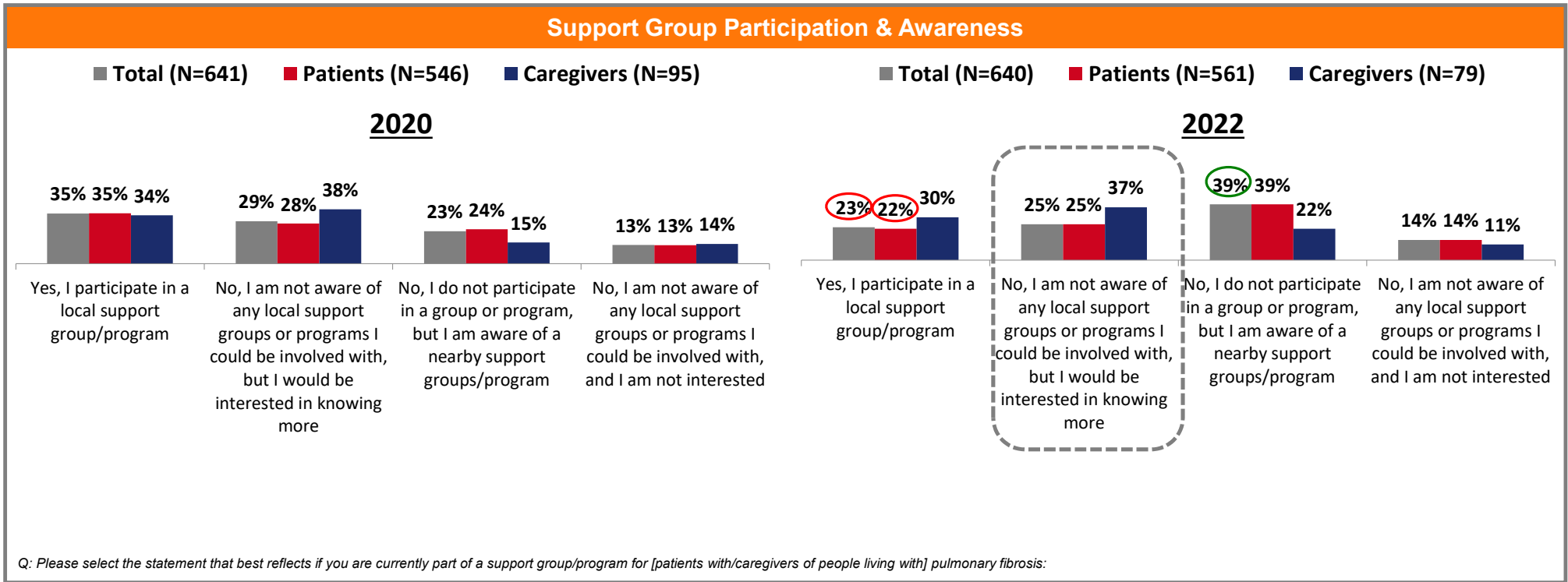


○ Indicates significantly higher vs. patient/caregiver

○ Indicates significantly lower vs. patient/caregiver

Support Groups

Participation in support groups, specifically among patients, dropped from 2020 to 2022 by 12ppts. Nearly 4 in 10 caregivers and one-quarter of patients are unaware and interested in local support groups.

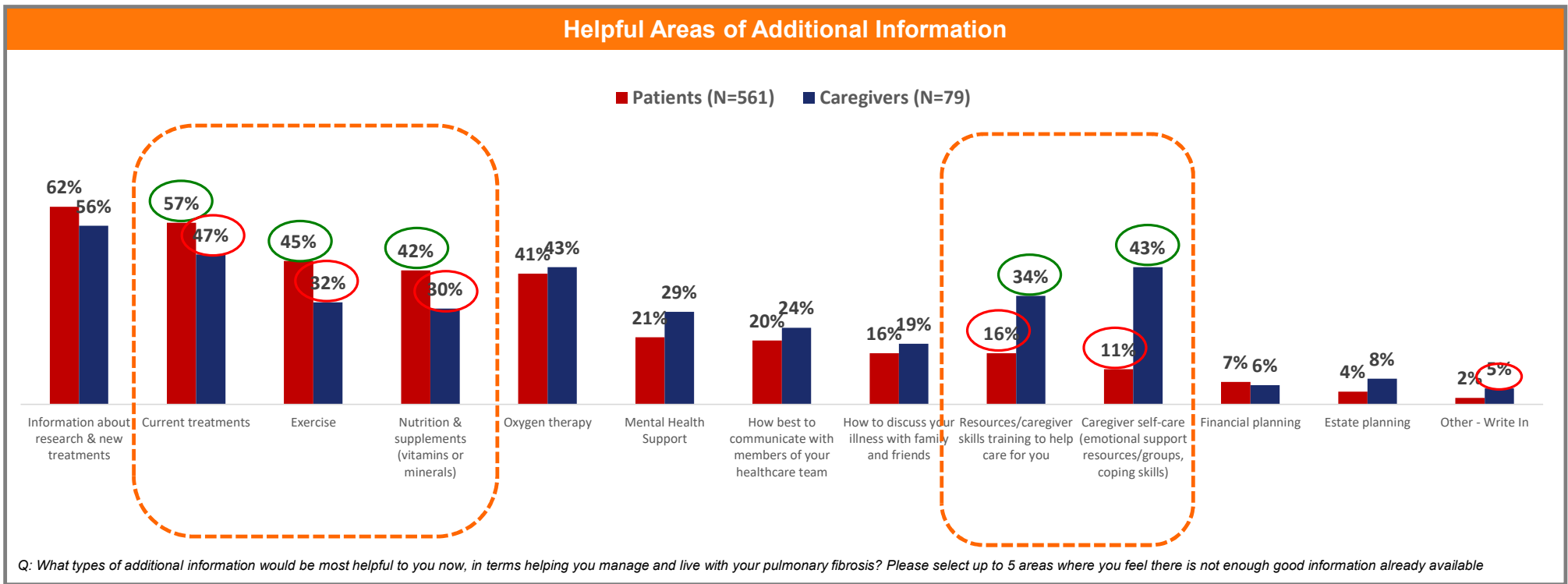


○ Indicates significantly higher vs. 2020

○ Indicates significantly lower vs. 2020

Information Needs – Patients vs. Caregivers

Patients have a higher need for information on current treatments, exercise, and nutrition. Caregivers have a higher need for resources on caring for their loved one and self-care.



○ Indicates significantly higher vs. patient/caregiver

○ Indicates significantly lower vs. patient/caregiver

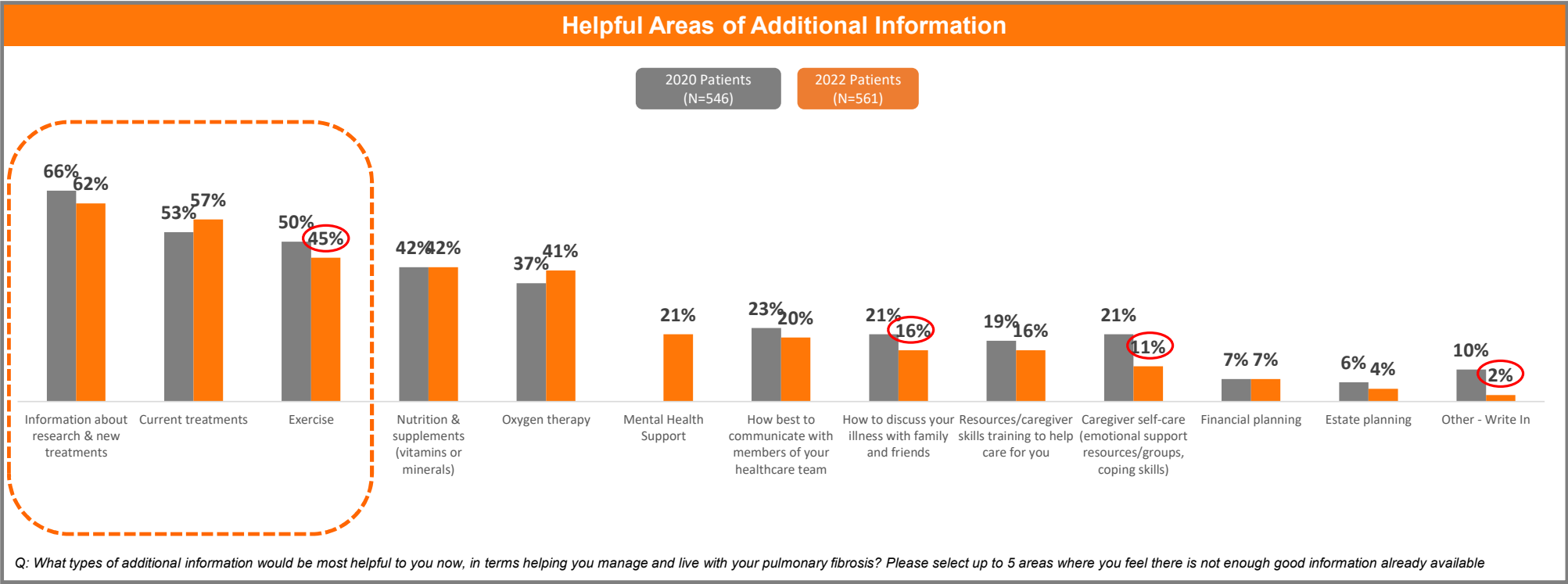
Information Needs – Patients vs. Caregivers

When comparing the top areas of information needs, patients and caregiver share the top areas. Caregivers have a higher need for caregiver self care information.

Top Rated Areas (30%+)	Patients (N=561)	Caregivers (N=79)
Information about research and new treatments	X	X
Current treatments	X	X
Exercise	X	X
Nutrition and supplements	X	X
Oxygen therapy	X	X
Caregiver self care		X

Information Needs – Patients

Information about research and treatments, current and new, remains the top patient information need.

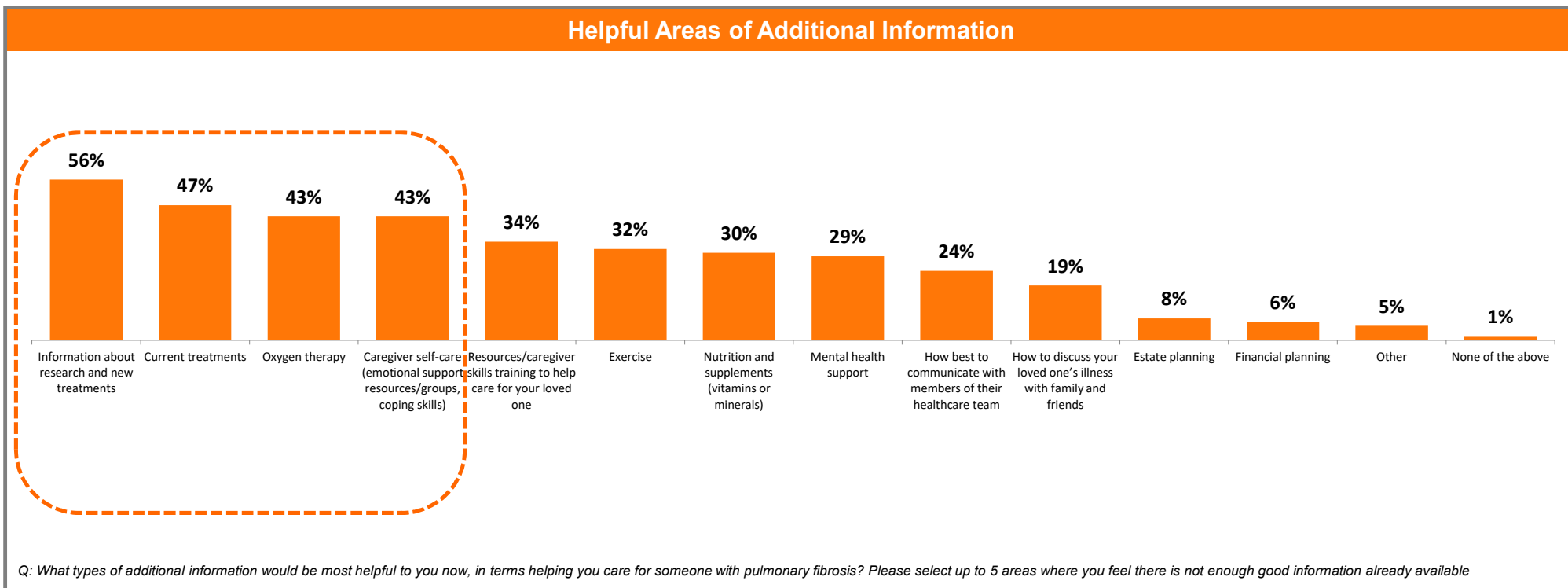


○ Indicates significantly higher vs. 2020

○ Indicates significantly lower vs. 2020

Information Needs – Caregivers

Top areas caregivers are looking for information on are research and new treatments, current treatments, oxygen therapy, and caregiver self-care.



Note: not compared vs. 2020 due to response list changes

Patient Information Needs

There are numerous aspects patients would like to know more about including support groups, their prognosis, new/alternative treatments and trials and exercise. Many also provided feedback about their doctors.

