

Needs Assessment on Activity and Lifestyle of People Living with NTM and Bronchiectasis in North America

This report was written by
WillKin Health in collaboration
with NTMir and the Canadian
Bronchiectasis-NTM
Education & Support Group.

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willkin

Needs Assessment on Activity and Lifestyle of People Living with NTM and Bronchiectasis in North America

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

It will also aid the development of the NTM/B 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 from a qualified health care professional. 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 written by WillKin Health in collaboration with NTMir and the Canadian Bronchiectasis-NTM Education & Support Group.

Respiplus, a non-profit organization, has contributed by creating awareness of this survey via their patient and healthcare professional communities.

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Acknowledgments

Introduction to the research

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

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 NTM and Bronchiectasis 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 and during waves of the COVID-19 pandemic. Some areas had partial restrictions lifted, but people's fears of the virus, as well as the significant impact 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 NTM and bronchiectasis patients?



Methodology

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

WillKin conducted this survey in collaboration with NTMir and the Canadian Bronchiectasis-NTM Education & Support Group.

SAMPLE

The sample was collected via the email databases of NTMir, the Canadian Bronchiectasis-NTM Education & Support Group and via RESPIPLUS' newsletter. A total of 290 North American NTM and Bronchiectasis patients and 18 Healthcare Professionals (HCP) working within this domain were surveyed through an online GOOGLE FORM between December 2021 and February 2022.

Because the survey was not part of a complete list of people living with the disease in North America, 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 NTM and Bronchiectasis population. However, the results are an effective tool for learning more about the surveyed sample.

SURVEY STRUCTURE

The survey was constructed with 42 patient and 24 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

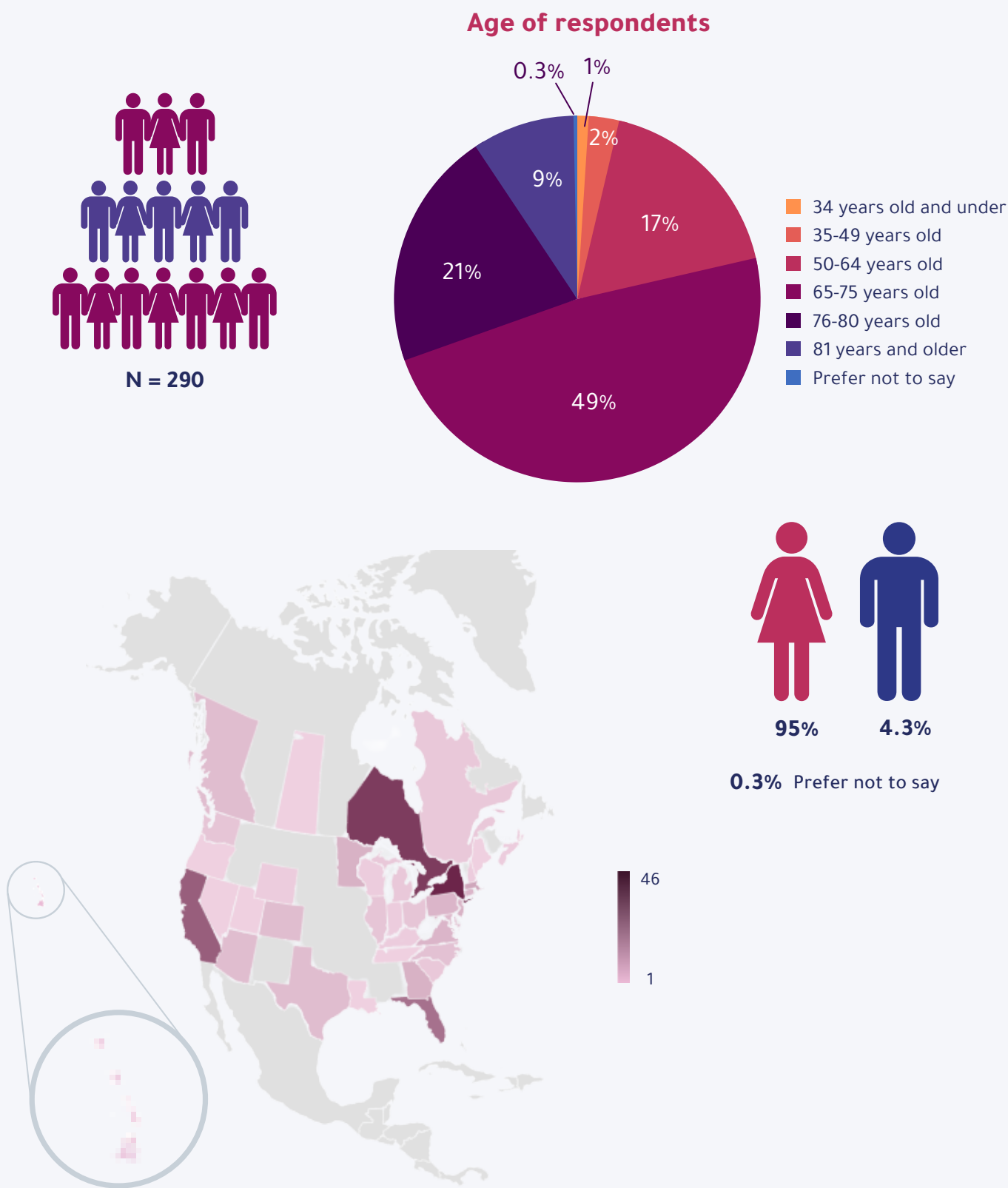
Both quantitative and qualitative method was used to analyze the data.

