



# Needs Assessment of People Living with PF in Canada



Market research in  
collaboration with Quebec  
Lung Association, Canadian  
Pulmonary Fibrosis  
Foundation and Living Well  
with Pulmonary Fibrosis

2021





# Needs Assessment of People Living with PF in Canada

*The content of this report is for information purposes only and serves to better understand the needs of those with Pulmonary Fibrosis, and the healthcare professionals who care for them, in regard to their physical activity and well-being.*

*It also helps to aid the development of the PF ConnEx exercise, education and lifestyle program and ensure that it is appropriate, relevant and acceptable to this population.*

*This report is not intended to serve as medical or professional advice. Medical advice should be sought-after from a qualified health care professional for any questions. Reliance on any information disclaimed in this report is solely at your own risk. We do not assume any responsibility or legal liability for the accuracy, completeness, timeliness, or quality of any information in this report.*

*Furthermore, the accompanying written interpretations have been formulated by the author based on time/budget and are not exhaustive. Further results can be drawn from a more detailed analysis.*



**This report was made possible thanks to the support of an unrestricted grant from Boehringer Ingelheim and in collaboration with RESPIPLUS™, Quebec Lung Association (L'Association pulmonaire du Québec), and Canadian Pulmonary Fibrosis Foundation.**

**This report is available on the website [www.willkin.ca](http://www.willkin.ca)**

**Copyright © 2021 WILLKIN HEALTH, All rights reserved.**

# Table of Contents

## 1 Introduction

- 2. Methodology
- 3. Description of the Sample - Patient
- 4. Description of the Sample - HCP

## 5 Physical Activity

- 6. Biggest Challenges (1/2)
- 7. Biggest Challenges (2/2)
- 8. Physical Activity Pre-Pandemic
- 9. Behavioural Change
- 10. Physical Activity Variation
- 11. Supervised Activity
- 12. Mental & Physical Health
- 13. Barriers to Program Participation
- 14. Interest in Help & Support
- 15. Referring to Exercise Programs

## 16 PF ConnEx Program Acceptability

- 17. Acceptability of the Program
- 18. Preferred Delivery for the Program
- 19. Understanding the Benefits of a Kinesiologist
- 20. Perceived Usefulness of the Program
- 21. Willingness to Pay
- 22. Price Point

## 23 Internet Behaviour

- 24. Digital Tools Used

## 25 Clinical Pulmonary Rehabilitation

- 26. Accessibility to Clinical PR

## 27 Appendix

## 29 Acknowledgments

# Introduction to the research

PF ConnEx | Needs Assessment Survey 2021

The objective of this research was mainly exploratory. Considering there is not a similar program currently available it is important, prior to developing such a solution, that we reach a community of people living with pulmonary fibrosis and healthcare professionals working within this domain, to understand their thoughts and experience on at-home and remote exercise programs.

It must be noted that the data collection was conducted between waves of the COVID-19 pandemic. Some areas had partial restrictions lifted, but people's fears of the virus were still present and significant impacts on clinical settings were still present.

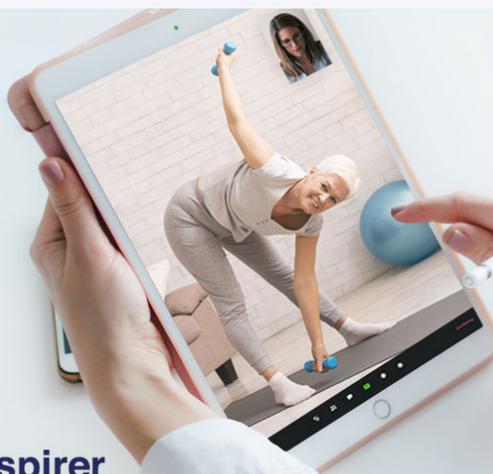
More specifically, the study is aimed at understanding the following questions:

## PATIENTS

1. What are the thoughts on starting an at-home, remote exercise, and lifestyle program?
2. What was the level and experience of respondents with exercise prior to, and during the COVID-19 pandemic?
3. What degree of motivation do they possess in order to begin this program remotely?
4. What are their thoughts on the structure of the program, ideal length and preference between small group or individual sessions?

## HEALTHCARE PROFESSIONALS

1. What are the opinions and motivations of HCPs for referring their patients to an exercise and lifestyle program?
2. What kind of physical activity delivery format (remote/in-person and individual/small group session) would they prefer for their PF patients?



**Mouvement. Santé. Inspirer**  
Movement. Health. Inspired

# Methodology

PF ConnEx | Needs Assessment Survey 2021

Willkin conducted this survey in collaboration with QUEBEC LUNG ASSOCIATION (APQ), CANADIAN PULMONARY FIBROSIS FOUNDATION (CPFF) and LIVING WELL WITH PULMONARY FIBROSIS, by RESPIPLUS™ (LWWPF).

## SAMPLE

The sample was collected via the email database of both organizations (APQ and LWWPF) and via CPFF's newsletter and Facebook. A total of 59 Canadian PF patients and 63 Healthcare Professionals (HCP) working in the field of PF were surveyed through an online GOOGLE FORM between July and August.

Because the survey was not part of a complete list of people living with the disease in Canada nor randomly surveyed the entire population, not every person had a "non-zero chance" of participating (eg. certain regions, or people without access to internet). Therefore, these results are NOT representative of the whole PF population. However, the results are an effective tool for learning more about the surveyed sample.



## SURVEY STRUCTURE

The survey was constructed with 32 patient and 20 HCP questions designed to collect information related to the following objectives:

1. What are the opinions of patients on starting an at-home, remote exercise, and lifestyle program (including structure and length).
2. What is the level and experience of the patient with exercise prior to and during the COVID-19 pandemic?
3. What are the different types of motivation patients have to begin an exercise program remotely.
4. What are the opinions and motivations of HCPs for referring their patients to an exercise and lifestyle program.

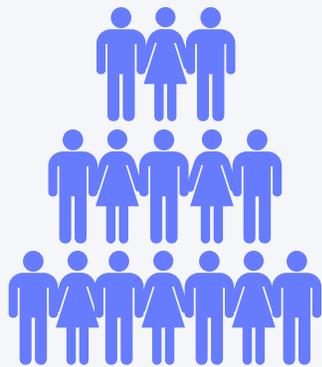
## ANALYSIS

Both quantitative and qualitative method is used to analyze the data.

The quantitative analysis is done by using formulas in the excel spreadsheet. The qualitative analysis is done by summarizing the findings of each response received from the respondents.