Are there other aspects of your disease or treatments you would like to know more about, or provide feedback about?*



Popular Themes Mentioned:

- More Info On Support Groups
- Understanding The Disease And Prognosis/End of Life
- New Or Alternative Treatments/Clinical Trials
- Exercise
- Expectation From Doctor/Doctor Feedback
- Better Coverage/Funding

Word cloud includes words with 7+ mentions

Patient Information Needs

Are there other aspects of your disease or treatments you would like to know more about, or provide feedback about?*

More Info On Support Groups

- *"Living in Sault Ste Marie there is no support group or therapy group for IPF.."*
- *"Everyone is different and how they cope with this condition is different. I think we need more support groups over all. Having someone who understands what you are going through and having them to talk to would be a great help."*
- *"Support groups in my area would ne an asset. Mental support as well"*
- *"I am fortunate to live near a recent lung recipient and he has been very supportive and willing to share information. I would certainly participate in a support group if one existed in my area."*

Understanding The Disease And Prognosis/End of Life

- *"I have been doing good . Would like to know what to expect in the long run . Would it be good for me to a dietitian Thank you"*
- *"I would like for patients to learn more about what this disease is and for them to understand what having this disease means for them and their future."*
- *"Would like more information about all of it . I am used to reading information, history, research , self help . A way to know if the information is real ,good, solid research backed"*
- *"I am recently diagnosed, so am trying to gather more information on the disease, it's treatment and any information on research of the disease (i.e. stem cell research, etc.). I have not started my meds yet, but understand they'll be provided in the next couple weeks. I am therefore waiting to better understand what side effects will affect me and to what extent."*

New Or Alternative Treatments/Clinical Trials

- *"Besides OFEV. are there other medications available ."*
- *"New drugs being developed that could to some degree reverse my PF. I have read research papers indicating that these types of drugs have been developed and proven to work in some labs using mouse/rat testing, but have not yet entered human clinical trials."*
- *"I took OFEV for a short time and the side effects were severe. I was not believed and became sicker and sicker and weeks later ended up in hospital with kidney failure. As a consequence, I now have to monitor my blood pressure and take two additional medications to control it. The push for patients to comply with new treatments by specialists AND the pharmaceutical company is not always in the patients best interest. New therapies are wonderful, but more care is needed."*

Word cloud includes words with 7+ mentions

Patient Information Needs

Are there other aspects of your disease or treatments you would like to know more about, or provide feedback about?*

Exercise

- *"Want guidance RE: exercise, I have asked my respirologist many times what exercise is should I do. Never referred me to any program where I can learn the most effective exercise for me...Wish there are programs, I could follow."*
- *"I'm interested in getting more information about exercise and living with ILD."*
- *"I find it hard to exercise would having oxygen make me feel better and be able to enjoy walking more"*
- *"Does exercise and diet mitigate the symptoms.."*

Expectation From Doctor/Doctor Feedback

- *"I would like my Specialist to be more forthcoming in discussing my disease. I know I'm dying, but I would like some indication of where I stand. I am on Ofev and after factoring that inam I doing better, worse or holding my own ?? I would like times discussed, as this seems to be the elephant in the room and I think patients are being denied all facts."*
- *"It is extremely important the constant feedback from Doctors. I am getting once a year of examinations and follow-ups. I haven't even met my lung s doctor in person, that's saying a lot about the medical system and patient care. I was diagnosed at JGH Montreal and informed by phone, and that is it"*
- *"Have not seen my lung Dr since being diagnosed. Feels like I'm being discriminated because of my age . But then this Dr said there was no treatment for it . I have done online research which say differently"*
- *"I would like my respirologist Dr. Janna to be more informative."*

Better Coverage/Funding

- *"Better coverage for drugs and future oxygen needs"*
- *"Getting help with mobility devices like a scooter. I have no coverage but it would greatly improve my quality of life. I can't walk anywhere."*
- *"Lung transplant if there's help for funding as I was told I'd need to go to Edmonton for months away & can't afford it"*
- *"What to do when funding has been cut"*
- *"government funding for Pulmonary Fibrosis treatment; I feel it's left behind on quicker access to treatment and transplant in comparison to other serious deadly diseases. it's a long delay for such deadly quick disease which is a death sentence"*

Word cloud includes words with 7+ mentions

Caregiver Information Needs

Caregivers are looking for more information about what to expect/future, mental health and support groups, and how best to support their loved one through challenges. Some are also seeking information about treatment options and financial assistance.

Q: Are there other aspects of caregiving, lung disease, or treatments you would like to know more about, or provide feedback about?



Popular Themes Mentioned:

- More Information About What To Expect/Future/End of Life
- Mental Health Support For Both Patient And Caregiver
- Helping & Supporting Patients Through Challenges
- Oxygen Therapy
- Lung Transplant
- Support Groups
- Financial Assistance
- Medication Management/Treatment Options

Word cloud includes words with 2+ mentions

Caregiver Information Needs

Q: Are there other aspects of caregiving, lung disease, or treatments you would like to know more about, or provide feedback about?

More Information About What To Expect/Future/End of Life

- *“More information about late age diagnosis disease progress and care.”*
- *“Knowing what to expect as disease progresses”*
- *“Tell us about some books to read on the topic.”*
- *“It’s too late for me as my mother is at end stage in hospital but things would have been easier for our family if we understood end stage better and we had some type of support/guidance.”*
- *“What needs to be done regarding palliative care and after-death arrangements.”*

Mental Health Support for both Patient and Caregiver

- *“How to encourage someone who also has depression and anxiety to use what time he has left more meaningfully and less prone to being in either their chair or the bed. Also, he is becoming very dependent on my presence close to him.”*
- *“Mental health support for both the patient and primary caregiver.”*
- *“Most people with this disease and their caregivers are of a generation where there is still a stigma around receiving supports for mental and emotional health. I wish we could talk about counselling the way we do about oxygen therapy.”*

Oxygen Therapy

- *“Oxygen availability and the accessories you could use for ease of use of oxygen”*
- *“how to get access to other specific needs i.e. oxygen”*
- *“I would like to know about more options for oxygen therapy.”*

Helping & Supporting Patients Through Challenges

- *“Challenge of convincing the IPF patient about the need for pulmonary rehab benefits. Doesn’t want to do anything physical which is making her worse. Is in denial, won’t go to rehab because she doesn’t want to leave my dad alone (82yo).”*
- *“How to provide meals for patient who has had major changes in appetite and tastes.”*
- *“How to best deal with side effects of Ofev.”*

Caregiver Information Needs

Q: Are there other aspects of caregiving, lung disease, or treatments you would like to know more about, or provide feedback about?

Lung Transplant

- *"we'd like more info about lung transplants, limits due to age"*
- *"Transplant information."*

Support Groups

- *"I had a breathing & walking test at our hospital & received oxygen in a couple of days. They were right on the ball."*
- *"My SpO2 level dropped significantly in my last 6MWT. Then, with Oxygen, my level was maintained at 95%+ on a shortened test so RRT recommended Oxygen to my Respirologist and he wrote the Rx and sent it back to the RRT who forwarded it to Oxygen."*
- *"There is a support group for caregivers I participate in occasionally but it's focus seems to be on those with transplants. My spouse does not qualify so doesn't seem very helpful"*

Financial Assistance

- *"Securing affordable insurances when you have a pre-existing condition including - travel, life, long term care"*
- *"obtaining travel insurance with pre-existing conditions"*
- *"Financial assistance and coverage"*

Medication Management/Treatment Options

- *"1) When coughing becomes choking, how can the caregiver assist? 2) Medication management for the PF patient who has other ailments in addition."*
- *"Interaction between meds."*
- *"What type of pain killer can be taken while on OFEV"*
- *"Yes. How do naturopaths treat people with IPF?"*
- *"What treatment options exist or are being discovered, how to get into any trial program that can increase the life span."*

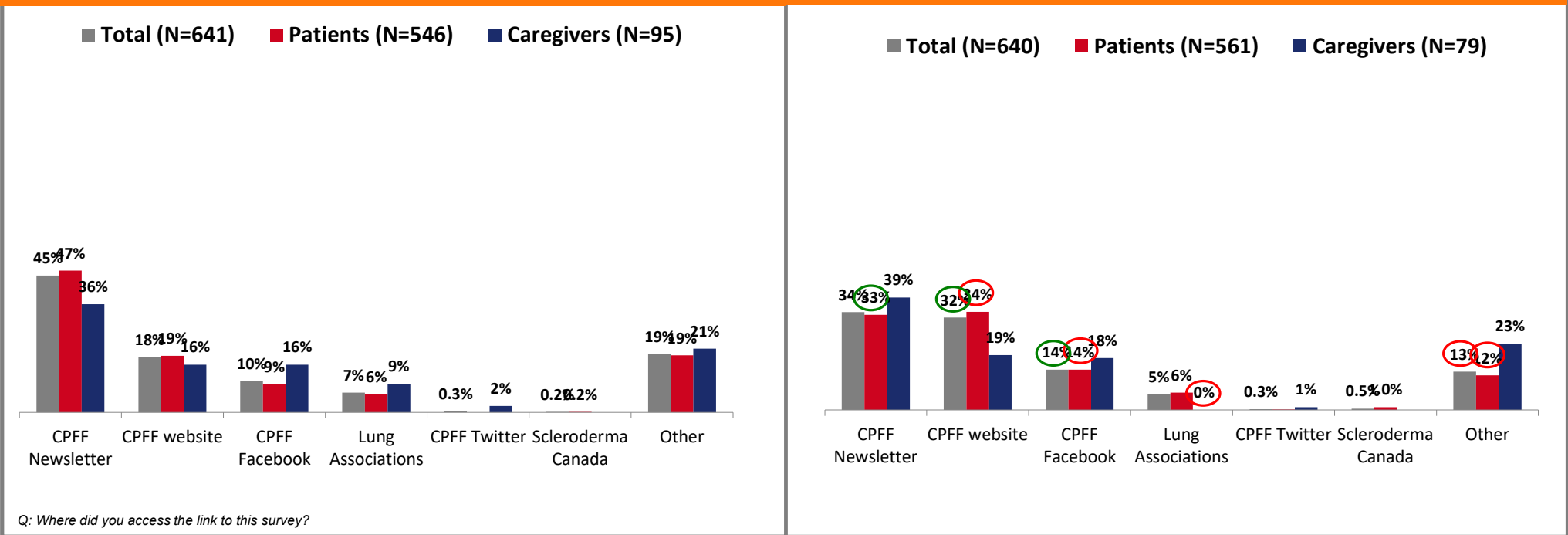
Appendix

Survey Performance – Sources

CPFF website and Facebook grew as a survey access point in 2022.

Sources for Accessing Link in 2020

Sources for Accessing Link in 2022

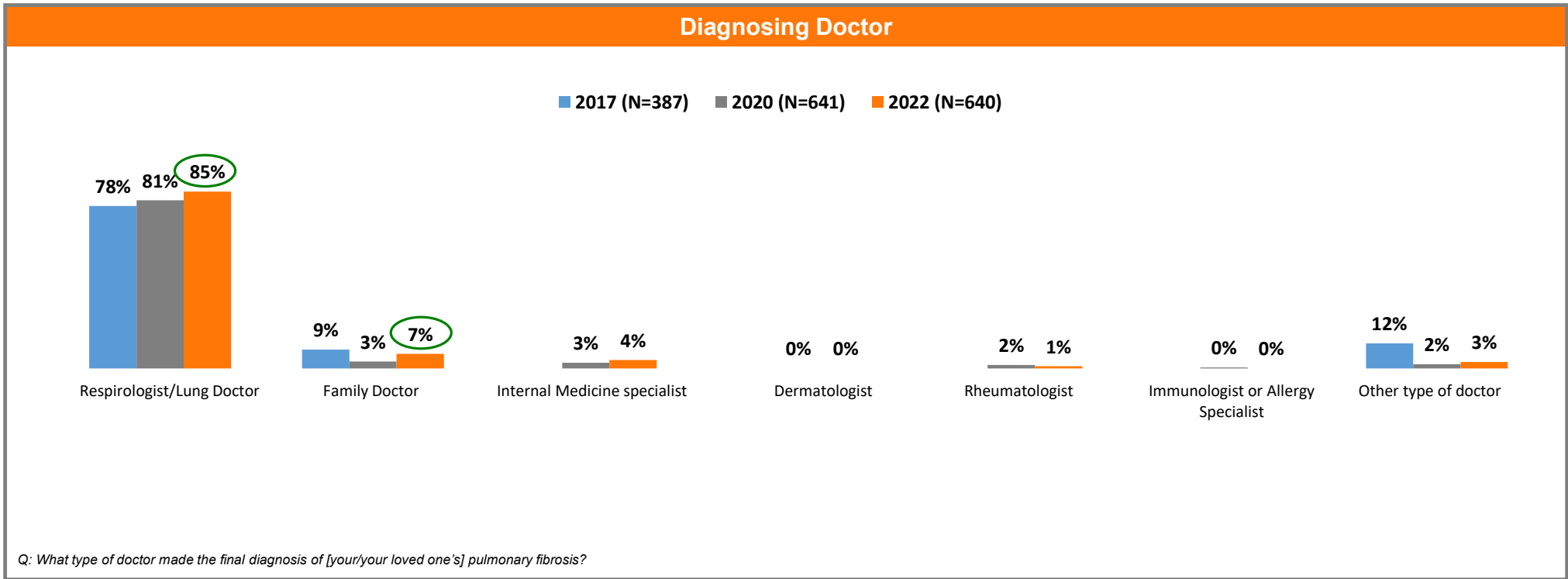


○ Indicates significantly higher vs. 2020

○ Indicates significantly lower vs. 2020

Diagnosing Doctor

Respirologists/Lung Doctors continue to be the top doctor type for diagnosing pulmonary fibrosis. Family Doctors have seen a slight increase from 2020 to 2022.



Indicates significantly higher vs. 2020

Indicates significantly lower vs. 2020



Canadian
Pulmonary
Fibrosis
Foundation

Canadian Pulmonary Fibrosis Foundation

Healthcare Professionals Survey Report

Pearl Strategy and Innovation Design

January 2023

Agenda

1. Objectives & Learning Goals
2. Methodology
3. Executive Summary
4. Healthcare Professional Profile
5. Patient Access
6. Treatment
7. Appendix

Objectives & Learning Goals

Objectives

- Provide insights to help CPFF understand healthcare professionals' perspective on oxygen therapy accessibility in order to advocate for change to benefit people living with this disease.