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



Description of the sample - Patient

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022



Description of the sample - Patient

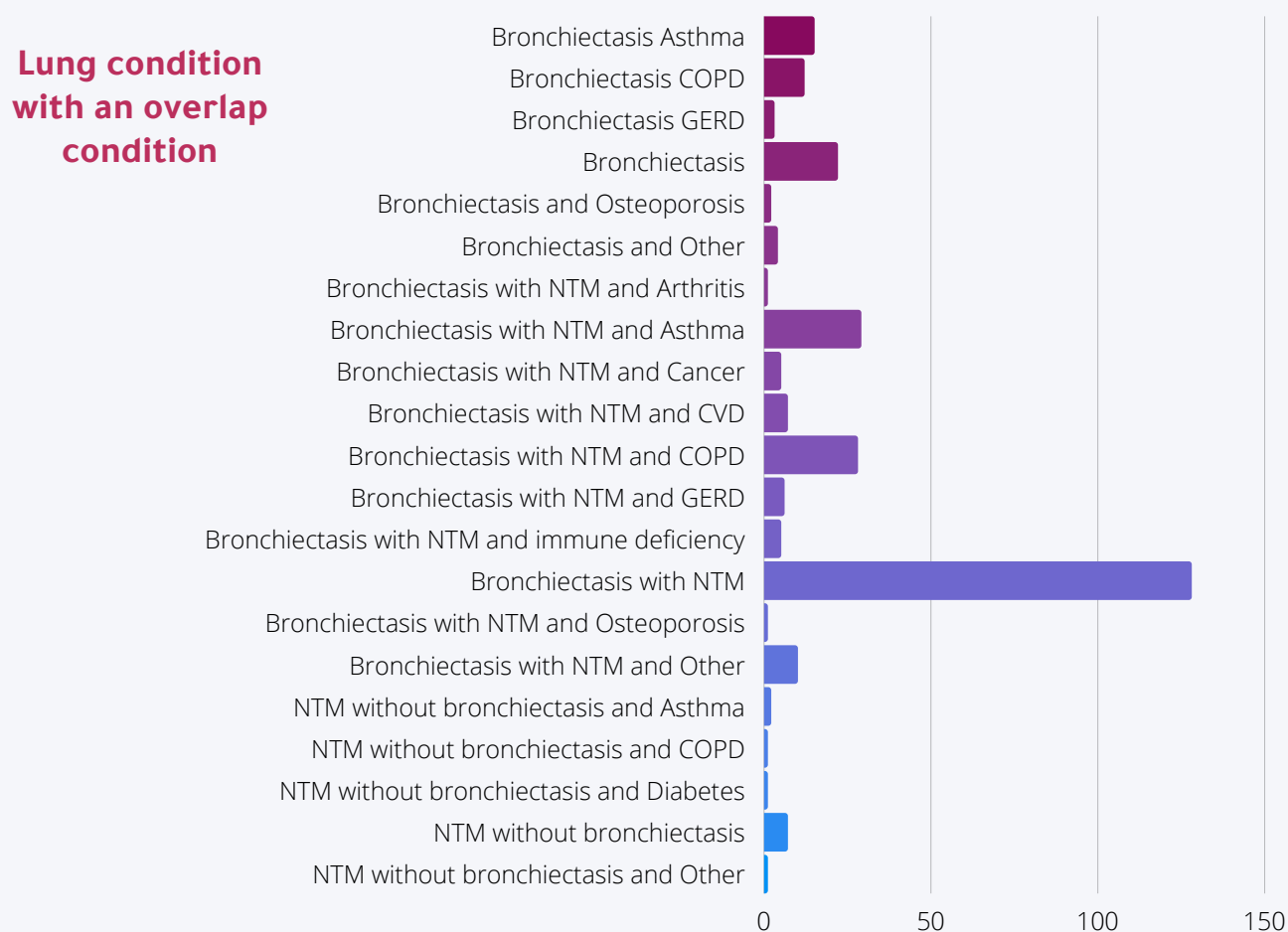
NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