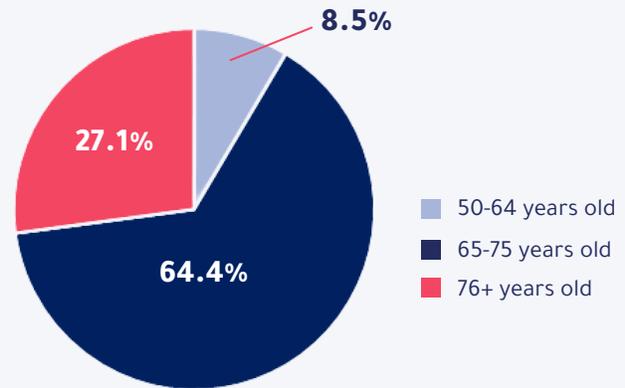
# Description of the sample - Patient

PF ConnEx | Needs Assessment Survey 2021



N = 59

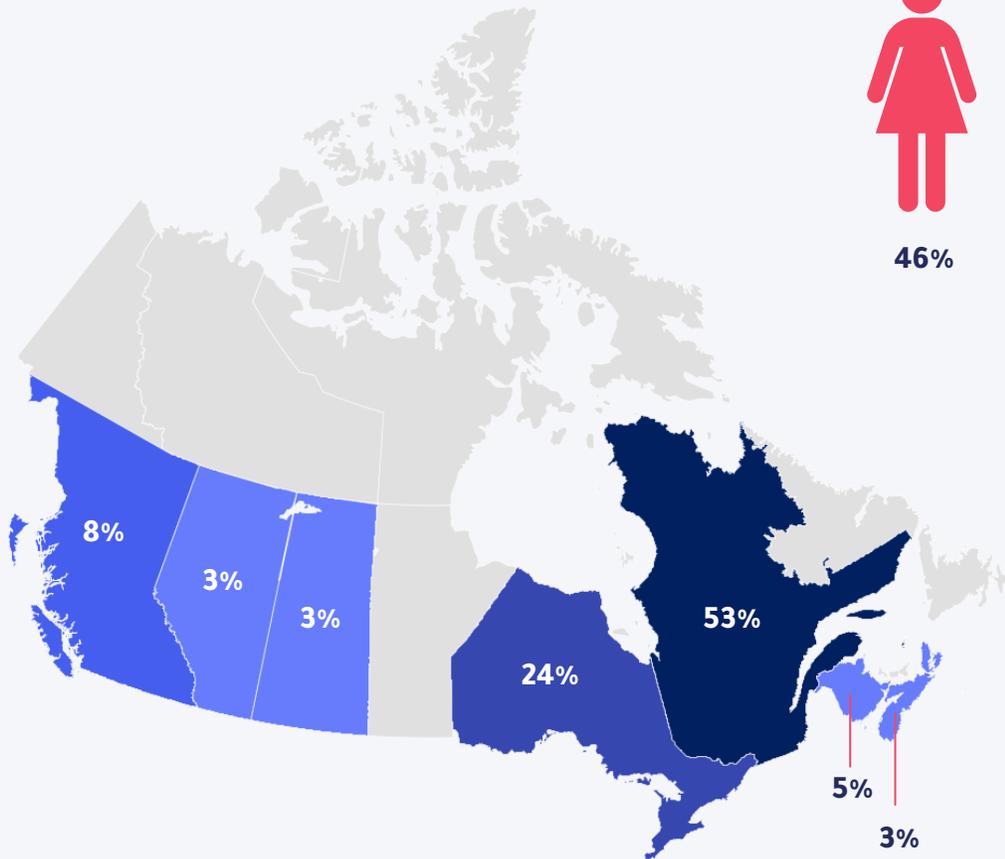
## Age of respondents



46%

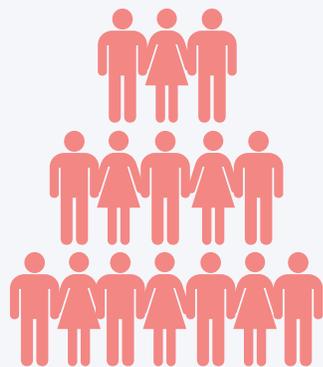


54%



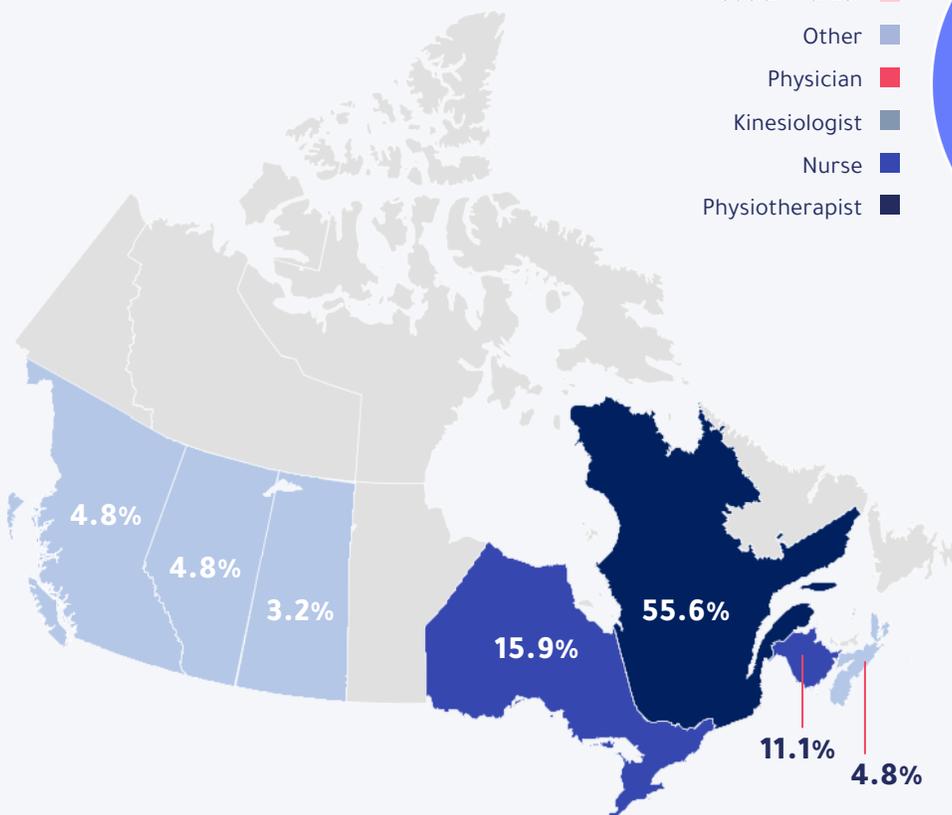
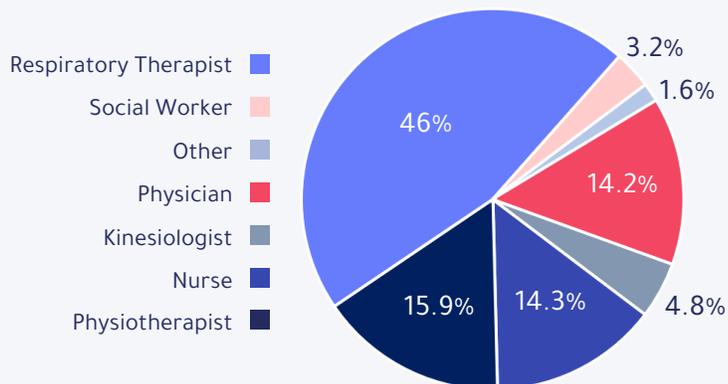
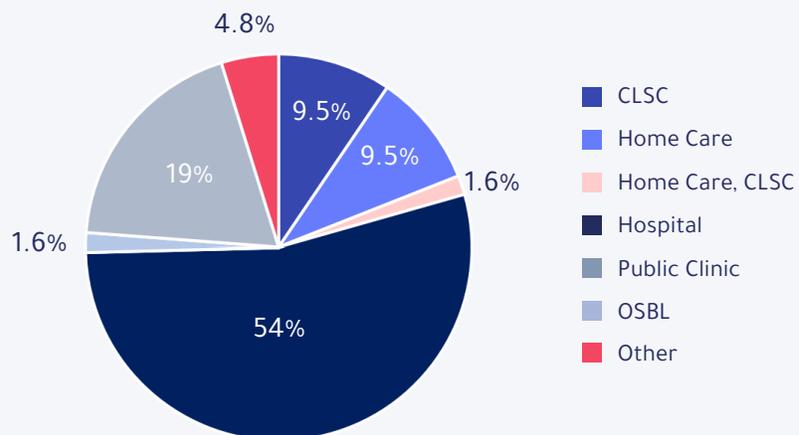
# Description of the sample - HCP

PF ConnEx | Needs Assessment Survey 2021



N = 63

## Professional Practice Setting





Part 1

# Physical Activity & People Living with PF

# Biggest Challenges

PF ConnEx | Needs Assessment Survey 2021

We asked respondents to tell us about their biggest challenges during the pandemic as a person living with PF\*. Among these results, we have compiled, in the form of a keyword cloud, the most frequently occurring terms.

Through these results, we note that the terms “Isolation” (17), “Staying Safe” (10), “COVID” (6), “Exercise” (6), “Keep Active” (5), “Motivation” (4), “Health” (4) and “Masks” (3) are those most frequently used by respondents regarding this thematic.



# Biggest Challenges

PF ConnEx | Needs Assessment Survey 2021

**Question: "During the COVID-19 pandemic, what has been your biggest challenge as someone living with pulmonary fibrosis?"** (The most relevant have been selected)

Isolation & loss of access to 3/week aquatic fitness classes I've lost muscle and tone and it's really feeding depression and a mounting sense of hopelessness

The same as before COVID: challenging myself to exercise within my current capabilities when it is no longer easy, painless and fun

Our usual gym where I exercised 3 times/wk was closed, and still is.

Along with pulmonary arterial hypertension trying just to walk

I found the masks too restrictive in breathing when leaving the house and in public

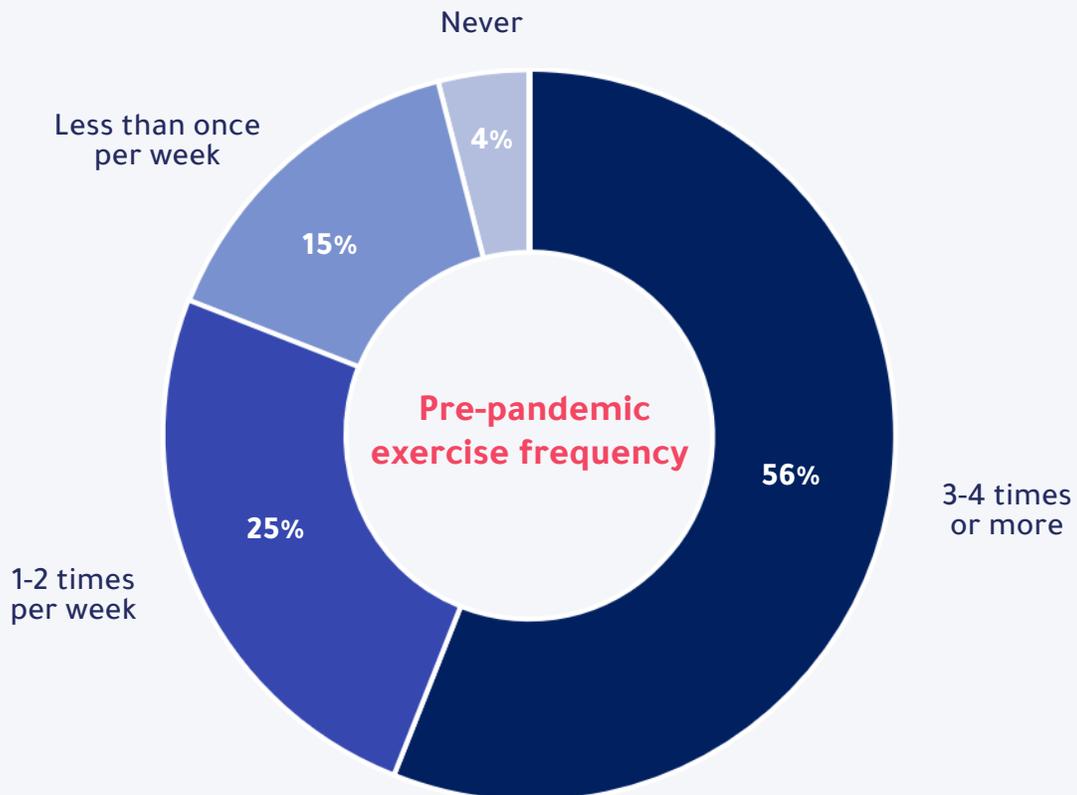
Lack of motivation to exercise

# Physical Activity Pre-Pandemic

PF ConnEx | Needs Assessment Survey 2021

Respondents were asked about their physical activity levels prior to the pandemic. From these numbers, we noted that more than half of the respondents (56%) were active 3 to 4 times a week, and a fourth (25%) were active 1 to 2 times a week. From the same sample, a small minority was inactive (4%).