Learning Goals

- Understand healthcare professionals' experiences as it relates to their patients and oxygen therapy
 - Access to oxygen therapy, systems used, provincial reimbursement, areas of improvement

Methodology

- Healthcare Professionals were recruited through CPFF's database and network (via patients and associations)
- Respondent Breakdown: **N=41 Total Respondents**
 - Respiriologists (N=19)
 - Respiratory Therapist (N=12)
 - Registered Nurse/Nurse/Clinician Nurse (N=5)
 - Caregiver on Transition Team (N=1)
 - General Practitioner (N=1)
 - Occupational Therapist (N=1)
 - Social Worker (N=1)
- **NOTE: Due to small sample sizes – results should be interpreted as directional**

Executive Summary

Executive Summary

Key Findings

Patient Access to Oxygen Therapy

- Oxygen saturation levels is the top indicator used to determine if patients require supplemental oxygen.
- PF patients experience many challenges in accessing sufficient oxygen at home, outside the home, and traveling.
- Key patient barriers to accessing oxygen therapy include rigid & unsuitable qualifying criteria, equipment allowance limitations, exertional oxygen needs are not covered, carrying equipment from home is difficult, and cost is prohibitive for travelers.

Oxygen Therapy Prescription

- 2 in 3 healthcare professionals feel that the provincial reimbursement guidelines **do not** allow them to prescribe oxygen therapy to all the patients that need it.
- Reimbursement criteria are too strict or not appropriate, limited availability of exertional oxygen and lack of coverage for other oxygen needs are the primary reasons healthcare professionals disagree they are able to prescribe oxygen therapy to patients that need it.

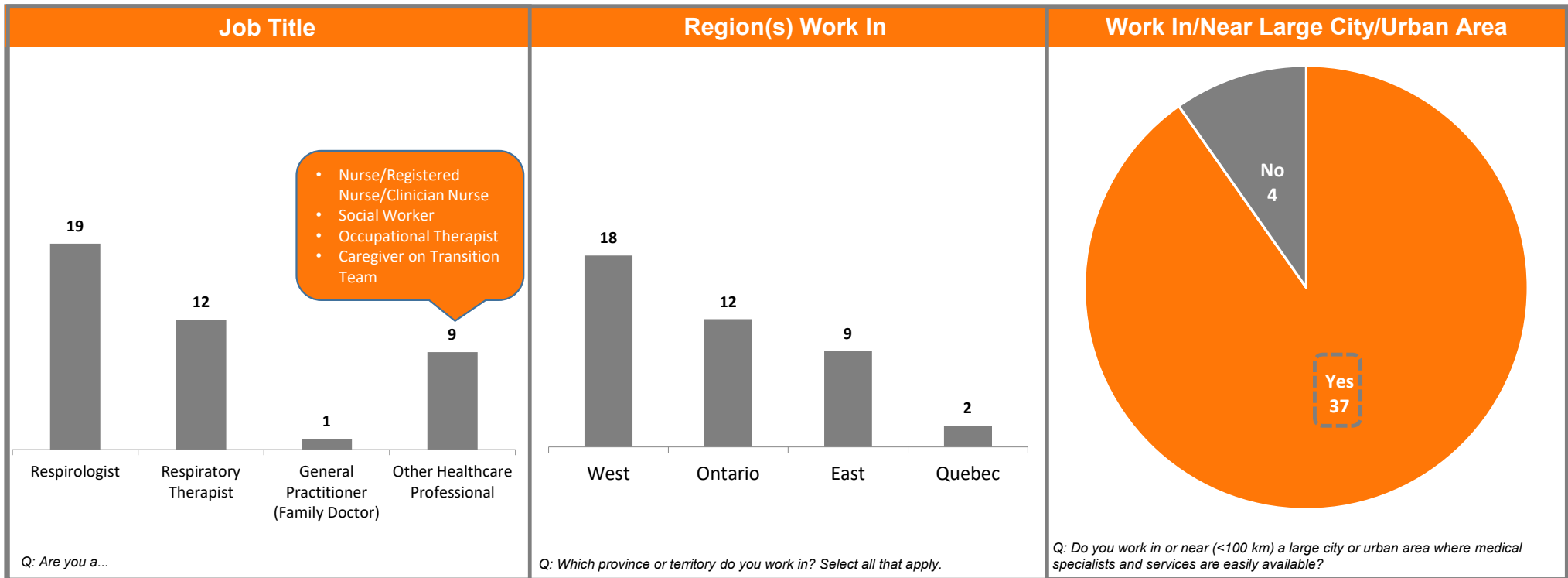
Patient Support & Improvement Opportunities

- Majority of healthcare professionals rely on oxygen providers to provide oxygen training and patient education.
- Top areas for improvement suggested by Healthcare Professionals were: Increase coverage for additional equipment, update criteria for other oxygen needs, more supportive funding criteria, training, and modern equipment.

Healthcare Professional Profile

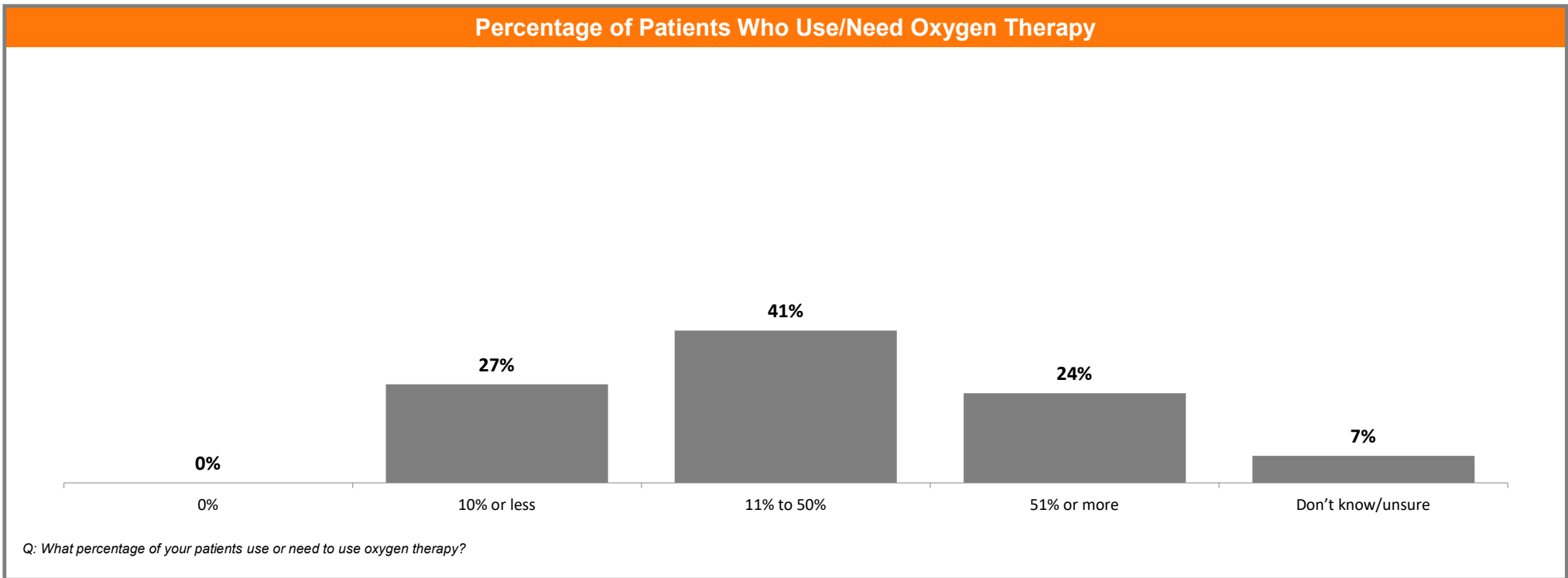
Healthcare Professional Demographics

Majority of healthcare professional survey participants were Respirologists and Respiratory Therapists. Most work in/near large cities in the West, Ontario or East.



Patient Oxygen Therapy

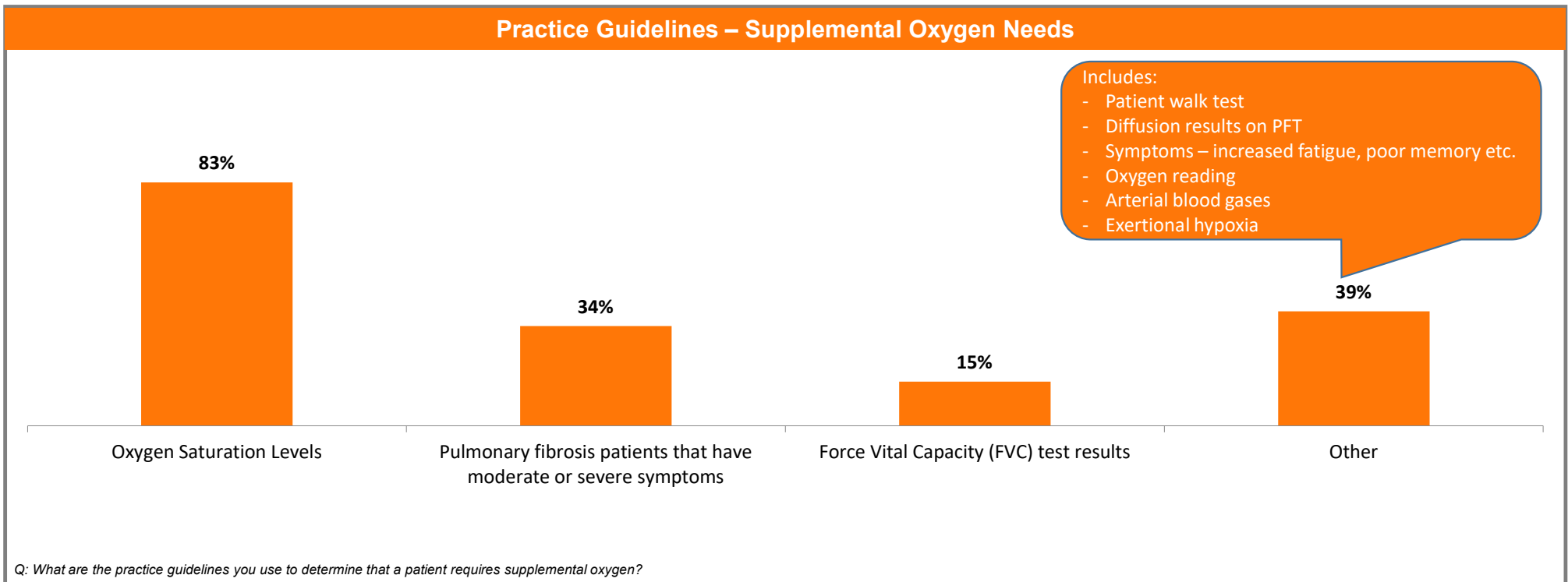
All healthcare professionals who participated had patients who use/need oxygen.



Patient Access

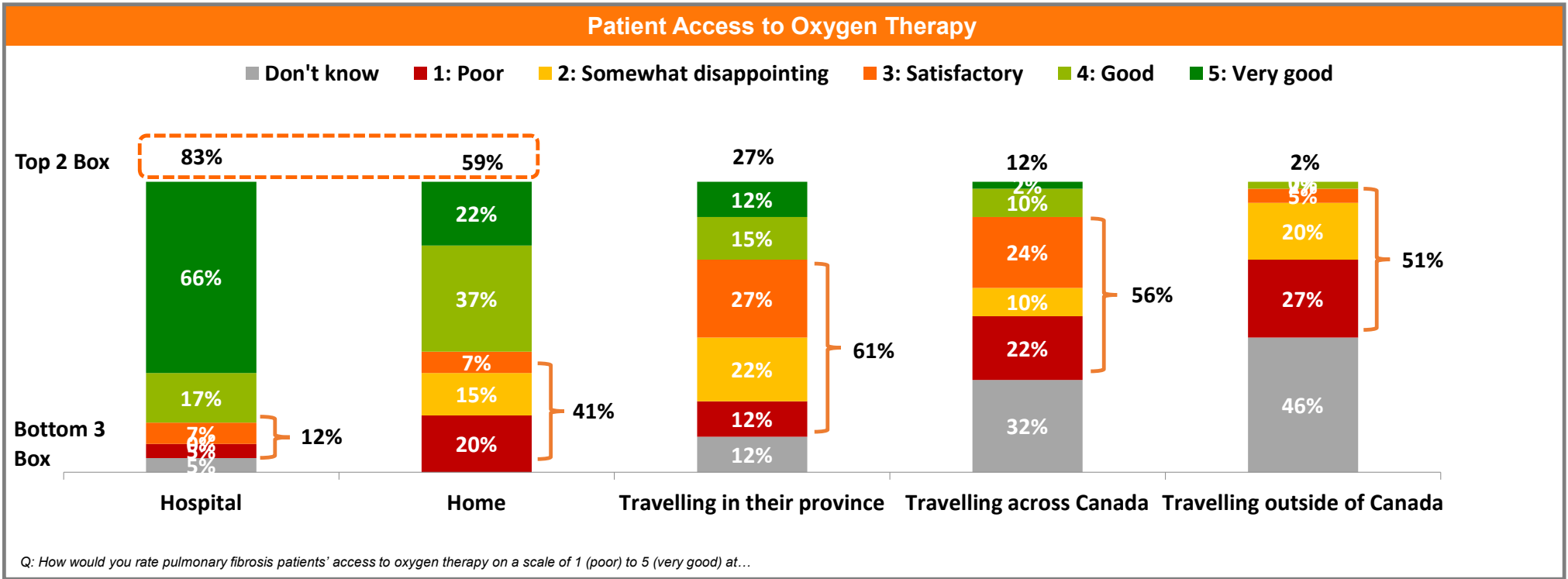
Practice Guidelines – Supplemental Oxygen Needs

Oxygen saturation levels is the top indicator used by healthcare professionals to determine if their patients require supplemental oxygen.



Patient Access to Oxygen Therapy

Over one-third of healthcare professionals feel that access to oxygen therapy at home needs improvement. Access to oxygen while travelling is also rated poorly.



Patient Access to Oxygen Therapy - Reasons

According to healthcare professionals key patient barriers to accessing oxygen therapy include rigid & unsuitable qualifying criteria, equipment allowance limitations, exertional oxygen needs are not covered, carrying equipment from home is difficult, and cost is prohibitive for travelers.