We asked respondents to tell us about their current lung condition. Additionally, we wanted to see what other conditions they are living with.

Almost half of the respondents (45%) are living with Bronchiectasis and NTM. The overlap of Asthma (10%) and COPD (9.7%) with Bronchiectasis and NTM was also common in our respondents. 4.8% of the total respondents with further overlapping conditions.

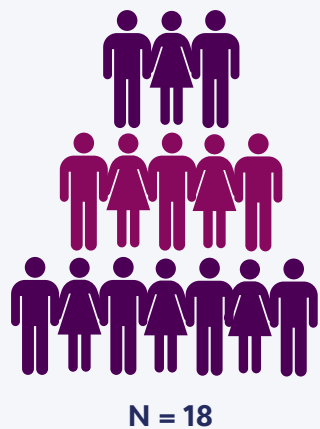
The "other" category includes: Thyroid, Aspergillosis, Pelvic floor weakness, Hiatus hernia, Pseudomonas, Depression, Sarcoidosis, Ulcerative Colitis, Anxiety, Fibromyalgia, Connective tissue disease, Alpha-1 Antitrypsin Deficiency, MAC, Scoliosis, and Cystic Fibrosis.

Any exercise program written and provided to this population would have to consider common symptoms and co-morbidities associated with NTM and bronchiectasis.