More women exercise 3 to 4 times or more per week (59% vs. 53%) compared to men, and the men exercised 1 to 2 times/week (31% vs 19%) or rarely (16% vs 15%) compared to women.



\*Question:

"5. Before the COVID-19 pandemic, how often did you participate in any physical activity (this includes exercise classes, walking, etc.)?"

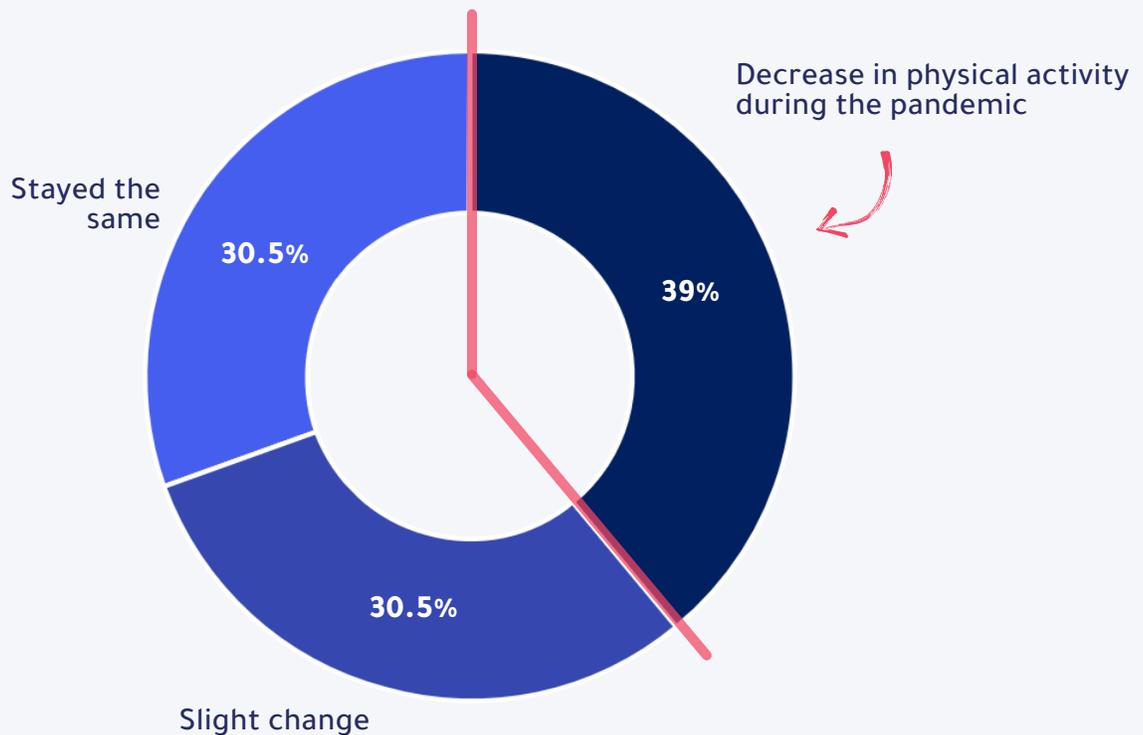
# Behavioural Change

PF ConnEx | Needs Assessment Survey 2021

Most of the respondents (39%) said they were not able to perform their regular activities as prior to the pandemic. The respondents that were not as active, were significantly more affected, reducing their exercise compared to others. Some of the other respondents (30.5%) said they can still perform **some, but not all**, of their regular activities, therefore indicating they were still impacted by the pandemic.

Those respondents that were active on a regular basis prior the pandemic had no change and, therefore we conclude had no impact on their physical activity. Equally, these respondents had positive thoughts about their health throughout the pandemic.

We can also find this same trend among both genders.



\*Question:

"6. I find it difficult to think positively about my health during the COVID-19 pandemic."

"8. During the COVID-19 pandemic, how has your level of physical activity changed?"

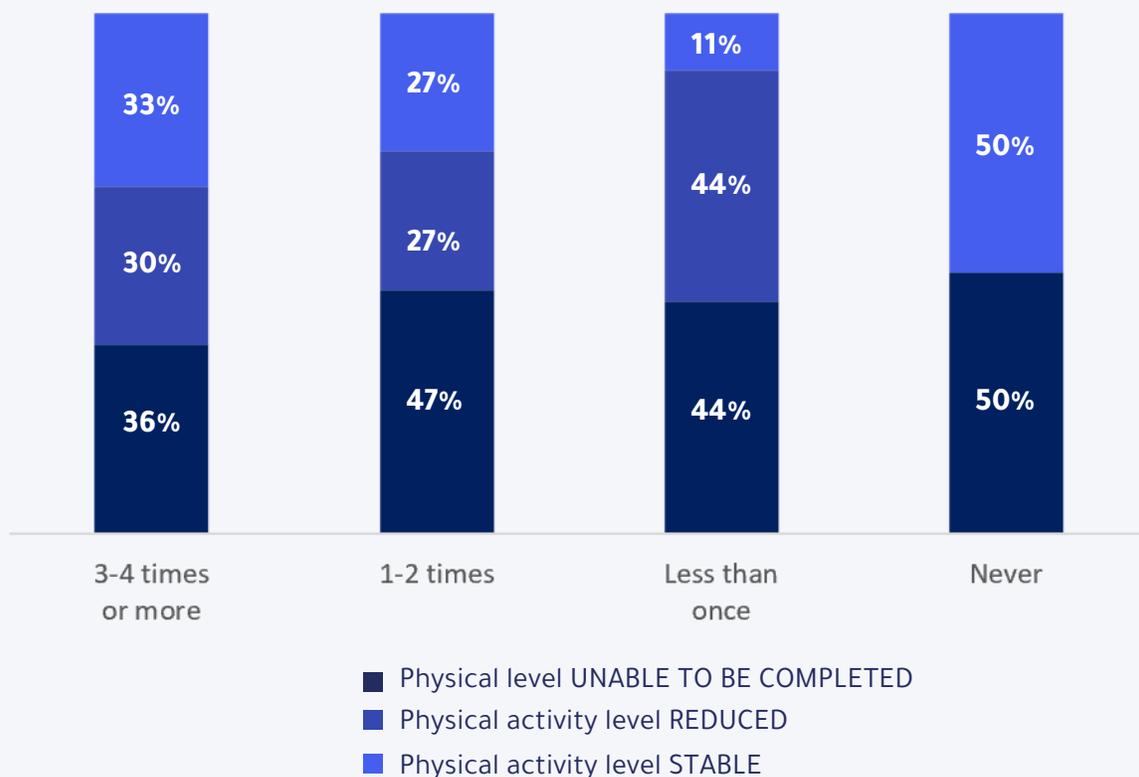
# Physical Activity Variation

PF ConnEx | Needs Assessment Survey 2021

It appears that the more active the respondent was prior to the pandemic, the less likely they were to reduce their level of exercise.

From this standpoint, we note that those who were not very active (rarely to never) were affected (18.6%) and reduced their exercise compared to the other groups.

It could be suggested that those who are active regularly (once a week and more) are less likely to reduce their physical activity despite the pandemic.



\*Question:

"5. Before the COVID-19 pandemic, how often did you participate in any physical activity (this includes exercise classes, walking, etc.)?"

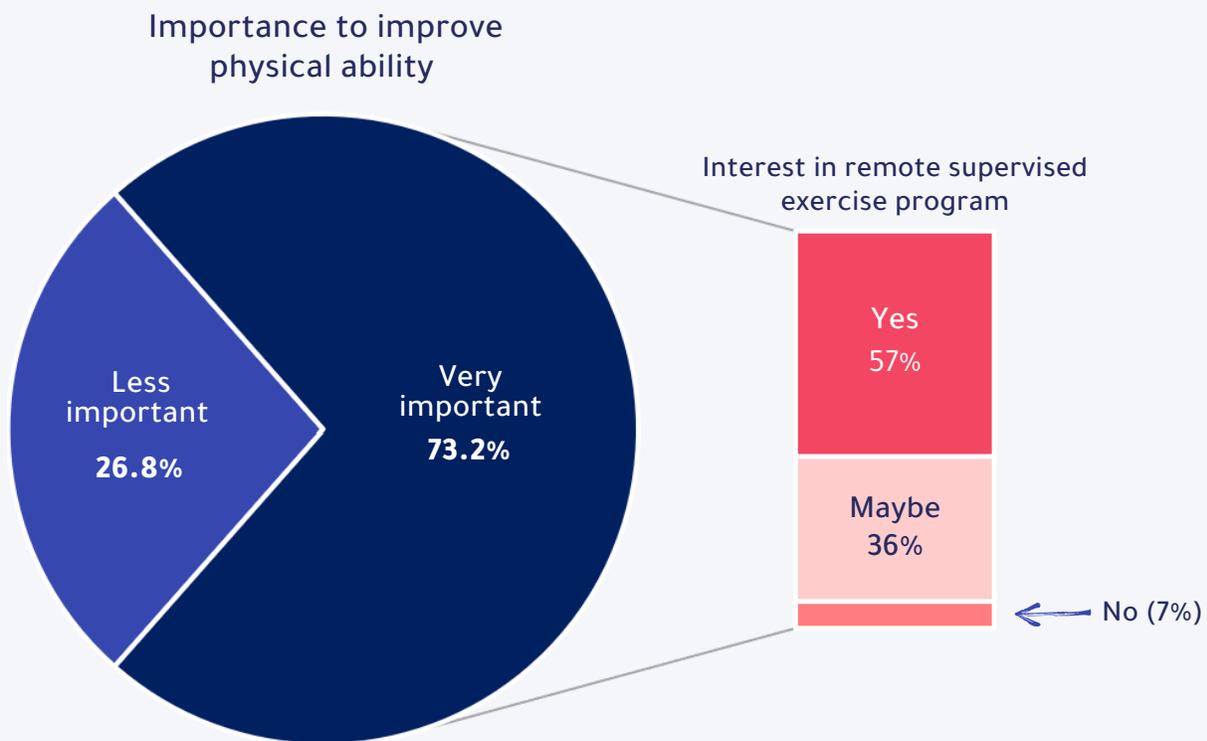
"8. During the COVID-19 pandemic, how has your level of physical activity changed?"