Please explain your rating scores for pulmonary fibrosis patients' access to oxygen therapy

Rigid & Unsuitable Qualifying Criteria

- *"The government criteria is rigid and overly complicated" – Registered Nurse*
- *"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*
- *"Qualifying for O2 is beyond challenging!! Exertional O2 funding requires desaturation 22 months, they need to go through the whole requalification process." - Respiriologist*
- *"Criteria for O2 access in Quebec are based on very old COPD literature and not at all applicable to ILD patients. There are no criteria for ambulatory O2 either" - Respiriologist*
- *"It has been difficult to get them started on home O2 therapy because SpO2s can be good at rest but decrease with exertion. Patients would benefit from O2 but rules are very black and white. They do not always fit the black and white rules and have to deal with SOB." - Respiratory Therapist*

Equipment Allowance Limitations

- *"Access to greater than 10 tanks per month for those on continuous oxygen or pulse oxygen concentrator access is poor" - Respiriologist*
- *"The only limitation is the number of oxygen tanks provided per month is 10. patients can determine size they wish but only 10 fills provided. This can be limiting if the patient is on a high flow of oxygen." - Respiratory Therapist*

Exertional Oxygen Needs Are Not Covered

- *"Coverage for supplemental oxygen at exertion is the main problem" - Respiriologist*
- *"I would like to see improved access to exertional oxygen for pulmonary fibrosis patients." - Respiriologist*
- *"Alberta's oxygen policy for exertional desaturation is horrible and unacceptable" - Respiriologist*

Carrying Equipment Away From Home is Difficult

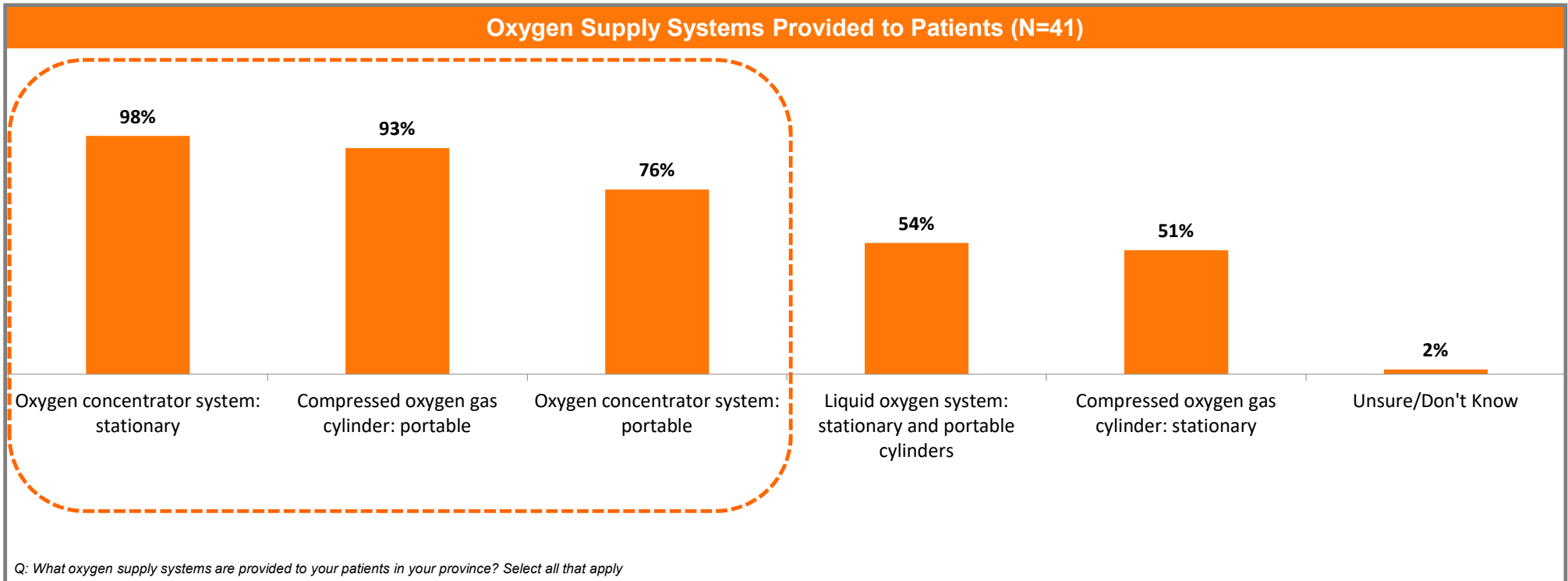
- *"The provincial government does not fund light weight portable oxygen systems and only provides small tanks. This is not convenient for patients and decreases their ability to do exercise and travel" - Respiriologist*
- *"The metal tanks are heavy and clunky and a lot of patients feel it is too much work to leave the house and essentially become house bound" - Respiriologist*
- *"No liquid O2 coverage. Difficult to travel on high flows with portable O2 and tanks" - Respiratory Therapist*
- *"They usually do not like cylinders or find them cumbersome. Liquid is okay at home, but with travel ... not too feasible" - Respiratory Therapist*

Cost is Prohibitive For Travelers

- *"Oxygen companies appear to charge a lot when their clients have to travel and making arrangements to have POC's or concentrators at the hotel on arrival also is an issue" - Respiratory Therapist*
- *"When travelling outside of the province (national and international), they sometimes need to deal with different oxygen providers and may incur extra costs" - Respiriologist*

Oxygen Supply Systems

Healthcare professionals believe oxygen concentrator systems and portable compressed oxygen gas cylinders are the main oxygen supply systems available to their patients.



Treatment

Oxygen Therapy Prescription

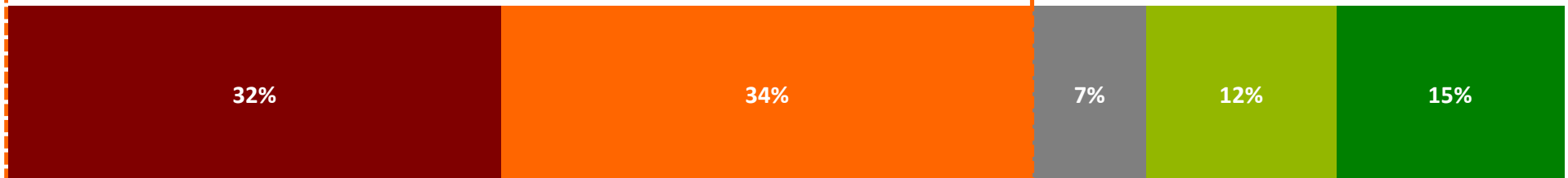
2 in 3 healthcare professionals feel the provincial reimbursement guidelines do not allow them to prescribe oxygen therapy to all the patients that need it.

“My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all the patients that need it”

■ Strongly Disagree ■ Somewhat Disagree ■ Neither Agree nor Disagree ■ Somewhat Agree ■ Strongly Agree

Bottom 2 Box: 66%

Top 2 Box: 27%



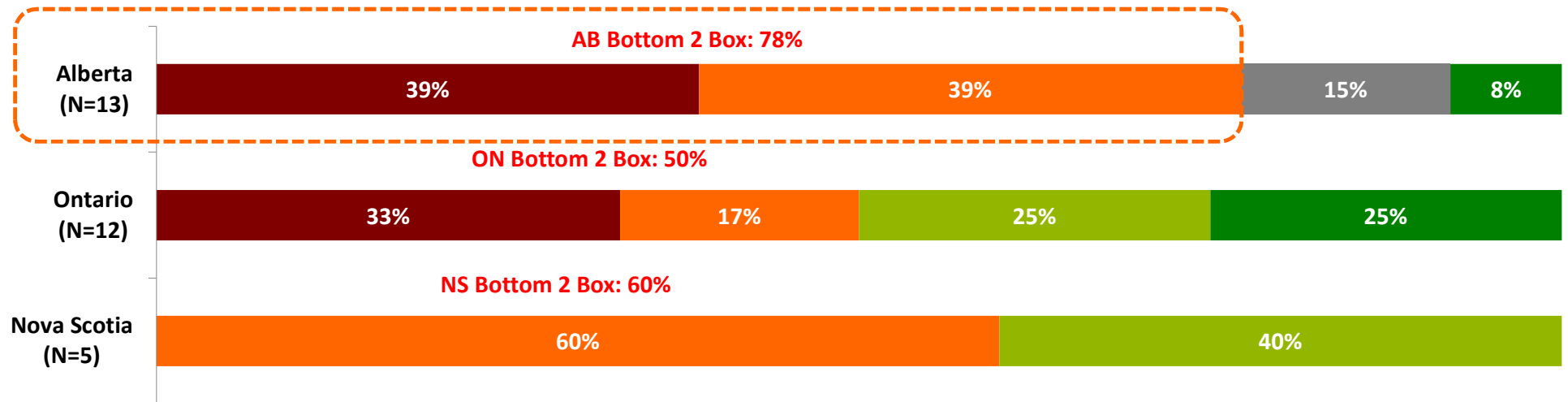
Q: Please rate how much you agree or disagree with this statement: “My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all the patients that need it.”

Oxygen Therapy Prescription - Provincial Breakdown

While healthcare professionals across the country do not feel that the provincial reimbursement guidelines are adequate, the issue appears to be most prevalent in Alberta.

“My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all the patients that need it”

■ Strongly Disagree
 ■ Somewhat Disagree
 ■ Neither Agree nor Disagree
 ■ Somewhat Agree
 ■ Strongly Agree



Q: Please rate how much you agree or disagree with this statement: “My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all the patients that need it.”

NOTE: Provinces with less than N=5 have been removed from this chart – this chart should be interpreted directionally in a qualitative nature

Oxygen Therapy Prescription – Disagree

Reimbursement criteria are too strict or not appropriate, limited availability of exertional oxygen and lack of coverage for other oxygen needs are the primary reasons healthcare professionals disagree they are able to prescribe oxygen therapy to patients that need it.

Respondents who DISAGREE with the statement “My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all the patients that need it.”

Reimbursement Criteria Too Strict Or Not Appropriate

- *“Provincial reimbursement as per specific criteria.” – General Practitioner, NS*
- *“The criteria are strict, much lower than guidelines suggest, and include excessive barriers that impact our ability to prescribe oxygen” –Registered Nurse, AB*
- *“Criteria for reimbursement is not appropriate for this patient population.”- ILD Registered Nurse, AB*
- *“Clients are expected to improve both in oxygen saturation and meters walked using two walking tests (with and without oxygen test). These are done back to back on the same day. This is a lot of exertion for many clients and they fail due to fatigue” – Respiratory Therapist, BC*
- *“Criteria for O2 access in Quebec are based on very old COPD literature and not at all applicable to ILD patients.” – Respiriologist, QC*
- *“The criteria are cumbersome and inapplicable to people with IPF” - Respiriologist, AB*
- *“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 of des” – Respiratory Therapist, AB*

Limited Availability of Exertional Oxygen

- *“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”- Respiriologist, SK*
- *“I would prescribe more exertional O2” - Respiriologist, BC*
- *“There are some patients with mild desaturation who may benefit from exertional oxygen, however access is limited.” - Respiriologist, ON*

Lack of Coverage for Other Oxygen Needs

- *“Coverage is given for those with pO2” - Respiriologist, NS*
- *“There are no criteria for ambulatory O2 either and it needs to be argued every time for coverage.” - Respiriologist, QC*
- *“Most often, when the needs is for effort or ambulation only, it won't be covered.” – Clinician Nurse, QC*

Oxygen Therapy Prescription – Agree

Some Healthcare professionals in Ontario agree they are able to prescribe oxygen therapy to patients that need it because it is easily accessible.

Respondents who AGREE with the statement “My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all the patients that need it.”

Easily Accessible

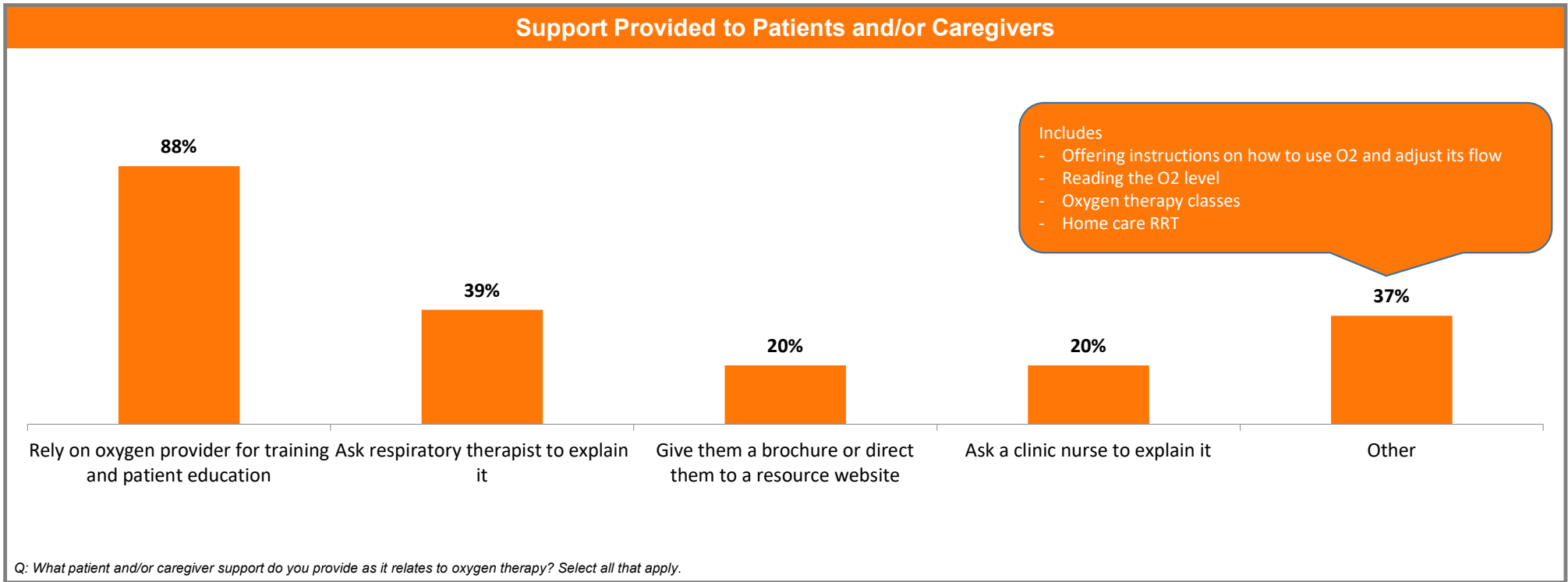
- *“Ontario has relatively easy access to Oxygen compared to other provinces in Canada. I am always able to access Oxygen when it is needed.”- **Respirologist, ON***
- *“Have never had a patient refused by the province” - **Nurse, ON***

Instant Service

- *“Had instant service to begin oxygen therapy at home”- **Registered Nurse, PEI***

Support

Majority of healthcare professionals rely on oxygen providers to provide oxygen training and patient education.