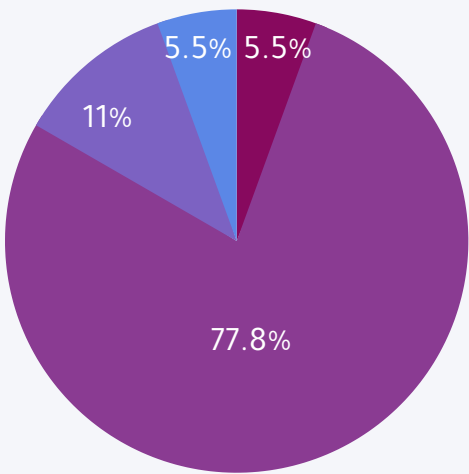
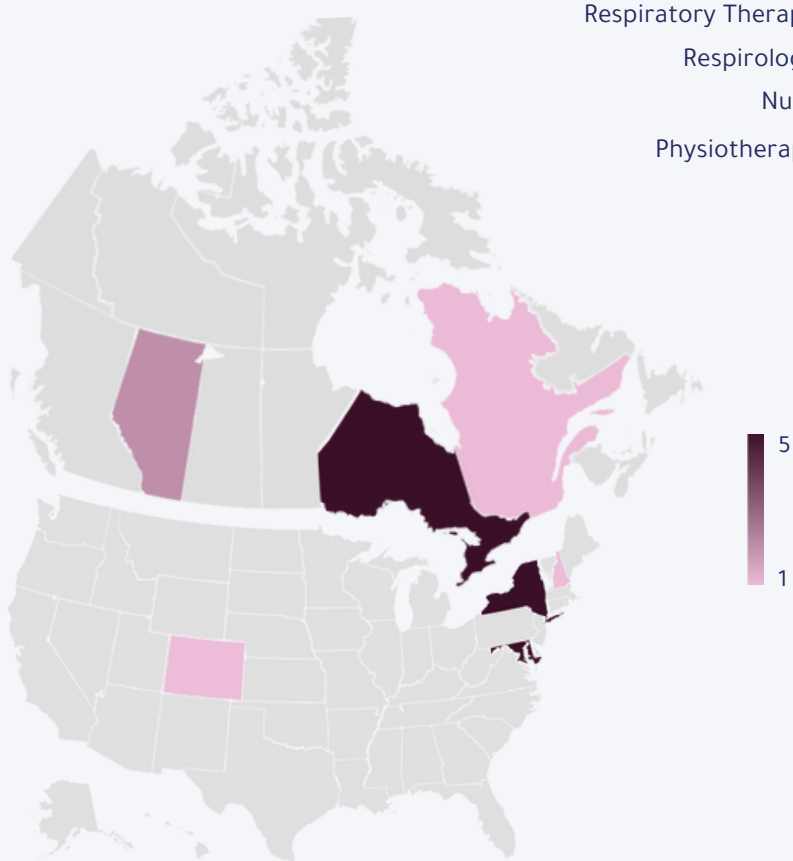
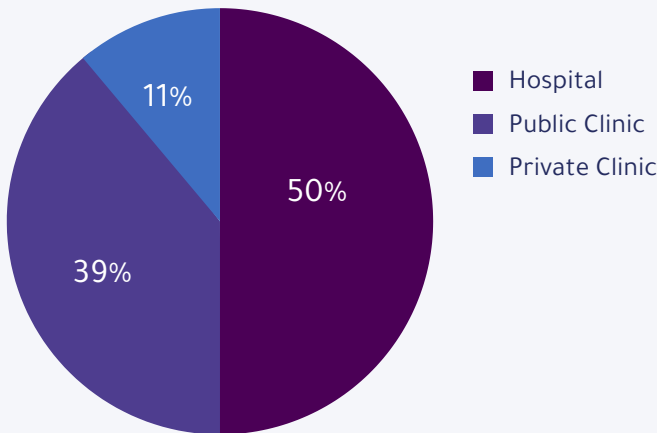