# Supervised Activity

PF ConnEx | Needs Assessment Survey 2021

Majority (57.6%) of respondents stated the importance of improving their physical ability. From this statistic, we can conclude that most patients who are concerned about improving their physical ability, are interested in a supervised exercise program. Approximately one third (27%) of respondents are confident about their physical ability to exercise independently.

Most of the respondents (57%) were interested in receiving help and guidance to manage their pulmonary fibrosis through a remote supervised exercise and lifestyle program. We can conclude that most of the respondents that were interested in the remote supervised exercise program would participate in a program twice a week and for a duration of 2 to 3 months.



**\*Question:**

"3. How important is it for you to improve your physical ability?"

"11. Would you be interested in receiving help and guidance to manage your pulmonary fibrosis through a remote supervised exercise/lifestyle program"

"12. How many times per week would you be willing to participate in a supervised exercise program at home?"

"13. What would your ideal program length be (assuming one supervised session per week)?"

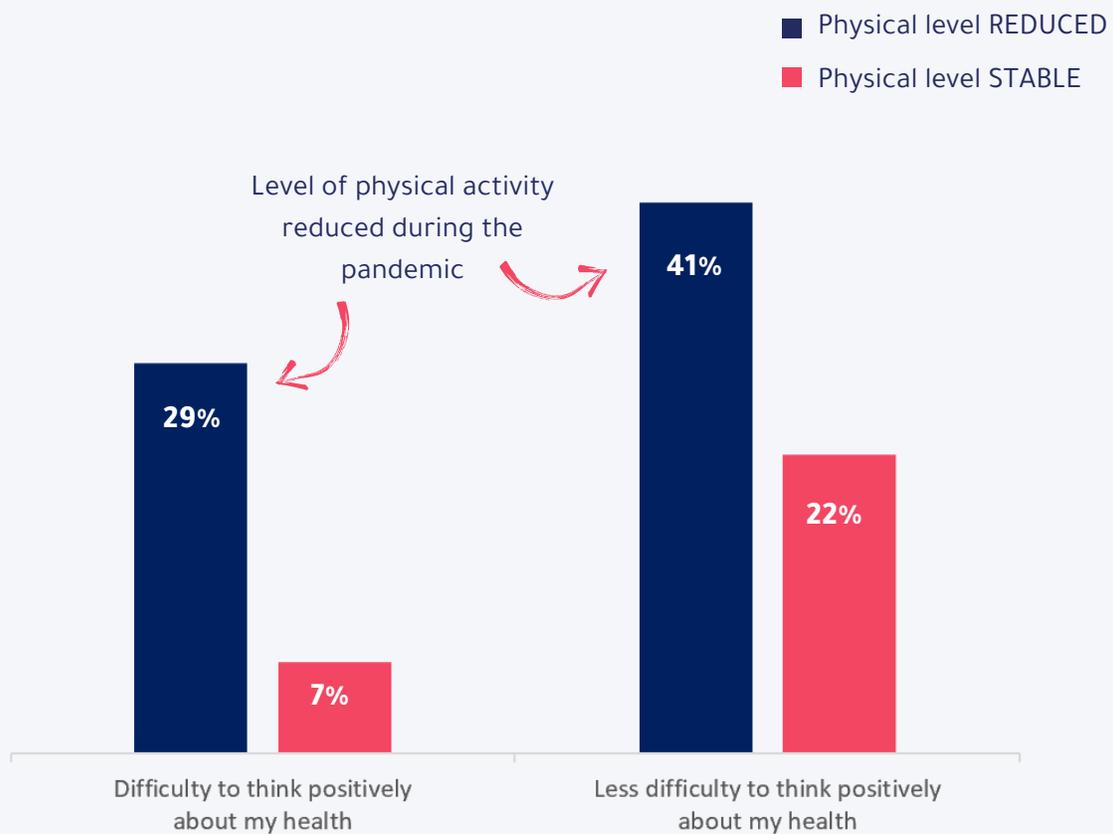
"14. With appropriate guidance, how confident are you with your physical ability to exercise independently?"

# Mental & Physical Health

PF ConnEx | Needs Assessment Survey 2021

By combining the data on lifestyle change with data on physical and mental health during the pandemic, it was found that those respondents who are concerned about their health were more physically active, which in turn helped them to think positively towards their life.

It was found that those respondents who were concerned about their health were more physically active, which in turn helped them to think positively about their health.



\*Question:

"3. How important is it for you to improve your physical ability?"

"6. I find it difficult to think positively about my health during the COVID-19 pandemic."

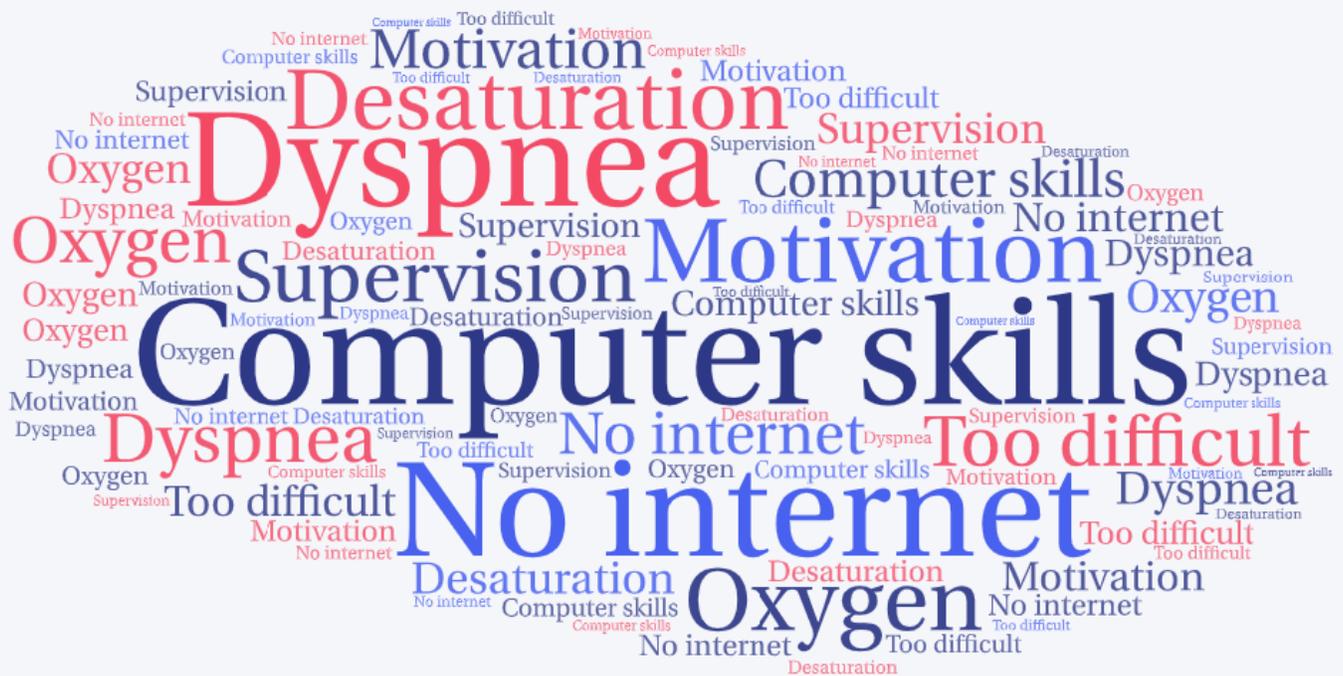
"8. During the COVID-19 pandemic, how has your level of physical activity changed?"

# Barriers to Program Participation

PF ConnEx | HCP - Needs Assessment Survey 2021

We asked HCP respondents to tell us what barriers may a patient with PF have to NOT want to participate in an at-home exercise program. Among these results, we have compiled, in the form of a keyword cloud, the most frequently occurring terms.

Through these results, we note that the terms “Computer Skills” (14), “Dyspnea” (10), “No internet” (9), “Motivation” (8), “Desaturation” (5), “Oxygen” (4), “Supervision” (4) and “Too difficult” (3) are those most frequently used by respondents regarding this thematic.