Improvements to Oxygen Therapy

Increased or modified coverage, patient education & training, and updated equipment are suggestions by healthcare professionals for improving oxygen therapy.

In your opinion, what should be done to improve oxygen therapy?

Increase Coverage/Reimbursement for Additional Monthly Oxygen

- *“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. And 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***

Change Medical Criteria to Match Unique PF Patient Needs

- *“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***

Patient Education & Training

- *“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***

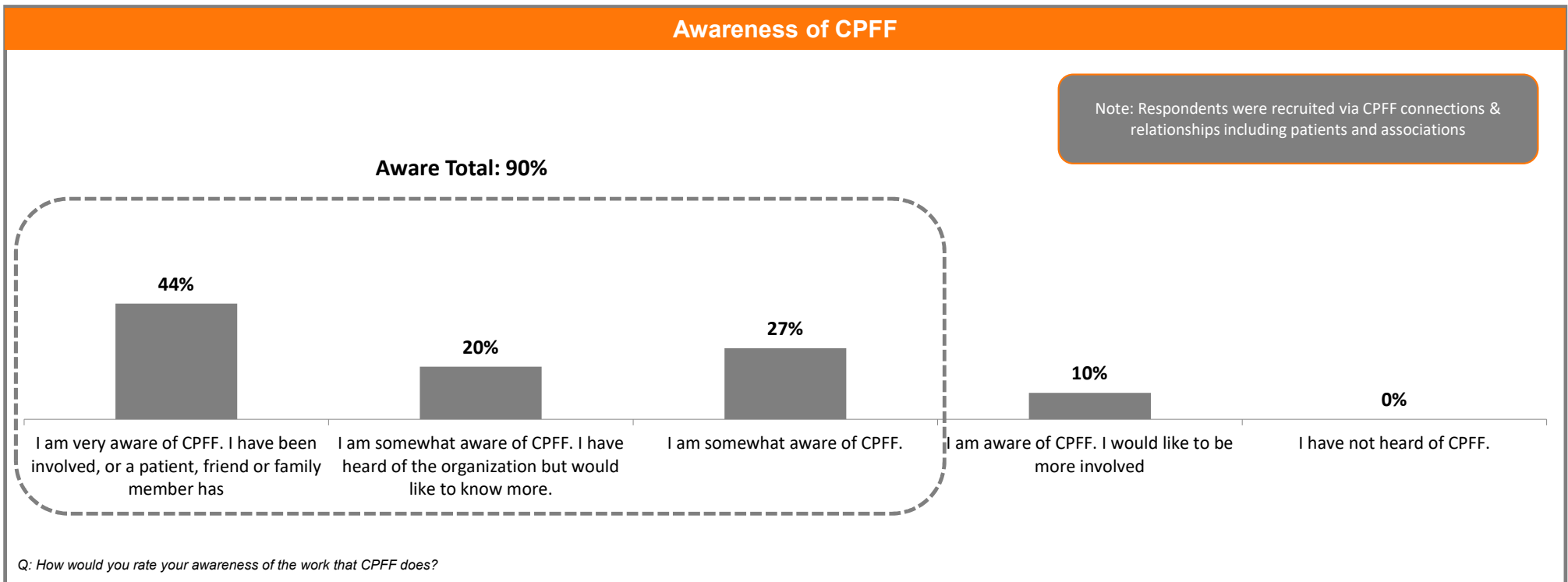
Updated Equipment

- *“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***

Appendix

CPFF – Awareness

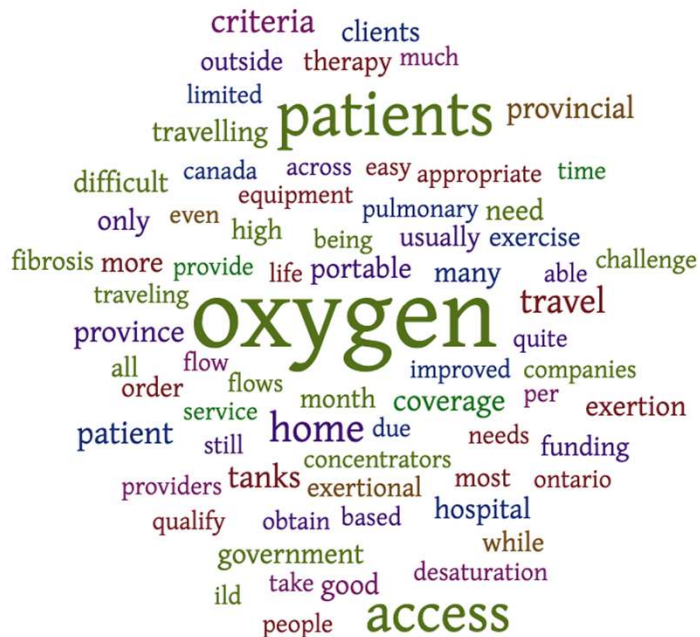
A majority of healthcare professionals are aware of CPFF. About one-tenth who are aware would like to be more involved.



Patient Access to Oxygen Therapy - Reasons

Limited equipment, difficulties in carrying portables, coverage for exertional oxygen, qualifying criteria and cost are the main barriers that impact access to oxygen therapy.

Please explain your rating scores for pulmonary fibrosis patients' access to oxygen therapy



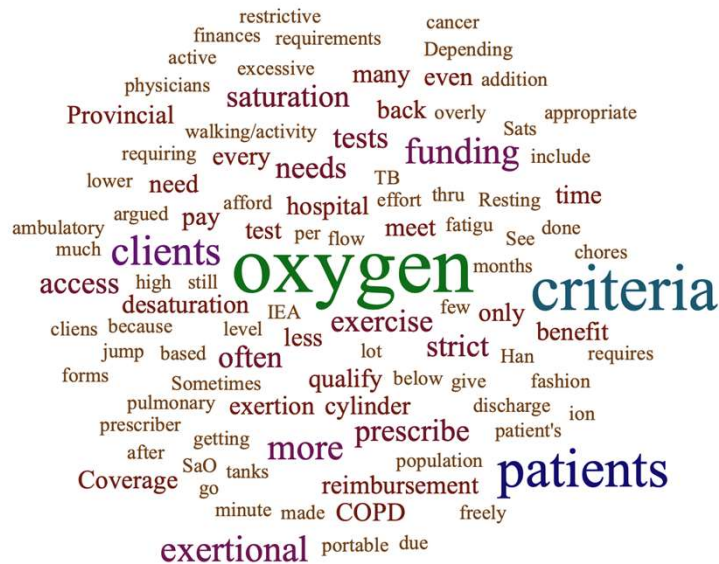
Popular Themes Mentioned:

- Limited equipment availability
- Difficulties in carrying portables
- Exertional oxygen needs
- Qualifying criteria
- Expensive

Oxygen Therapy Prescription – Disagree

Among those who do not feel that the provincial reimbursement allow prescription of oxygen therapy, strict criteria for reimbursements, limited availability of equipment, and lack of specific criteria for other oxygen needs are the top reasons

Respondents who DISAGREE with the statement “My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all the patients that need it.”



Popular Themes Mentioned:

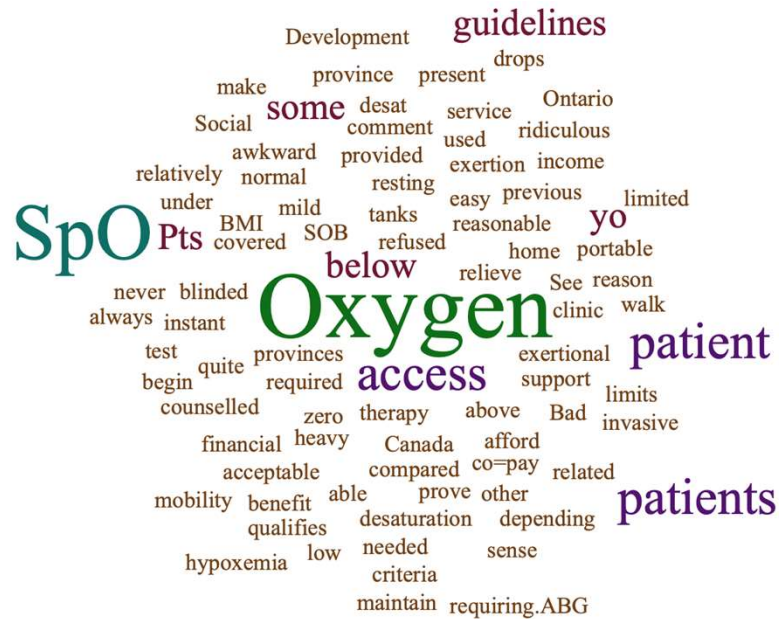
- Strict criteria for reimbursements
- Limited availability of equipment
- Lack of specific criteria for other O2 needs

Word cloud includes words with 3+ mentions

Oxygen Therapy Prescription – Agree

Among those who feel that the provincial reimbursement allow prescription of oxygen therapy, easily accessible and instant service are the top reasons.

Respondents who AGREE with the statement “My provincial reimbursement guidelines allow me to prescribe oxygen therapy to all the patients that need it.”



Popular Themes Mentioned:

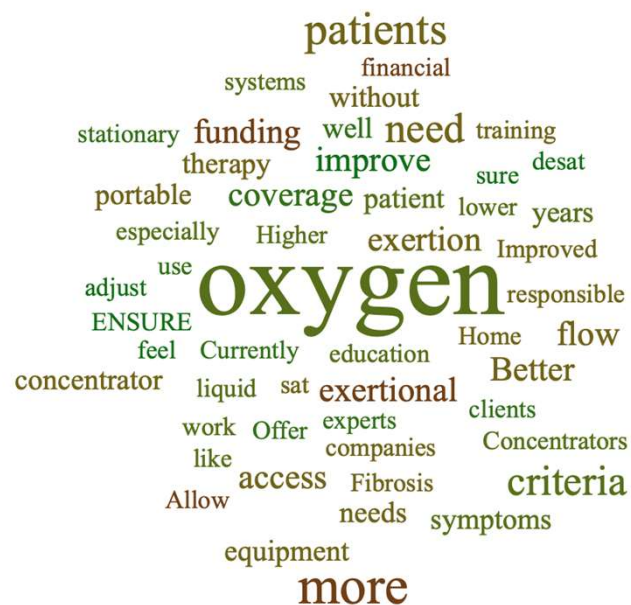
- Easily accessible
- instant service

Word cloud includes words with 3+ mentions

Improvements to Oxygen Therapy

Increase coverage for additional equipment, update criteria for other O2 needs, more supportive funding criteria, training, and modern equipment are the top suggestions to improve oxygen therapy

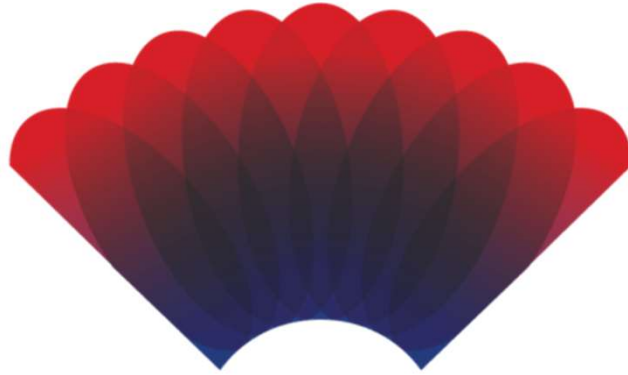
In your opinion, what should be done to improve oxygen therapy?



Popular Themes Mentioned:

- Increase coverage for additional equipment
- Add/modify criteria for other O2 needs
- More supportive funding criteria
- Training/Education
- Modern equipment

Word cloud includes words with 3+ mentions



Canadian
Pulmonary
Fibrosis
Foundation

Canadian Pulmonary Fibrosis Foundation

Oxygen Providers Survey Report

Pearl Strategy and Innovation Design

January 2023

Agenda

1. Objectives & Learning Goals
2. Methodology
3. Executive Summary
4. Oxygen Provider Profile
5. Patient Needs & Access

Objectives & Learning Goals

Objectives

- Provide insights to help CPFF understand an oxygen provider's perspective on oxygen therapy accessibility in order to advocate for change to benefit people living with this disease.

Learning Goals

- Understand barriers to oxygen therapy and areas of need for patients and/or caregivers
- Key areas that CPFF should prioritize to make the biggest impact on the lives of PF/IPF patients and caregivers

Methodology

- Oxygen Providers were recruited through CPFF's database and network (newsletter, social media, associations) and asked to complete an online survey.
- Respondent Breakdown: **N=27 Total Respondents**
- **NOTE: Due to small sample sizes – results should be interpreted as directional**

Executive Summary

Executive Summary

Key Findings

Access to Oxygen Therapy

- Beyond the hospital, access by patients to oxygen therapy shows room for improvement in all situations.
- Access to funding is a key barrier mentioned by oxygen suppliers, particularly in Alberta. Other national barriers include the need for higher oxygen flow equipment, travelling with oxygen and access to equipment.

Provincial Coverage

- Provincial coverage for oxygen therapy is rated as disappointing in Alberta and Ontario.
- Limited and reduced coverage for oxygen therapy are the top mentioned reasons for low accessibility ratings.