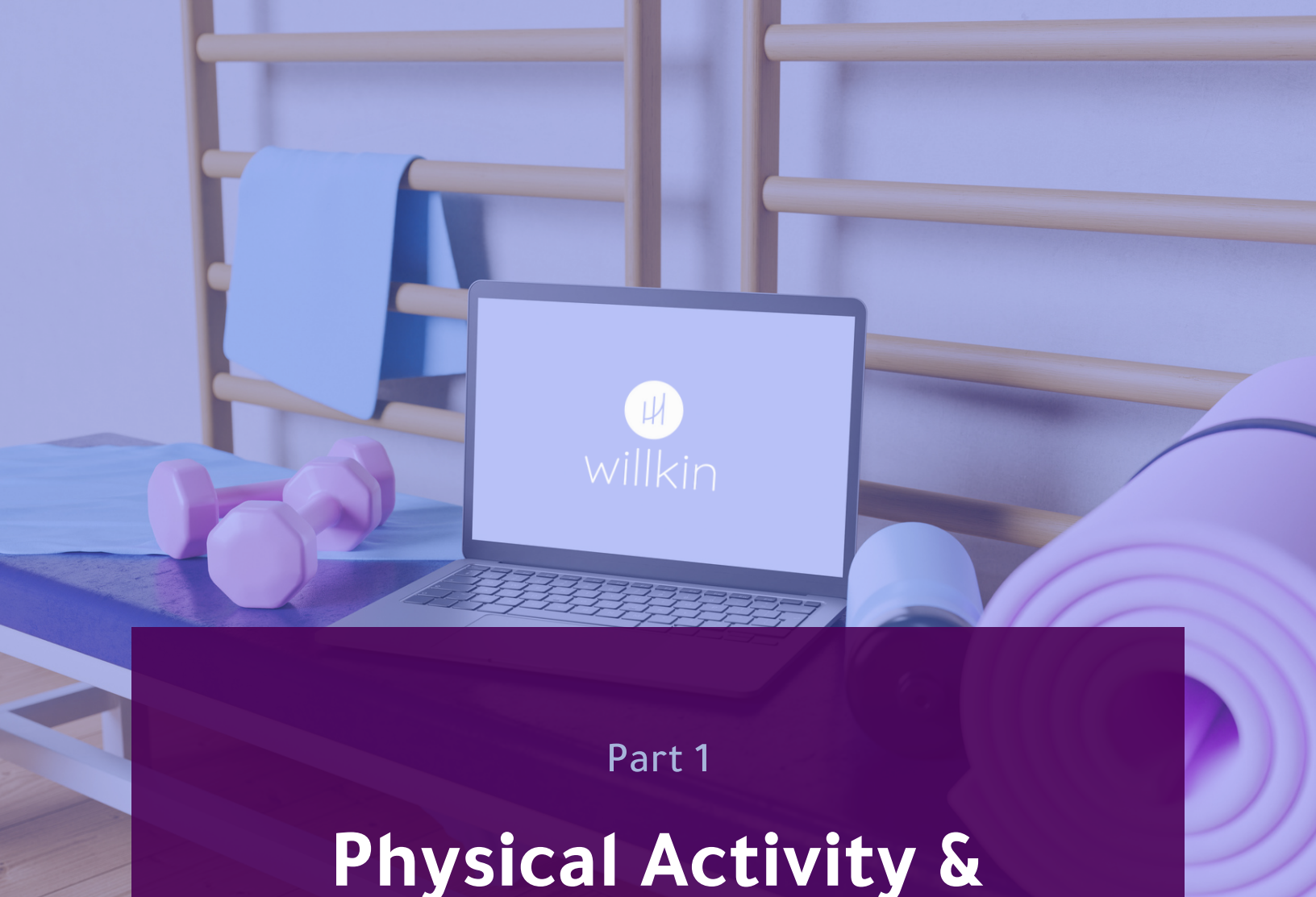
Description of the sample - HCP

NTM/B ConnEx | Needs Assessment Survey 2021-2022



Professional Practice Setting





Part 1

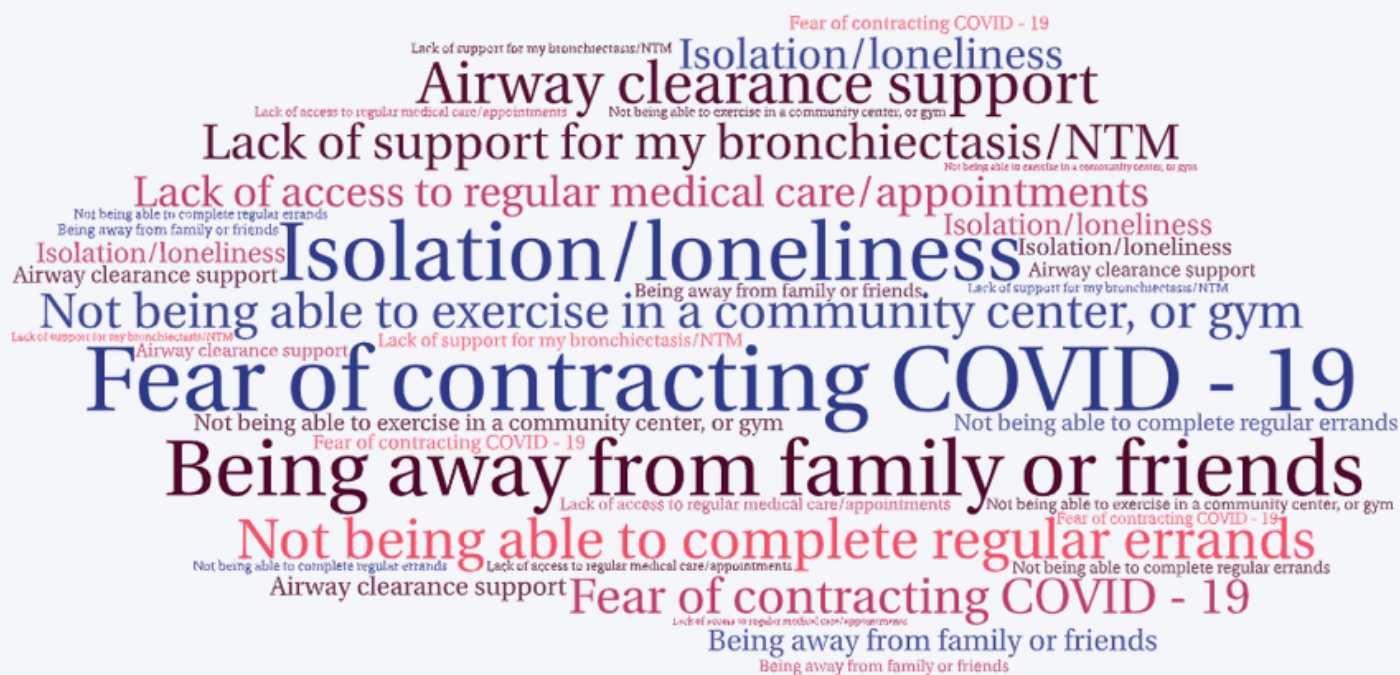
Physical Activity & People Living with NTM and/or Bronchiectasis