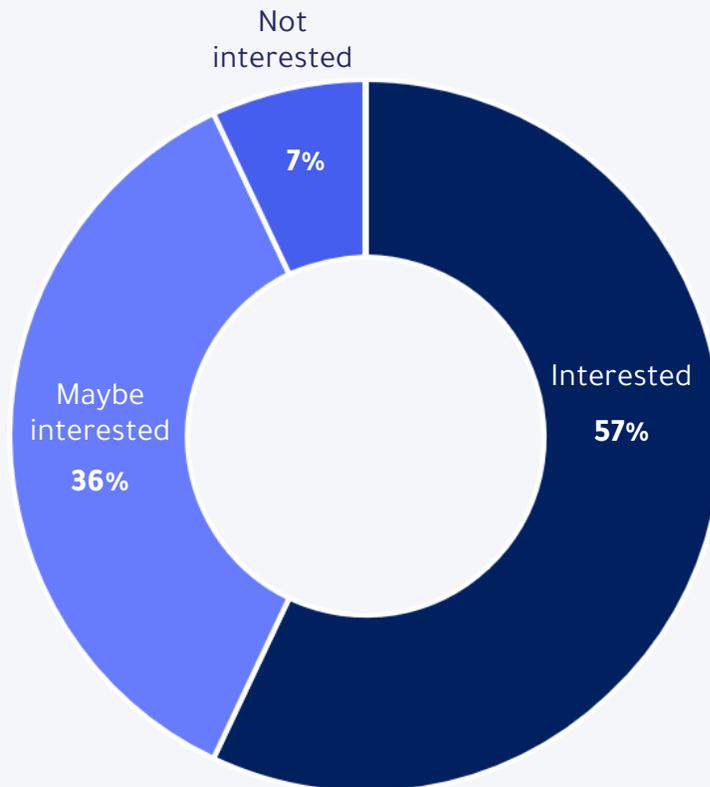


# Interest in Help/Support

PF ConnEx | Needs Assessment Survey 2021

Almost all respondents were either “interested” (57%) or “maybe interested” (36%), demonstrating an acceptability for this type of service, but with some ambiguity about the type of program and what it might offer.

It can be concluded that almost all the respondents are either interested or maybe interested in an at-home supervised program as it would help them maintain their independence without anyone’s helps and feel confident.



\*Question:

"11. Would you be interested in receiving help and guidance to manage your pulmonary fibrosis through a remote supervised exercise/lifestyle program"

"19. What would motivate you to be part of an at home exercise program?"

# Referring to Exercise Programs

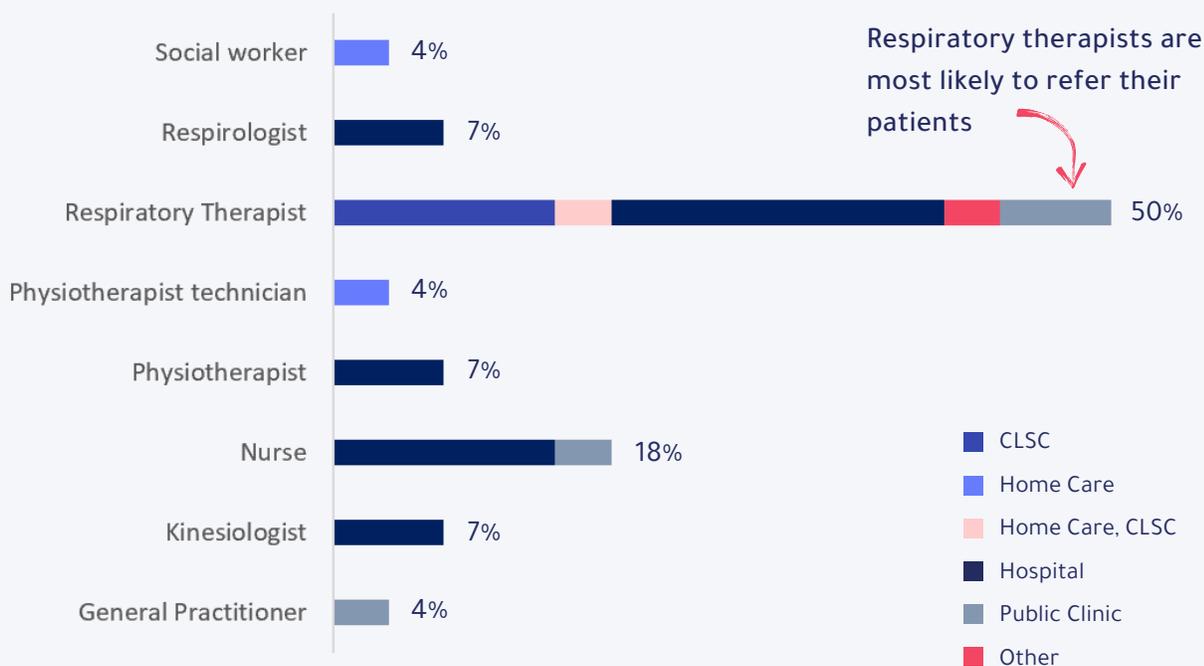
PF ConnEx | HCP - Needs Assessment Survey 2021

Nearly half (46%) of the HCPs respondents were respiratory therapist, with (11.1%) being Respiriologists. More than half (54%) of the HCP came from hospitals.

From these respondents, almost half (44.4%) are likely to refer their patients to the PF ConnEx program. It should be noted that Respiratory therapists (22%) are more likely to refer their patients to the PF ConnEx program.

It should be noted that (47.6%) have already referred their patients to an at-home exercise program in the past.

### Likelihood to Refer to the PF ConnEx Program



\*Question:

"2. What is your professional practice setting?"

"3. What is your main role at work?"

"11. Have you referred your patient to an at-home exercise program in the past?"

"16. Are you likely to refer your patient to this PF ConnEx program?"



Part 2

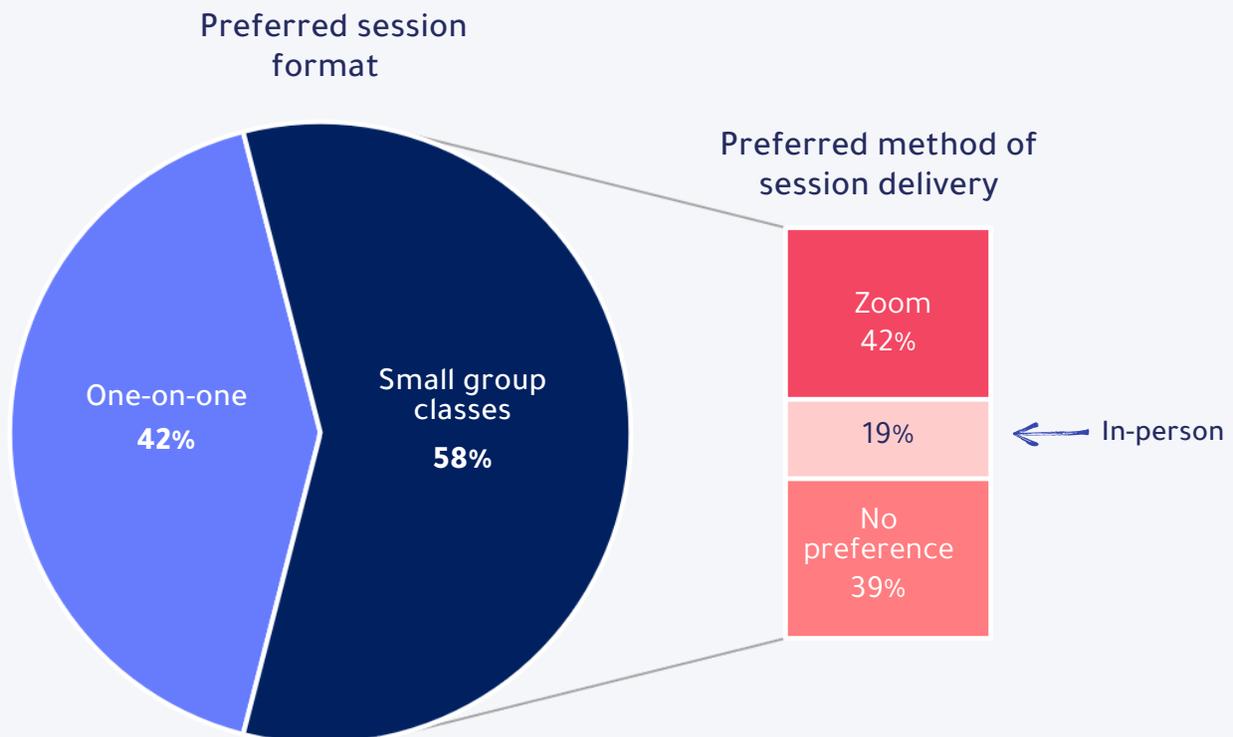
# Interest & Perception towards the Program

# Acceptability of the Program

PF ConnEx | Needs Assessment Survey 2021

Majority of the respondents prefer to participate twice a week in small group classes conducted via Zoom. Almost half (42%) respondents prefer one-on-one and more than half (58%) prefers small group classes.

It should be noted that this segment is primarily composed of respondents who were practicing physical activity prior to the pandemic and have knowledge of internet.



\*Question:

"20. How many times a week would you be able to participate in this program?"

"21. Would your preference be one-on-one or small group classes?"

"22. Would your preference be in person or on Zoom?"