Access to New Oxygen Therapy Prescription

- About 1 in 5 of oxygen providers feel its not easy for a patient to receive an oxygen therapy prescription when needed.
- Availability of physicians was a widespread barrier to getting a new oxygen therapy prescription in the East. Respiriologist accessibility and restrictive criteria were also barriers in other provinces.

Oxygen Deliveries & Patient Support

- More than half of oxygen providers feel that patients do not have equal access to timely oxygen deliveries.
- Most oxygen providers' organizations offer In-person training, appointment scheduling, phone support, and easy written instructions.

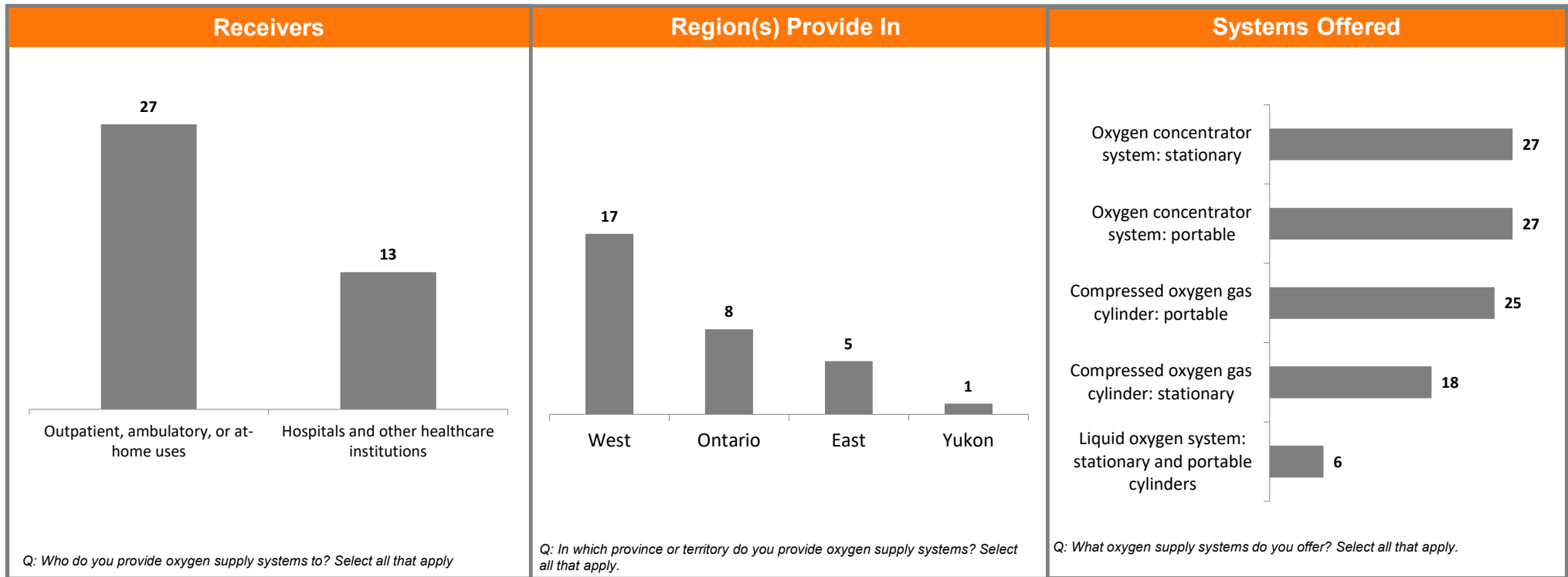
Patient Challenges

- Knowing when and how to get changes to oxygen therapy is the biggest challenge for patients. Other notable challenges include getting reassessed and delays in reimbursement or equipment delivery.

Oxygen Provider Profile

Oxygen Provider Demographics

Majority of oxygen provider survey participants supply in the West and Ontario. All provide oxygen supply systems to outpatient, ambulatory, or at home users and offer oxygen concentrator systems.

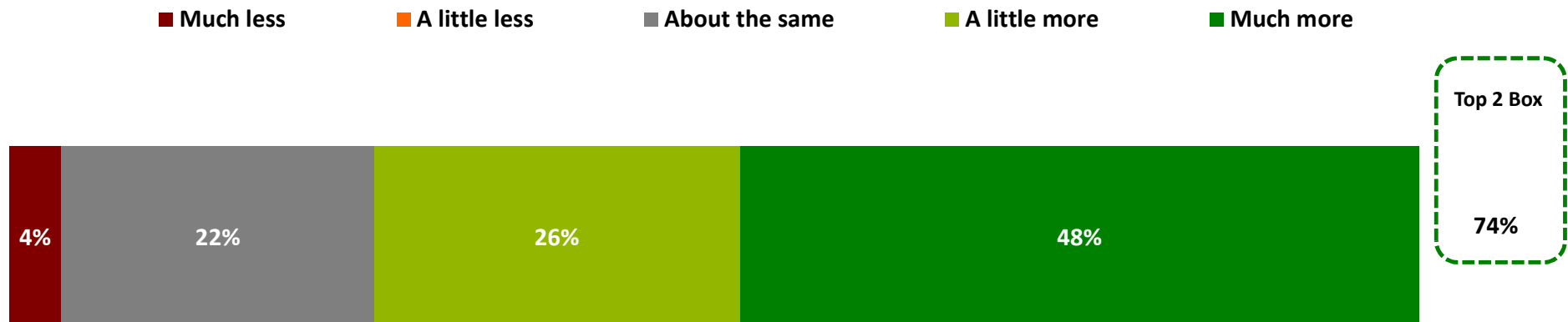


Patient Needs & Access

Oxygen Needs

About 3 in 4 oxygen providers feel that pulmonary fibrosis patients have higher oxygen needs than COPD patients.

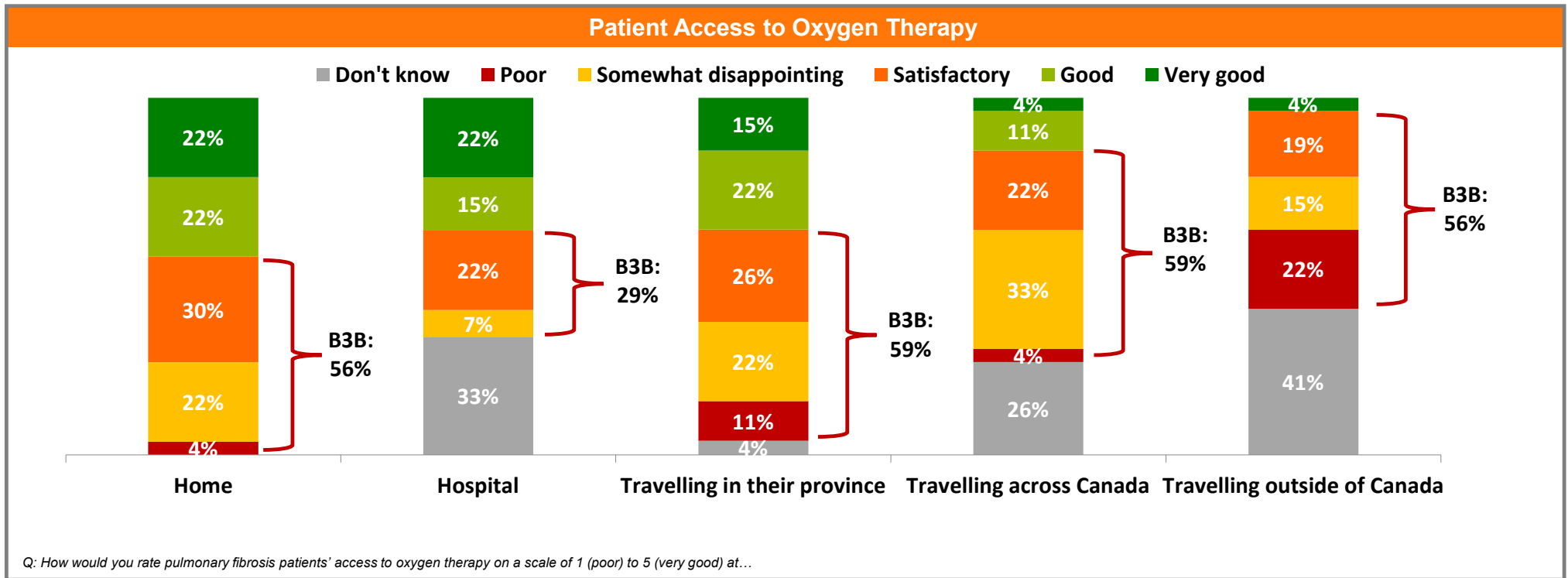
Oxygen Needs of Pulmonary Fibrosis Patient Compared to COPD Patient



Q: How would you rank the oxygen needs of a pulmonary fibrosis patient compared to a Chronic Obstructive Pulmonary Disease (COPD) patient? Pulmonary Fibrosis patient oxygen needs are...

Patient Access to Oxygen Therapy

Beyond the hospital, access by patients to oxygen therapy shows room for improvement in all situations.



Patient Access to Oxygen Therapy - Reasons

Access to funding is a key barrier mentioned by oxygen suppliers, particularly in Alberta. Other national barriers include the need for higher oxygen flow equipment, travelling with oxygen and access to equipment.

Please explain your rating scores for pulmonary fibrosis patients' access to oxygen therapy

Access to Funding

- *"Funding agencies often don't effectively support these needs and complexity to arrange oxygen increases exponentially when travelling inter-city, interprovincially, cross-border or internationally" - AB, MB*
- *"The most difficult thing in my experience is the access to funding for the necessary equipment" - AB*
- *"Access to O2 in the community only if you qualify for funding unless you want to pay privately" - AB*
- *"The issue becomes funding and whether it is paid for by a third party agency (ie government) or if the patient wishes to pay for the therapy themselves or through private insurance" - ON*

Need for Higher Oxygen Flow Equipment

- *"It depends on the flow rate required. Pulmonary Fibrosis patients sometime require higher flows that is challenging to provide with stationary & POC's." - NS*
- *"Pulmonary Fibrosis patients often require higher litre flows that other patients with respiratory diseases." -NF*
- *"Travelling with O2 can be challenging for pulmonary fibrosis patients due to their frequent need for higher flows on exertion. Access to higher flow equipment can be an issue" - PEI*

Travelling with Oxygen

- *"However, traveling the world gets very very difficult and sometimes impossible requiring them to take equipment from Canada elsewhere, the issue here is the stress caused as often the airlines lose it etc." - AB*
- *"Travelling with O2 can be challenging for pulmonary fibrosis patients due to their frequent need for higher flows on exertion." - PEI*
- *"NL is vast and we have large areas with no tank depot so lots of pre-planning for travel is necessary". -NF*

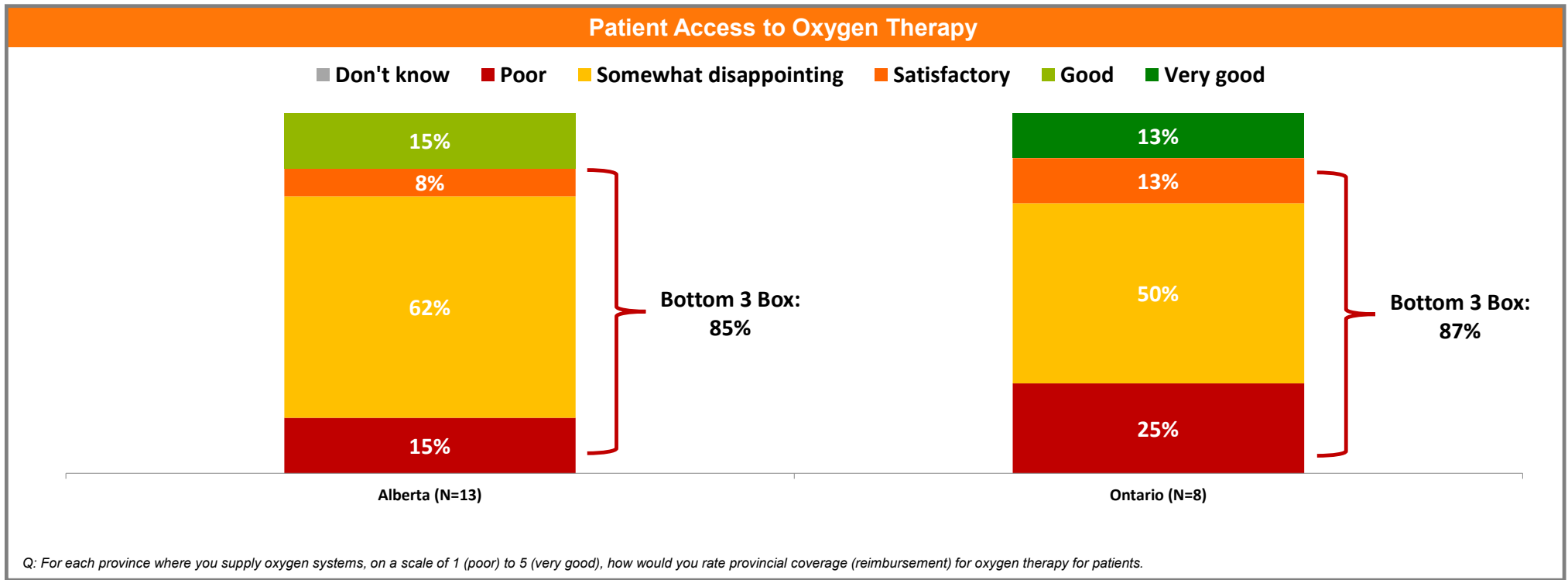
Access to Equipment

- *"Liquid oxygen is the best way to provide this. Many jurisdictions do not provide liquid oxygen at all"- ON*
- *"Extremely difficult to obtain home oxygen for this demographic. It was very frustrating for both the patient and the provider" - AB*

Word cloud includes words with 8+ mentions

Provincial Coverage for Oxygen Therapy for Patients

Provincial coverage for oxygen therapy is rated as disappointing in Alberta and Ontario.