Biggest Challenges

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were asked to report their biggest challenges during the pandemic as someone living with Bronchiectasis and/or NTM. The most frequently occurring terms have been compiled in the form of a keyword cloud.

Through these results, it can be noted that the terms “Fear of contracting COVID - 19” (243), “Being away from family or friends” (181), “Not being able to exercise in a community center, or gym” (145), “Isolation/loneliness” (114), “Not being able to complete regular errands” (84), “Lack of access to regular medical care/appointments” (73), “Lack of support for my bronchiectasis/NTM” (39) and “Airway clearance support” (39) are those most frequently reported by respondents regarding this thematic.



Biggest Challenges

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Question: "During the COVID-19 pandemic, what have been your biggest challenges as someone living with Bronchiectasis and/or NTM?"

(The most relevant have been selected)

Inability to walk to work. Due to work from home mandates.

Further loss of independence, limiting my ability to live a somewhat full life.

Other health issues makes me extremely vulnerable if I get COVID

Lack of regular exercise programs

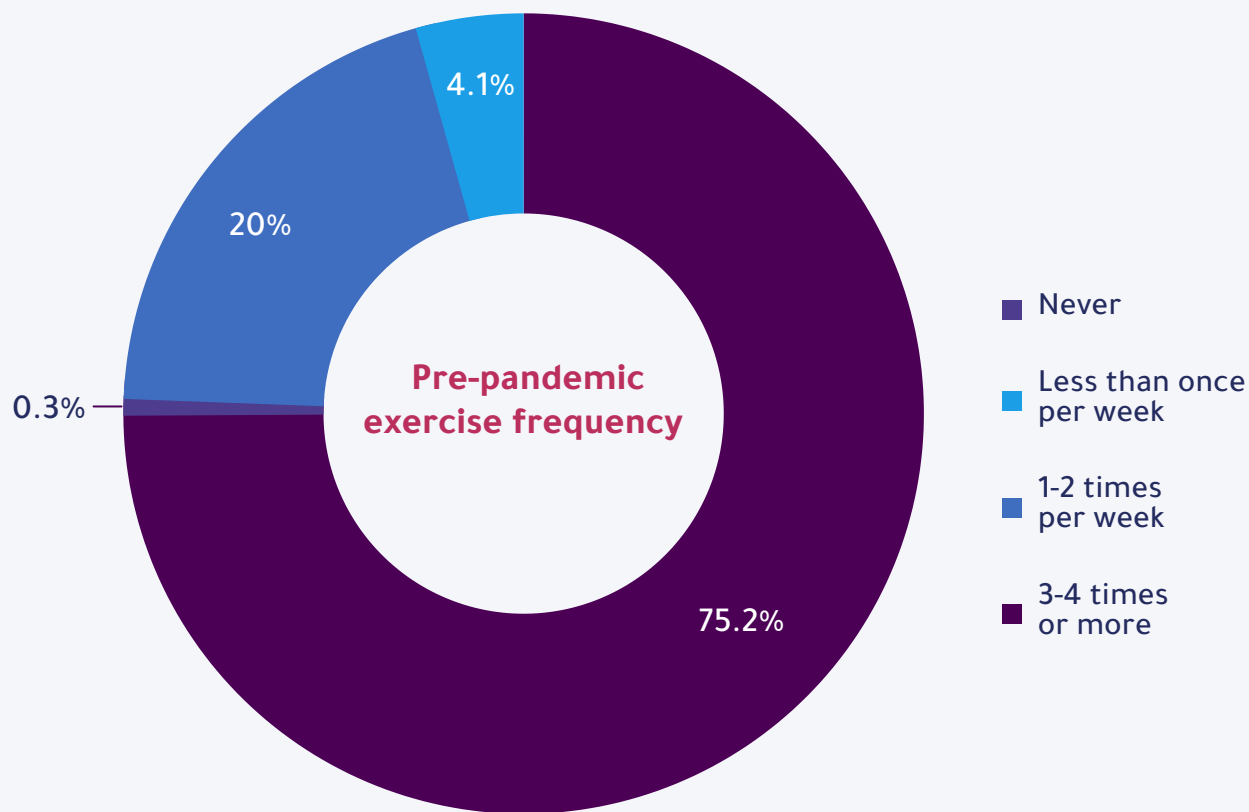
I cannot be certain in my state that others are vaccinated. This includes those who might come into my home to assist me.