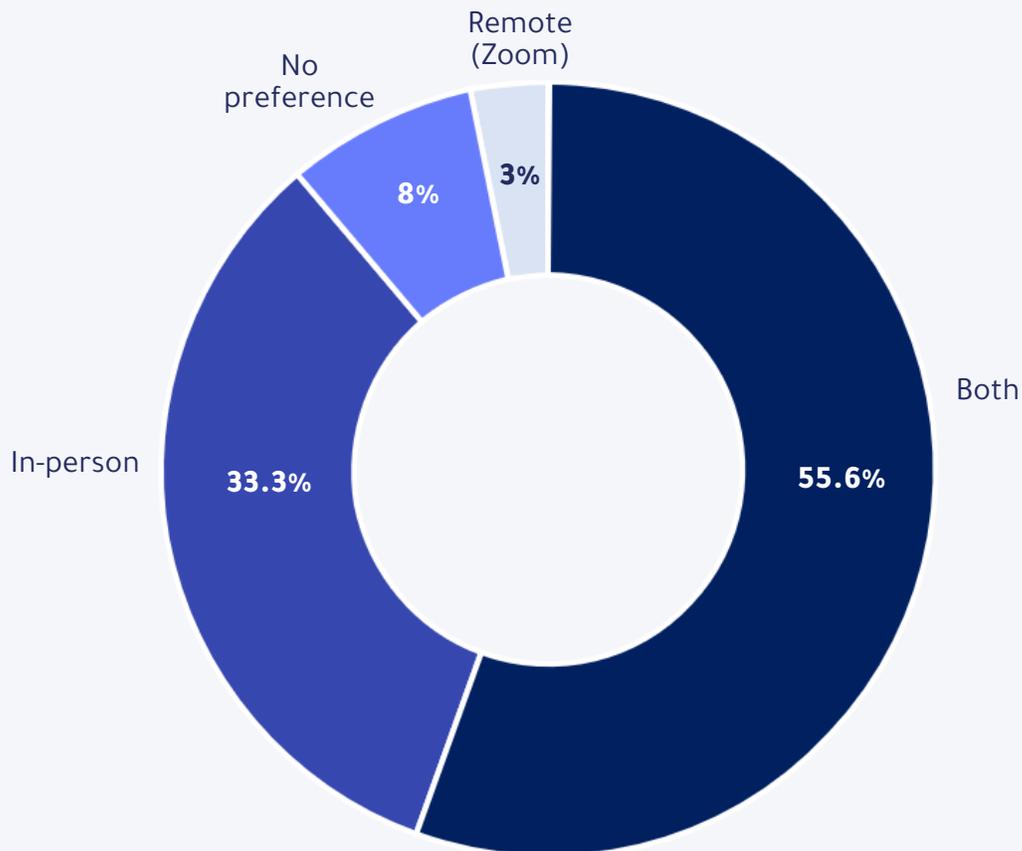
# Preferred Delivery for the Program

PF ConnEx | HCP - Needs Assessment Survey 2021

More than half (55.6%) of the HCP respondents said that both in-person and online delivery would be the preferred methods for PF patients.

A third of the respondents (33.3%) would prefer to have in-person delivery of the program.

It should be noted that an option to have in-person and remote delivery for the program would be appreciated by referring HCP.



\*Question:

"10. What type of program delivery would you prefer for your patients?"

# Understanding the Benefits of a Kinesiologist

PF ConnEx | Needs Assessment Survey 2021

We asked respondents to describe what their understanding was of a Kinesiologist. Among these results, we have compiled, in the form of a keyword cloud, the most frequently occurring terms.

Through these results, we note that the terms “Exercise” (6), “Body” (6), “Motivation” (3), “Don’t know” (5), “Muscle” (3) and “Health” (4) are those most frequently used by respondents regarding this thematic.



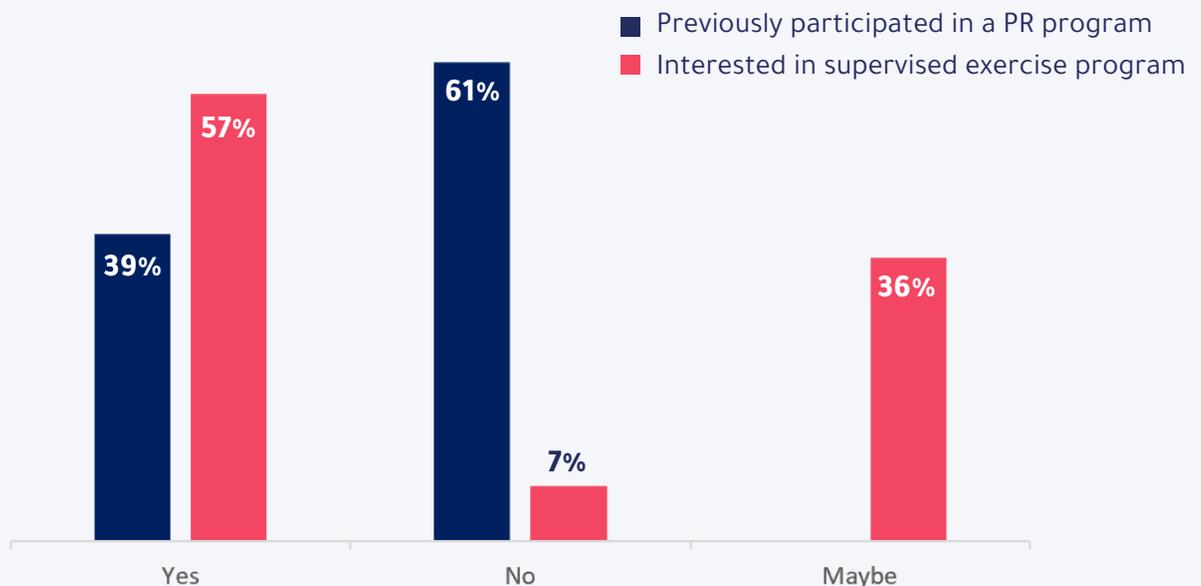
# Perceived Usefulness of the Program

PF ConnEx | Needs Assessment Survey 2021

We asked respondents about their perception on the usefulness of the program. In addition to the fact that majority (57%) would be interested in receiving help and guidance to manage their pulmonary fibrosis. Most of the respondents actively participated in supervised physical activity sessions 3 to 4 times a week prior to the pandemic. We can assume this is the reason they showed interest in participating in these sessions during the pandemic. Most likely they would prefer to participate twice a week in such program.

This key element marks an opportunity in an area of the market that does not have access to this type of service, despite some perceived usefulness.

Though majority of the respondents were previously aware of supervised exercise programs, only a small segment have participated in pulmonary rehabilitation in the past. Lack of knowledge about the program and its benefits and not having access to such a program might be the reason.



**\*Question:**

"5. Before the COVID-19 pandemic, how often did you participate in any physical activity (this includes exercise classes, walking, etc.)?"

"11. Would you be interested in receiving help and guidance to manage your pulmonary fibrosis through a remote supervised exercise/lifestyle program"

"12. How many times per week would you be willing to participate in a supervised exercise program at home?"

"26. Have you participated in pulmonary rehabilitation in the past?"

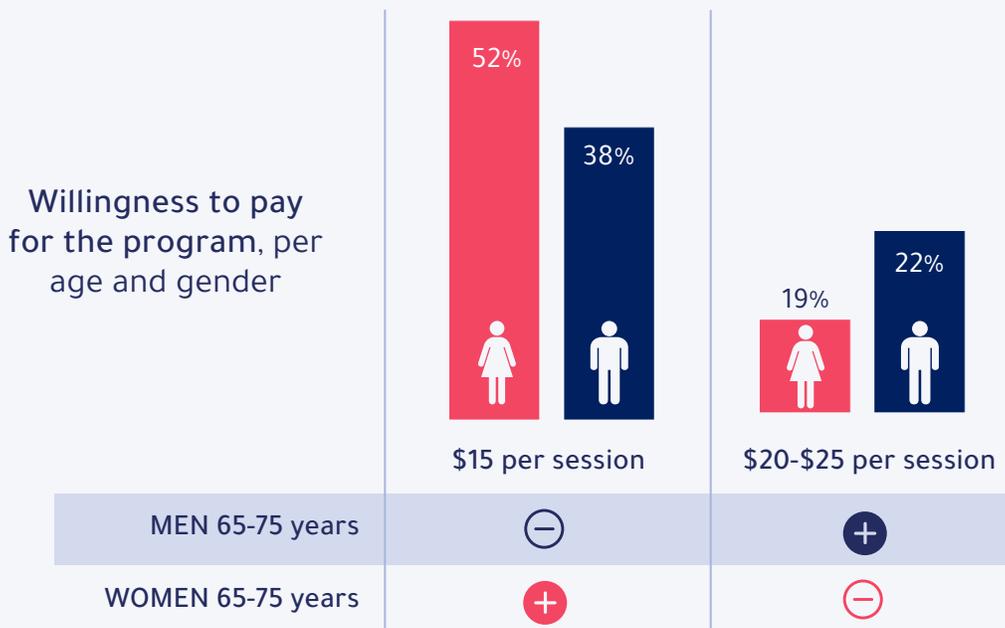
# Willingness to Pay

PF ConnEx | Needs Assessment Survey 2021

By asking respondents to estimate the value of such a program (remote format), highly convergent results were revealed. Approximately half (43%) would be willing to pay more than \$15 per session for this program.

It is important to note that men appear significantly more willing to pay for this type of program than women. Men are willing to pay \$20 - \$25 per session compared to female respondents (22% vs 7%).

Majority of female respondents (52%) are willing to pay less than \$15 per session compared to men (38%). Of those female respondents, 37% are within the age range of 65-75 years. Of those male respondents, 31% are within that same age range. Respondents from Quebec (22% men, 19% female) are willing to pay less than \$ 15 per session.



\*Question:

"29. If this were a paid per session program, what would be the maximum amount you would pay per session?"