Q: For each province where you supply oxygen systems, on a scale of 1 (poor) to 5 (very good), how would you rate provincial coverage (reimbursement) for oxygen therapy for patients.

NOTE: Provinces with less than N=5 have been removed from this chart

Provincial Coverage for Oxygen Therapy for Patients

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

Please explain your scores...

Alberta

Not enough coverage

- *"Only 1 stationary and 1 portable system are covered through provincial funding. If you want more, then you have to pay or the provider has to swallow the costs"*
- *"Very poor coverage, inadequate for patients"*
- *"Not enough funding"*

Ontario

Reduced funding/inadequate coverage

- *"Over the last decade, the HOP program has decreased the funding for oxygen several times. Over that same period the price of gas, equipment costs and staffing costs have all increased which makes it more difficult to provide oxygen services and still make a profit."*
- *"Ontario government slashed reimbursement by 17% in 2019, and offer no mechanism to increase rates in the face of high inflations"*
- *"The Ontario government has cut funding so severely that we are having a hard time seeing out patients as often as we would like"*

Saskatchewan

- *"Saskatchewan has a reasonable reimbursement model which supports increased portable oxygen use with increased reimbursement to providers"*

Manitoba

Limited coverage and distribution resources

- *"Portable is not covered for prov program so can be pricy for patients unable to reach their pharmacare deductible"*
- *"Manitoba offers some ambulatory oxygen support, the greater challenge in that province is to supply across such a large and varied geography with limited resources"*

Newfoundland & Labrador

No coverage/Difficult to qualifying

- *"There is no provincial coverage for oxygen in Newfoundland. Patients must contact a private supplier and pay at their own expense"*
- *"Our provincial government program is based financials only. Most seniors with any pension do not qualify."*

Nova Scotia

- *"Home oxygen model based on income and could often have two pensioners required co-pay to be unaffordable."*

Yukon

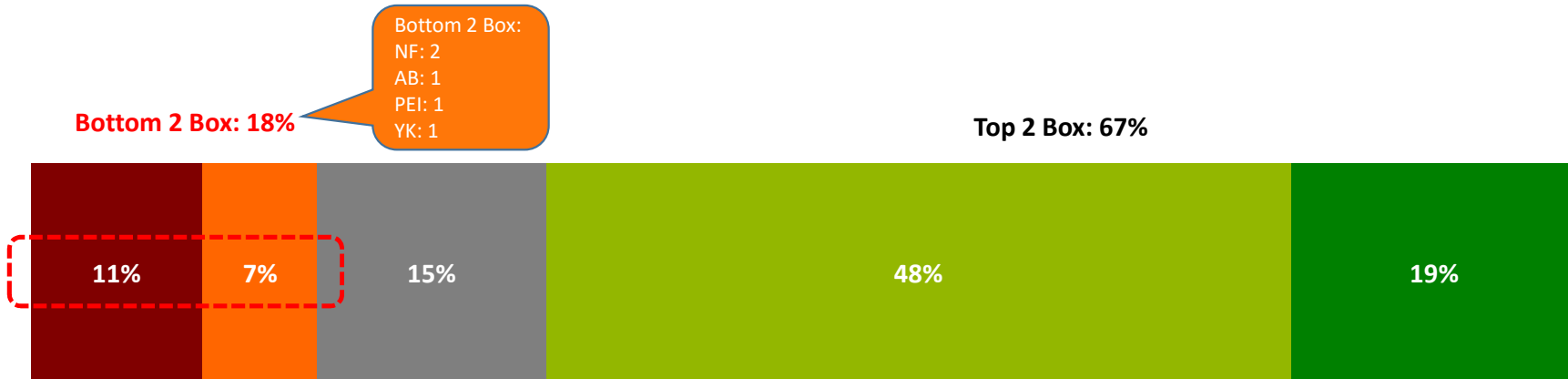
- *"There is no territory-wide plan that covers home oxygen. coverage varies based on funding agency"*

Access to New Oxygen Therapy Prescription

About 1 in 5 of oxygen providers feel its not easy for a patient to receive an oxygen therapy prescription when needed.

“When a patient’s needs change, it is easy for them to get a new oxygen therapy prescription”

■ Strongly Disagree ■ Somewhat Disagree ■ Neither Agree nor Disagree ■ Somewhat Agree ■ Strongly Agree



Q: Please rate how much you agree or disagree with this statement: “When a patient’s needs change, it is easy for them to get a new oxygen therapy prescription”

Access to New Oxygen Therapy Prescription – Disagree

Availability of physicians was a widespread barrier to getting a new oxygen therapy prescription in the East. Respiriologist accessibility and restrictive criteria were also barriers in other provinces.

Respondents who DISAGREE with the statement: "When a patient's needs change, it is easy for them to get a new oxygen therapy prescription"

Availability of Physicians/Family Doctor

- *"We have an extremely alarming level of physician vacancies. Our patients are struggling with getting the follow-up care they need as outside of the Avalon we do not even have access to a walk in clinic" - NF*
- *"A significant portion of the population does not have access to a family doctor." PEI*
- *"Unfortunately there is a family physician shortage in Newfoundland. Many of our patients are no longer followed by a primary healthcare physician." – NF*

Inaccessible Respirologist

- *"The wait to see Respirology is also 1-2 years currently. We fax doctors often for prescription changes/updates but often do not receive a response." -NF*
- *"often IPF patients are covered by respirology in a neighbouring province for their home oxygen needs as a result. we have no visiting respirologist". -YK*

Restrictive Criteria

- *"A COPD patient who does not qualify at rest and has not needed exertional oxygen in the past, now needs exertional oxygen. Many unnecessary hoops to jump through and frustrating criteria to meet in order to obtain supplemental oxygen. Again, this is Alberta I am speaking about. I cannot speak to anywhere else" - AB*

Access to New Oxygen Therapy Prescription – Agree

Oxygen providers who feel it's easy for patients to get a new oxygen therapy prescription acknowledge responsive physicians/doctors. Some mention respirologists and respiratory therapists can also initiate a new prescription.

Respondents who AGREE with the statement: "When a patient's needs change, it is easy for them to get a new oxygen therapy prescription"

Responsive Physician/Doctor

- *"Doctors are usually receptive in Alberta for when the patients needs change"- AB*
- *"We do assessment, we contact physician and they respond within 24 hours with a new prescription". -AB*
- *"If needs change and we require a prescription, we typically do not have an issue with requesting and receiving one in a timely manner." - AB*
- *"I don't feel oxygen prescriptions or changes are particularly difficult from a patient's most responsible physician." - AB, MB*

Respirologists & Respiratory Therapists Can Initiate New Prescriptions

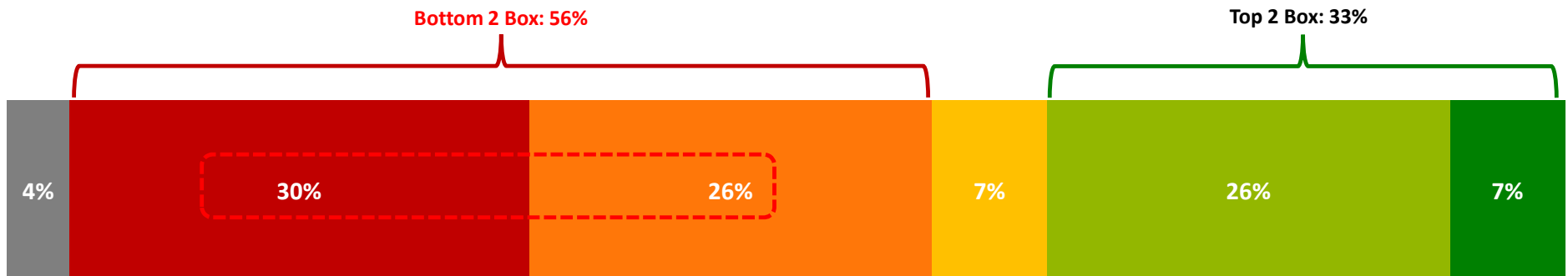
- *"In Ontario, a Registered Respiratory Therapist can initiate a new oxygen prescription". - ON*
- *"Generally, in Ontario, the home care Respiratory Therapist is allowed to adjust oxygen prescription as needed. Then a follow up with the doctor can lead to a prescription change". -ON*
- *"In my area of the Province a Respirologist has to write the prescription in order to get coverage through the Home O2 program." - NS*

Access to Timely Oxygen Deliveries

Over half of oxygen providers feel patients do not have equal access to timely oxygen deliveries.

"It doesn't matter where you live in a province, you have equal access to timely oxygen deliveries"

■ Don't Know ■ Strongly Disagree ■ Somewhat Disagree ■ Neither Agree nor Disagree ■ Somewhat Agree ■ Strongly Agree



Q: Please rate how much you agree or disagree with this statement: "It doesn't matter where you live in a province, you have equal access to timely oxygen deliveries"

Access to Timely Oxygen Deliveries - Disagree

Deliveries to rural/remote areas is a major barrier to timely oxygen deliveries, particularly in Ontario and Newfoundland. Shipping cost and staffing are also negative impacts.

Respondents who DISAGREE with the statement *"It doesn't matter where you live in a province, you have equal access to timely oxygen deliveries"*

Rural/Remote Areas

- *"Because of our isolated communities (Labrador, Northern NL, Port Aux Basques, Burgeo, Baie Verte etc) you have minimal access to hospitals, physicians, specialists and home oxygen services." - NF*
- *"Rural Newfoundland is quite isolated from the rest of the province. Some oxygen patients live 6+ hours from the nearest home oxygen provider. The further you live away, the longer it takes for you to receive supplies/higher the cost of your bill" -NF*
- *"Rural Ontario is currently underserved and, in my opinion, the gap will widen." - ON*
- *"Patients in rural zones don't have great access to oxygen delivery". - AB*
- *"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." - ON*
- *"If you live North of Sudbury, timeliness can be an issue due to distances" - ON*
- *"Definitely depends on how close the Home Care Company is to you or drop off location". - ON*
- *"Rural and Remote Canada pose challenges in delivery time, weather conditions and road access, including the need for ferries, winter roads or fly-in services."*
- *"More remote areas are harder to get to in a timely matter". - ON*

Cost and Staffing

- *"depends on office locations and number of therapists". -ON*
- *"shipping costs are often not covered for community patients. shipping companies dictate their own schedules." - YK*
- *"Due to cost and staffing availability, providers cannot have oxygen in every community as well." - ON*

Access to Timely Oxygen Deliveries - Agree

Adequate notice is a key enabler to timely oxygen deliveries.

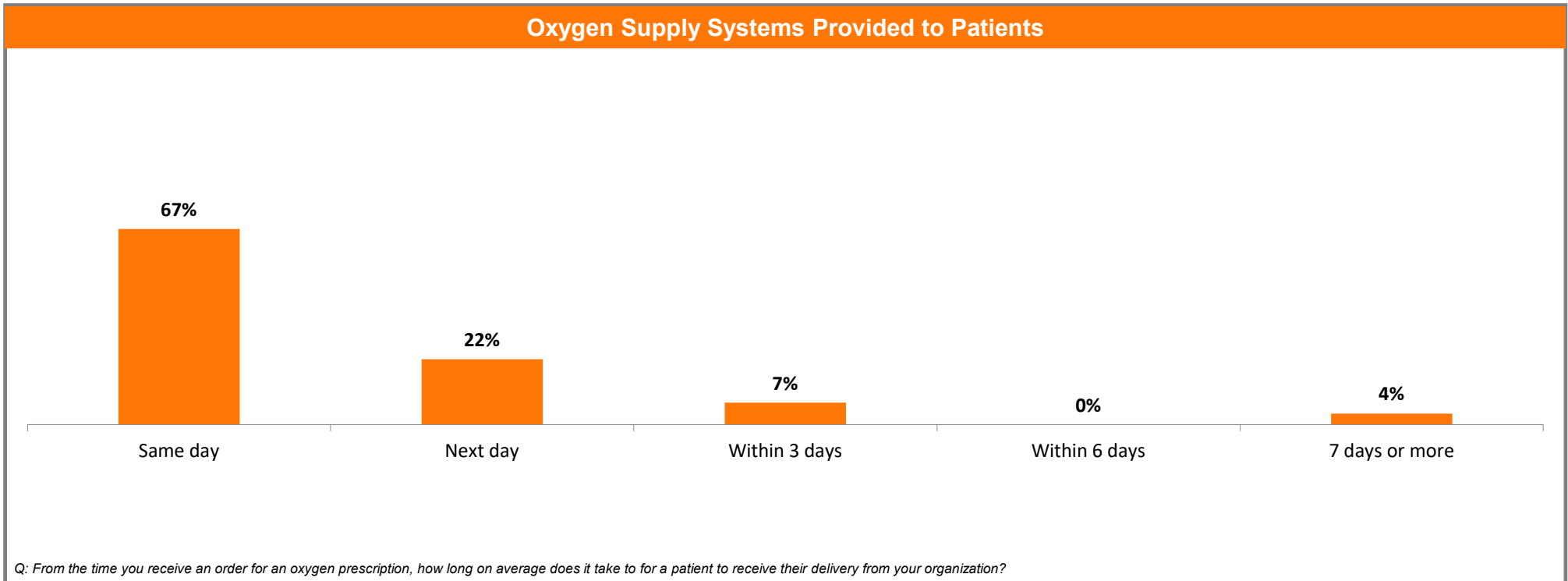
Respondents who AGREE with the statement *"It doesn't matter where you live in a province, you have equal access to timely oxygen deliveries"*

With adequate notice, delays can be avoided

- *"In some remote communities deliveries can be slightly delayed. That being said most providers provide systems and quantities to allow for that so that the patient is not impacted" - ON*
- *"We will always do our best to service each and every client to the best of our ability, but there can be situations where a little extra time and notice is required in order for us to arrange deliveries adequately" - AB*