Not being able to travel

Physical Activity Pre-Pandemic

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were asked about their physical activity levels prior to the pandemic. From these numbers, it was noted that almost three quarters of the respondents (75.2%) were active 3 to 4 times a week, and less than one quarter (20%) were active 1 to 2 times a week. From the same sample, a small minority was inactive (4.5%).



*Question:

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

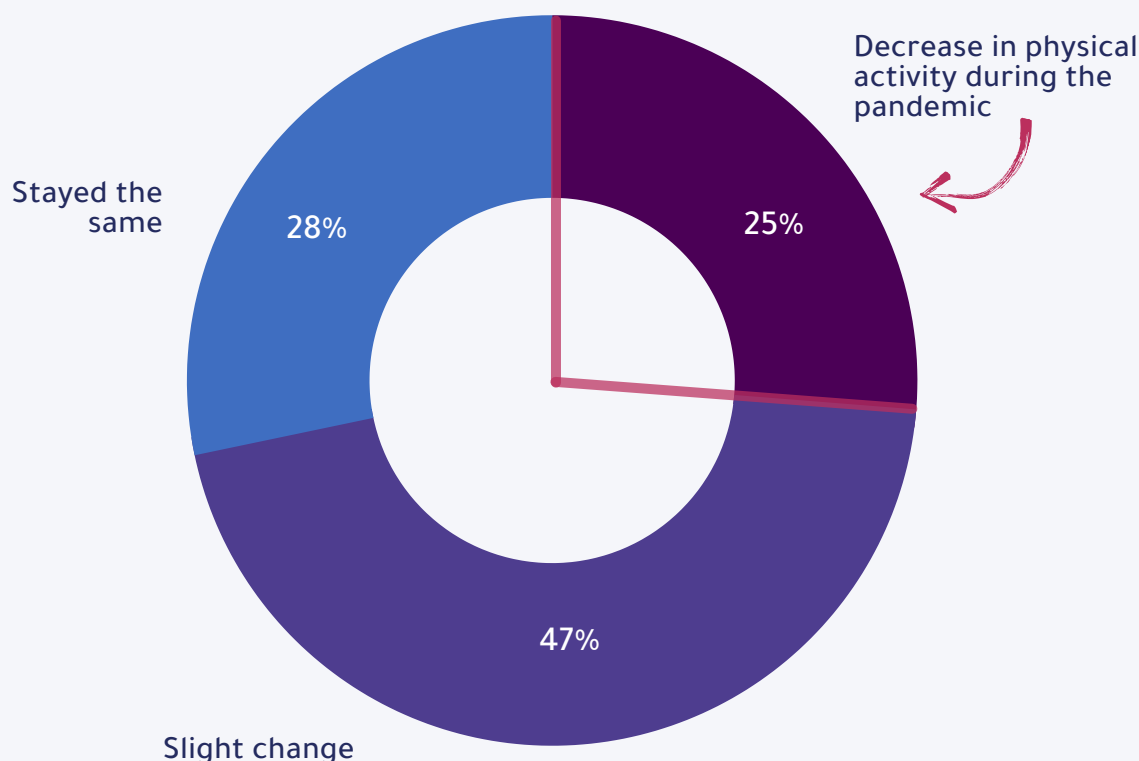
Behavioural Change

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

One quarter of respondents (25%) said they were not able to perform their regular physical activities compared to prior to the pandemic. Of these respondents, about 66% had difficulty thinking positively about their health throughout the pandemic.