"30. Please indicate your age category"

"31. Please indicate your gender"

"32. Where in Canada, are you currently located?"

# Price Point

PF ConnEx | Needs Assessment Survey 2021

For respondents willing to pay for this type of program, the trends between gender, location and age group seem to be relatively similar. Both segments are willing to pay less than \$15 per remote session.

Some female respondents (22%), aged 65-75 years, are interested in paying between \$15 - \$20 per session. While some men respondents (18%), aged 65 years and older, are interested in paying \$15 - \$25.

It can be concluded that a small group remote session would be easily created to suit the price point of our respondents.



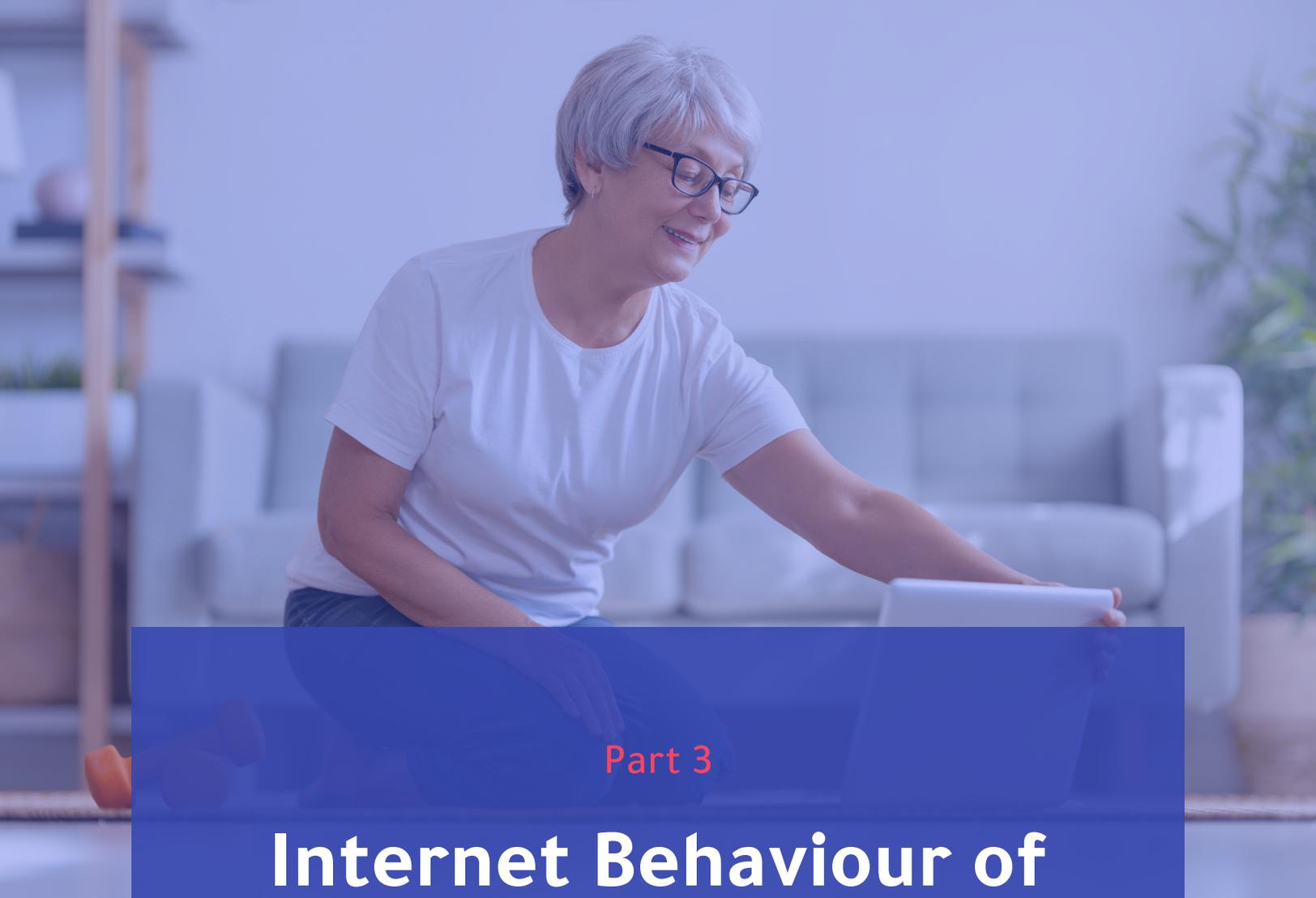
**\*Question:**

"29. If this were a paid per session program, what would be the maximum amount you would pay per session?"

"30. Please indicate your age category"

"31. Please indicate your gender"

"32. Where in Canada, are you currently located?"



Part 3

# Internet Behaviour of People Living with PF

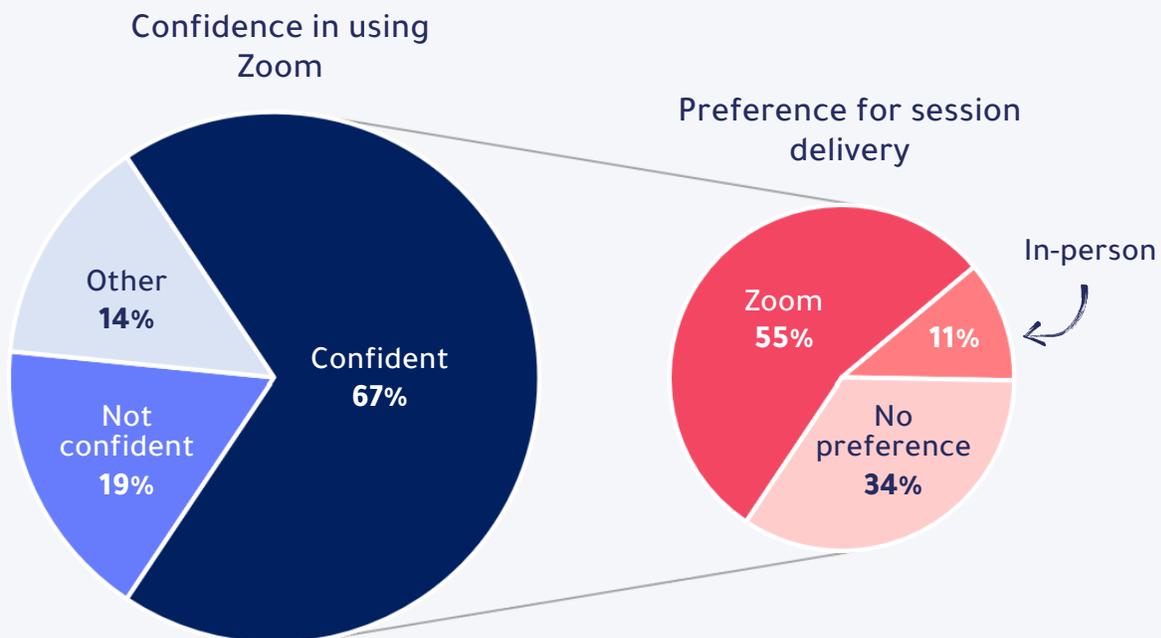
# Digital Tools Used

PF ConnEx | Needs Assessment Survey 2021

More than half of the respondents (67%) are confident in using Zoom for a remote supervised exercise session.

It could be noted that most respondents prefer remote session through Zoom. It seems that people have significant online experience and are more comfortable in online sessions.

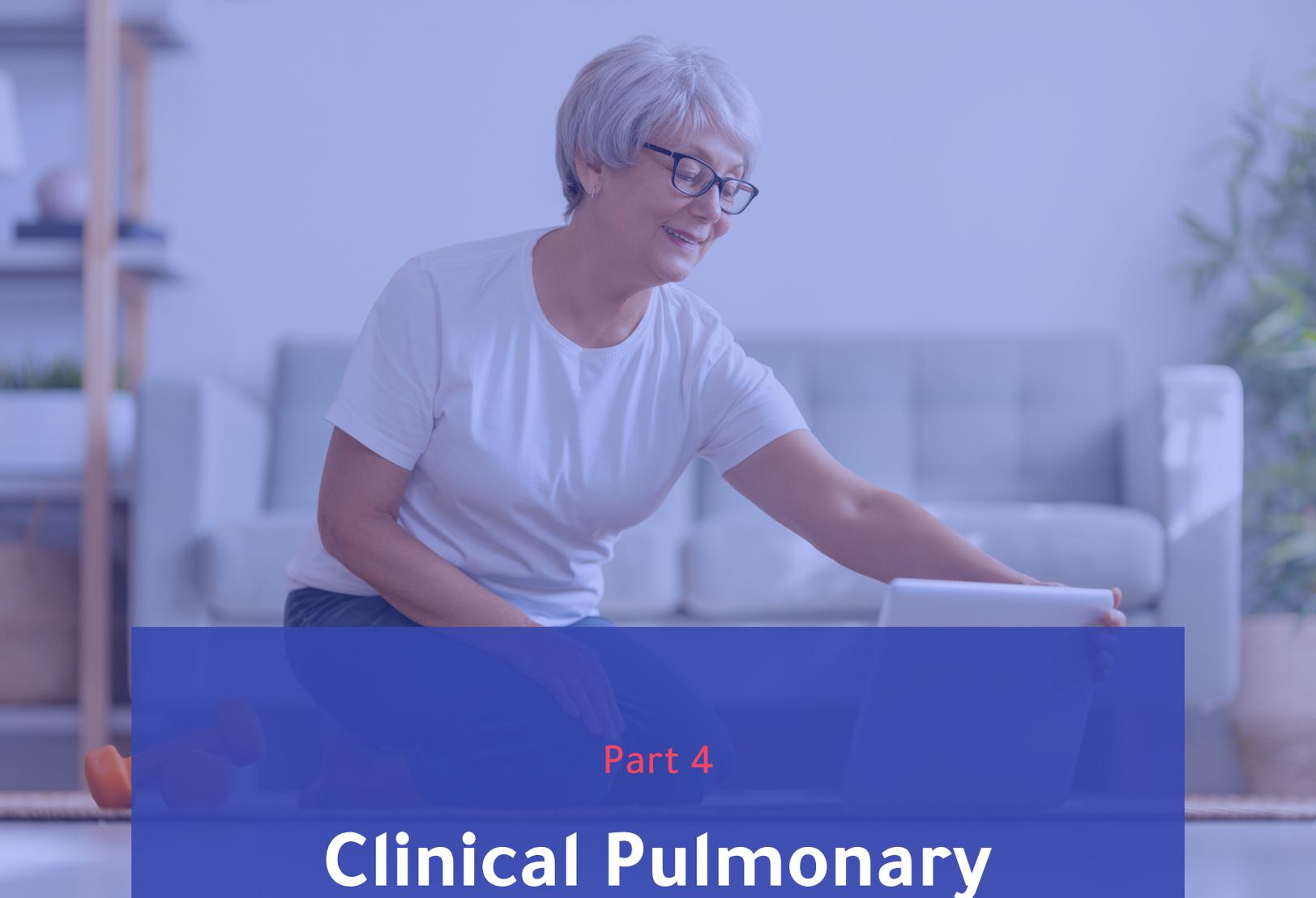
Increased awareness about the use of internet and onset of the pandemic has led to the acceptance of online medium more than pre-pandemic.