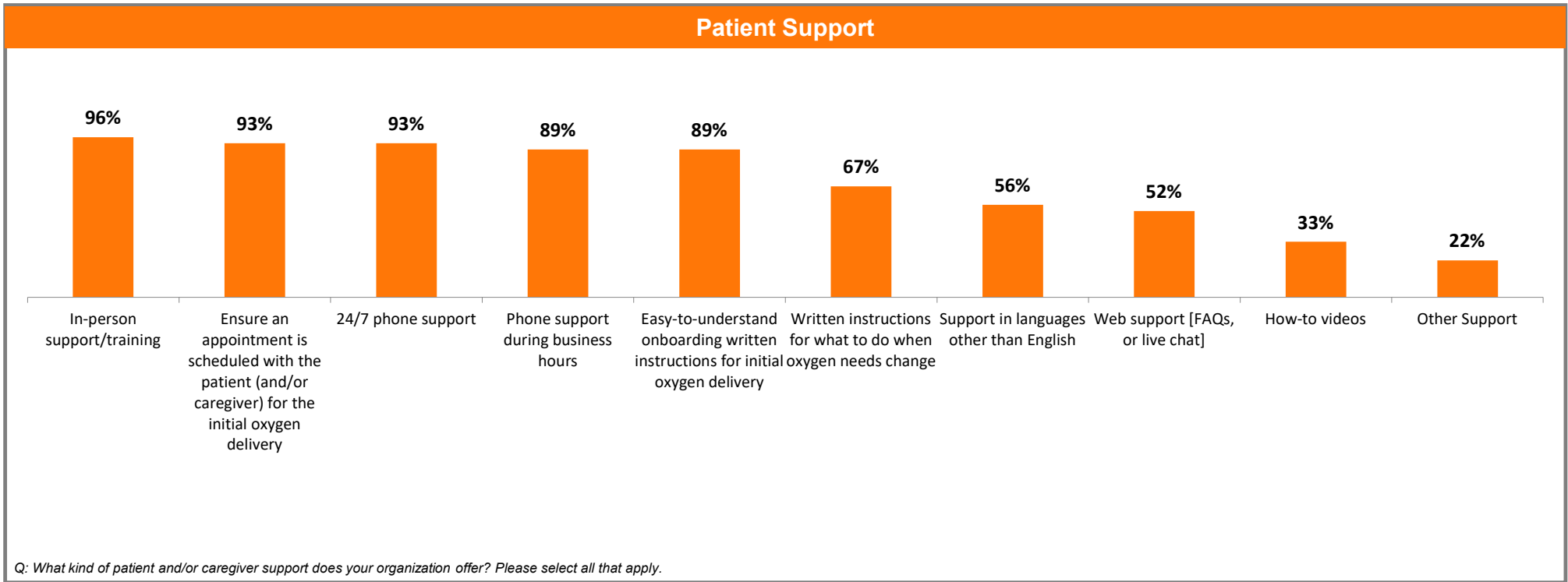
Delivery Wait Time

After oxygen providers receive an order, majority of patients receive their oxygen delivery on the same or next day – about 1 in 10 wait 3 or more days.



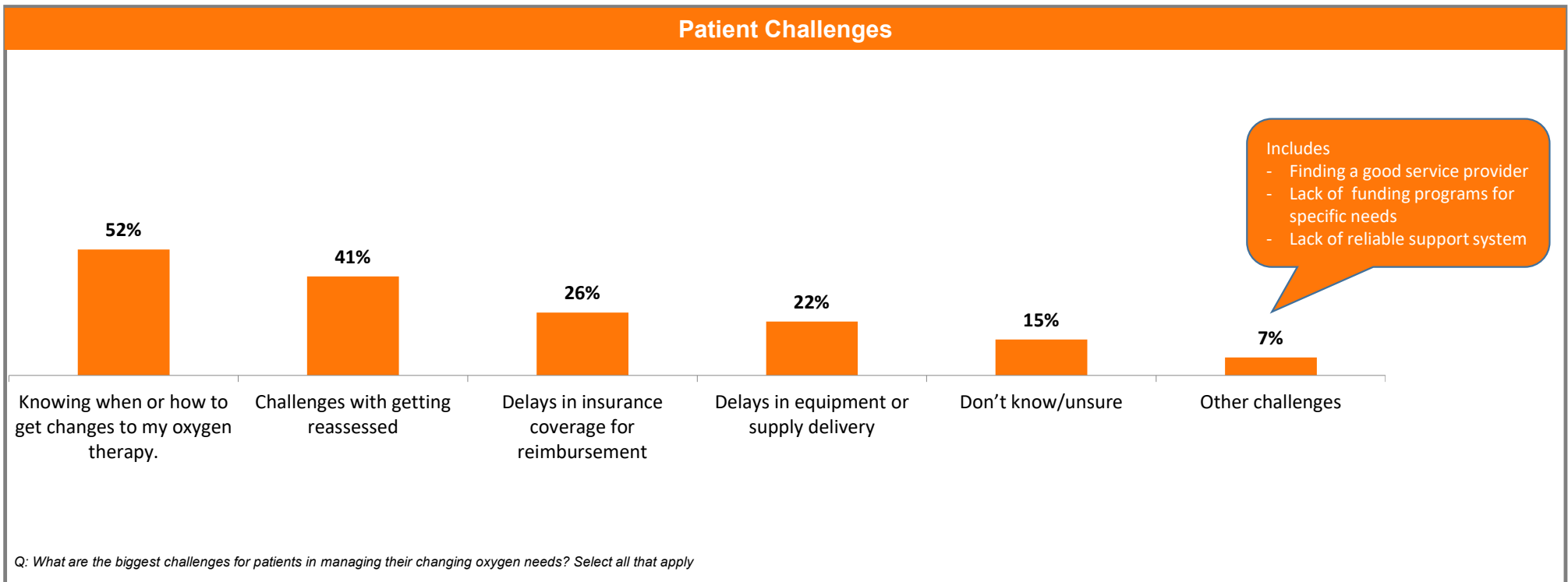
Patient Support

In-person training, appointment scheduling, phone support, and easy written instructions are the main support offered by oxygen providers.



Patient Challenges

Knowing when and how to get changes to oxygen therapy is the biggest challenge for patients. Other notable challenges include getting reassessed and delays in reimbursement or equipment delivery.



Improvements to Oxygen Therapy

Increased funding, modifying qualifying criteria, ensuring equal access and updating equipment technology are opportunities to improve oxygen therapy.

In your opinion, what should be done to improve oxygen therapy?

Increase Funding

- *"Increase reimbursement and enhance fairness in hospitals making client choice a legal right". -AB*
- *"Increased funding for high flow needs." - PEI*
- *"Larger provincial coverage". -AB*
- *"Increase coverage from provincial government". -AB*
- *"Provincial governments should offer home O2 services to patients or at least provide coverage under our provincial health plan". -NF*
- *"Increase funding". -ON*
- *"Make it more funded by the government for all people" - AB*
- *"Increase maximum income guidelines, coverage for POC's." - NS*
- *"Tired funding based on the patients needs, higher needs patients need more equipment and RT visits, therefore they are more costly to care for". -ON*

Modify Qualifying Criteria

- *"Increase access to funding by removing many of the hoops that patients need to jump through to qualify. Other provinces have very minimal requirements." - AB*
- *"Retool and update qualification criteria". -AB*
- *"we hope to see funding qualifications become easier to access" - AB*
- *"territorial home oxygen program with medically sound criteria for funding." - YK*

Equal Access

- *"equal access that doesn't depend on where you live. Private pricing to some isolated areas would be far too expensive for a senior to pay" - NF*
- *"Increase the monthly rate, ensure all providers are accredited/ISO certified, the MOH should take steps to verify that providers comply with the terms of their vendor agreements to ensure all patients have equal access to quality care". -ON*

Updated Equipment Technology

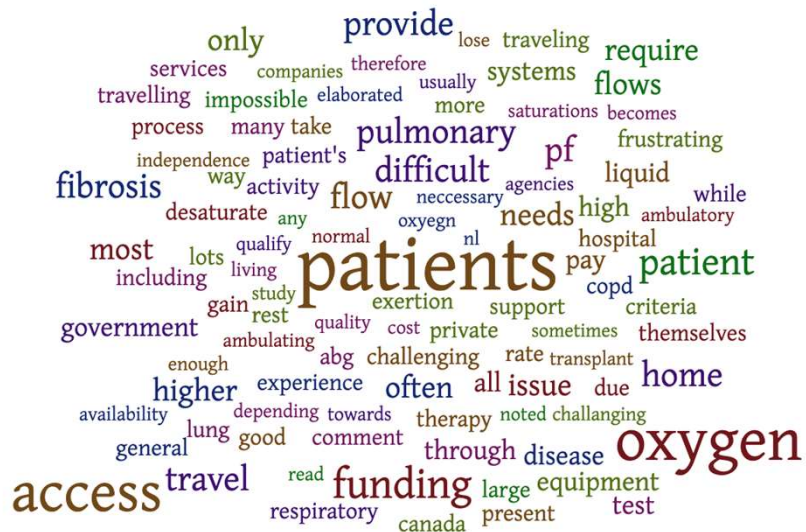
- *"We hope that technology will continue to develop and we will get portable units that can give higher flows and that last longer, we hope to see funding qualifications become easier to access, we hope to see more exceptional criteria for oxygen patient". -AB*
- *"Look at limitations of technology."*

Appendix

Patient Access to Oxygen Therapy - Reasons

Accessibility to funding, a need for higher oxygen flow equipment, travelling with oxygen tanks, and access to equipment are the main barriers to access oxygen therapy for PF patients

Please explain your rating scores for pulmonary fibrosis patients' access to oxygen therapy



Popular Themes Mentioned:

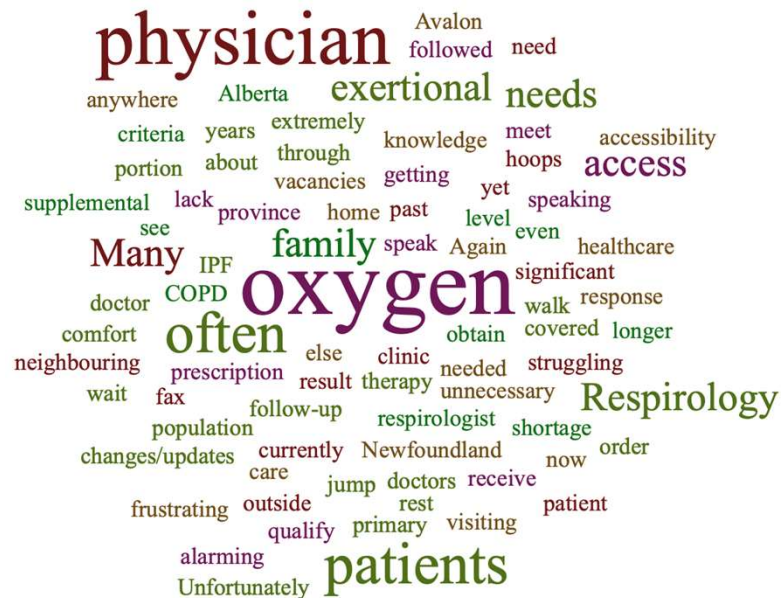
- Access To Funding
- Need For Higher Oxygen Flow Equipment
- Travelling With Oxygen
- Access To Equipment

Word cloud includes words with 8+ mentions

Access to New Oxygen Therapy Prescription – Disagree

Among those who feel it is not easy to get a new oxygen prescriptions, non-availability of physicians and respirologists are the top mentioned reasons.

Respondents who DISAGREE with the statement: "When a patient's needs change, it is easy for them to get a new oxygen therapy prescription"



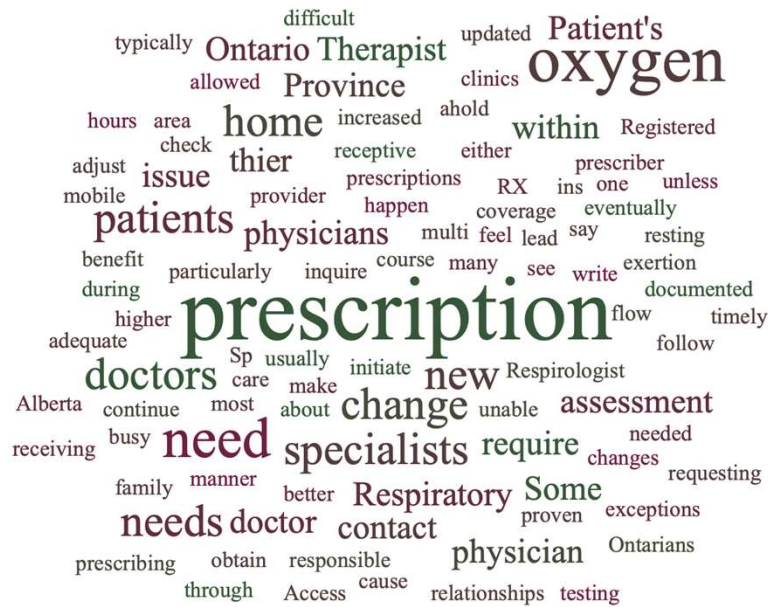
Popular Themes Mentioned:

- Availability Of Physicians/Family Doctor
- Inaccessible Respirologist
- Criteria Hurdles

Access to New Oxygen Therapy Prescription – Agree

Among those who feel it is easy to get a new oxygen prescriptions, top reasons are receptive physician/doctor and respirologists who can initiate issuance of new prescriptions.

Respondents who AGREE with the statement: *“When a patient’s needs change, it is easy for them to get a new oxygen therapy prescription”*



Popular Themes Mentioned:

- Receptive Physician/Doctor
- Respirologists Can Initiate New Prescriptions

Word cloud includes words with 3+ mentions

Access to Timely Oxygen Deliveries - Agree

Among those who feel that everybody has equal access to timely oxygen deliveries, believe that with adequate notice or planning any delays can be avoided

Respondents who AGREE with the statement “It doesn’t matter where you live in a province, you have equal access to timely oxygen deliveries”



Popular Themes Mentioned:

- With adequate notice, delays can be avoided

Word cloud includes words with 3+ mentions