\*Question:

"15. Are you confident in using Zoom for a remote supervised exercise session?"

"22. Would your preference be in person or on Zoom?"



Part 4

# Clinical Pulmonary Rehabilitation

# Accessibility to Clinical PR

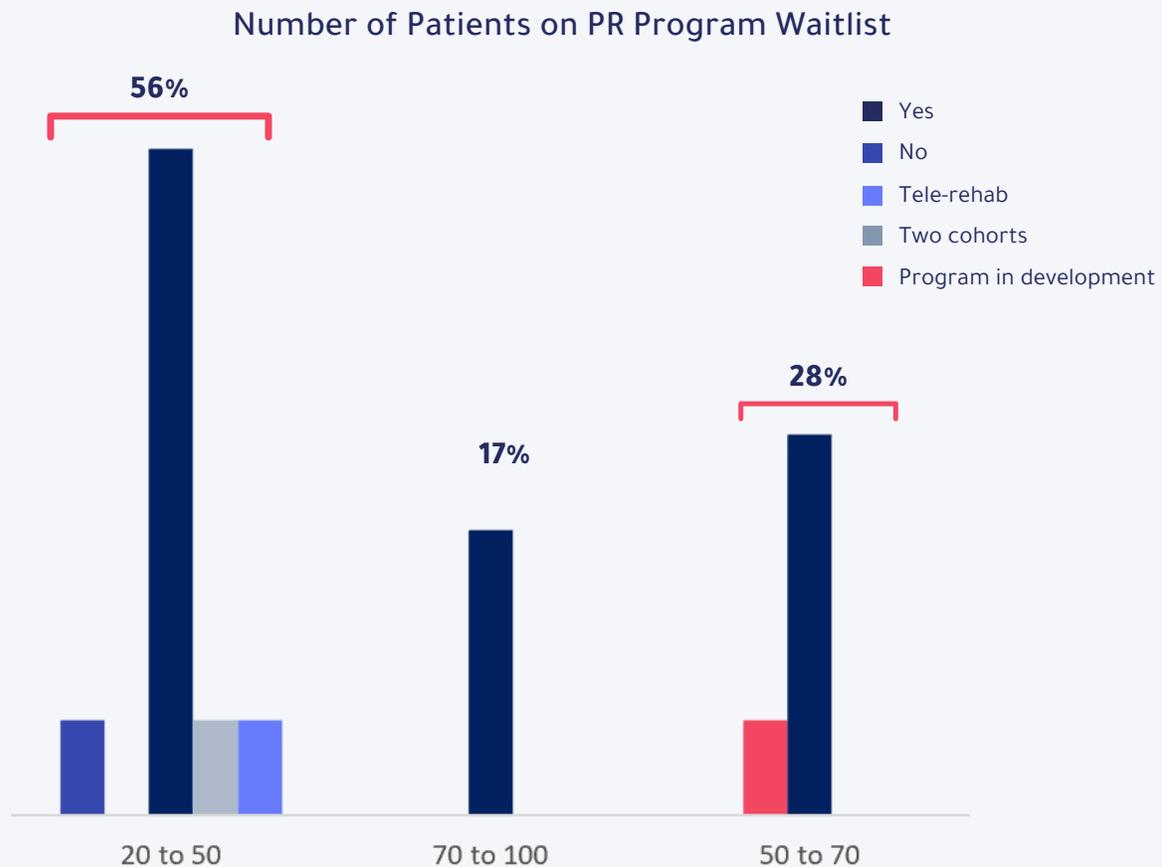
PF ConnEx | HCP - Needs Assessment Survey 2021

More than half of the respondents (63.5%) said that they have pulmonary rehabilitation in their hospital or clinics. Whereas 20.6% respondents said that they don't have pulmonary rehabilitation at their facility.

From these respondents, almost one third (28.6%) have a waiting list between 20-100 patients.

Almost one third of the respondents (28.6%) have waiting times that are less than 3 months long.

The key point here is the importance having a program, PF ConnEx, readily available to those that are on the waiting lists.



\*Question:

"6. Is there a pulmonary rehabilitation at your facility?"

"7. At your facility, how many patients are on a waiting list for pulmonary rehabilitation?"

"8. What is the average waiting time for a patient with PF for pulmonary rehabilitation?"

# APPENDIX I

## Biggest Challenges

**QUESTION : "DURING THE COVID-19 PANDEMIC, WHAT HAS BEEN YOUR BIGGEST CHALLENGE AS SOMEONE LIVING WITH PULMONARY FIBROSIS?"**

Fear of contracting Covid
Protection from community
Isolation & loss of access to 3/week aquatic fitness classes I've lost muscle and tone and it's really feeding depression and a mounting sense of hopelessness
I have severe IPF and rarely left the house until I had two vaccine shots. I found at first I did very little but soon realized if I didn't do more physically I wouldn't be able to do much when Covid 19 ended. Unable to be with family especially was difficult. Having a chronic disease that can change very quickly, the future is already uncertain.
The same as before COVID: challenging myself to exercise within my current capabilities when it is no longer easy, painless and fun
Staying healthy, avoid contracting covid-19
Living with an Alzheimer's wife, my biggest challenge has been to keep moving!
Our usual gym where I exercised 3 times/wk was closed, and still is.
Anxiety
Not only have I been locked down due to Covid but also because I am listed for transplant and have to be available on a moment's notice to go to TGH. Therefore each day is the same. So the biggest challenge? BOREDOM
Staying safe and isolating
Not much has changed
Along with pulmonary arterial hypertension trying just to walk
No visitors
I found the masks too restrictive in breathing when leaving the house and in public
Unable to socialize.
Depression
Staying safe
Being isolated on the farm

**QUESTION : "DURING THE COVID-19 PANDEMIC, WHAT HAS BEEN YOUR BIGGEST CHALLENGE AS SOMEONE LIVING WITH PULMONARY FIBROSIS?"**

Fear of going out in public
Motivation lacking due to fear of virus
No challenges for myself
Avoiding Covid infection
Being out in a safe environment
Lack of motivation to exercise
None. I live in isolation, so little has changed.
The isolation
Accessing health care remotely
Isolation not seeing friends and family. No face to face in person medical appointments.
Having others run errands as didn't feel comfortable going into stores, etc.
Keeping motivated
Not being able to get out
Being doubly confined to the house
An additional fear with anxiety that I would not make it if I got COVID
I strongly limited my contacts, my outings.
Not seeing my son, sister and friends and not having any activities
The mask and the meetings outside
Avoid all contact
Limited exercise
Getting used to a fairly rapid decline.
Wear the mask for activities
Degradation of my physical abilities, Shortness of breath.
Walking every day
Stay isolated, and increase the level of security
Confined living
Healing from my surgeries one in 2020 and the other in 2021
I've had the chance to do my training through my enrollment with PPMC virtually for a few weeks.
Not to see anyone for fear
Independent, I have not changed my physical activities, only social
Fear of COVID 19
Keep myself physically active
Do weight training and control my weight.
Stay in shape
I didn't want to get contaminated because I am fragile to viruses and others.

# Report Details

PF ConnEx | Needs Assessment Survey Report 2021

## This study was conducted by:

Becky Zucco | WillKin Health

## Analysis and writing:

Brickwork India

Emily Horvat | WillKin Health

## Project management, survey and content review:

Julie Lopez | WillKin Health

## Collaborators:

Living Well with Pulmonary Fibrosis

(RESPUPLUS™), Quebec Lung

Association (L'Association pulmonaire

du Québec) and Canadian Pulmonary

Fibrosis Foundation

## Sponsor:

Unrestricted educational grant

provided by Boehringer Ingelheim



**Bridging the gap  
between health care &  
self-motivated exercise.**

At WillKin, we specialize in  
developing programs for  
patients living with chronic  
health conditions