Nearly half of the respondents (47%) said they could still perform **some, but not all**, of their regular activities, therefore indicating they were still impacted by the pandemic.

About 56% of the respondents that were active on a frequent basis (3-4 times per week) prior to the pandemic, had either no change to their activity or were only able to complete **some** of their regular physical activity. From these respondents, less than half (44%) were able to think positively about their health throughout the pandemic.



***Question:**

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

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

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

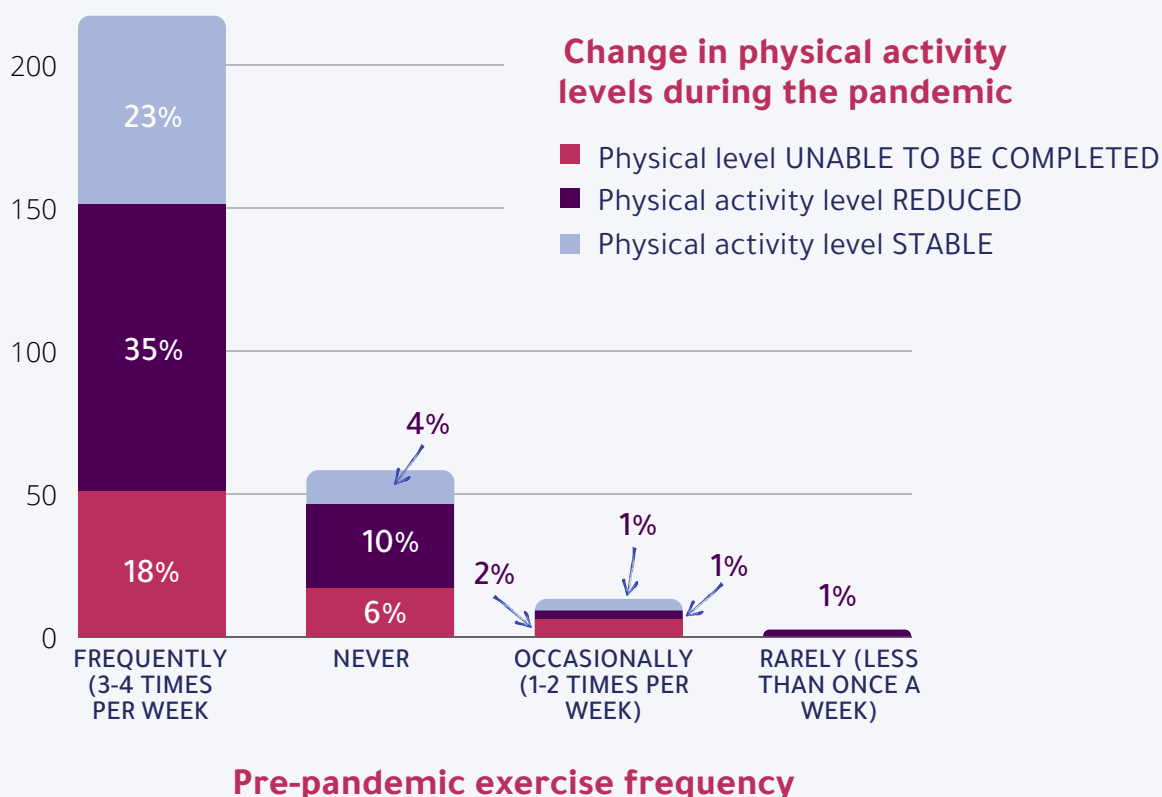
Physical Activity Variation

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

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

It was noted that of those who were regularly active (95%), once a week or more, before the pandemic, about 27% had no change in their physical activity despite the pandemic.

For those who were relatively active prior to the pandemic, 45% had to slightly shift the way they were exercising and were only able to do some of their regular physical activity. This highlights the importance of adopting an exercise routine. By finding intrinsic motivation, people are able to continue on with their physical activities despite a pandemic.



*Question:

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

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

Supervised Activity

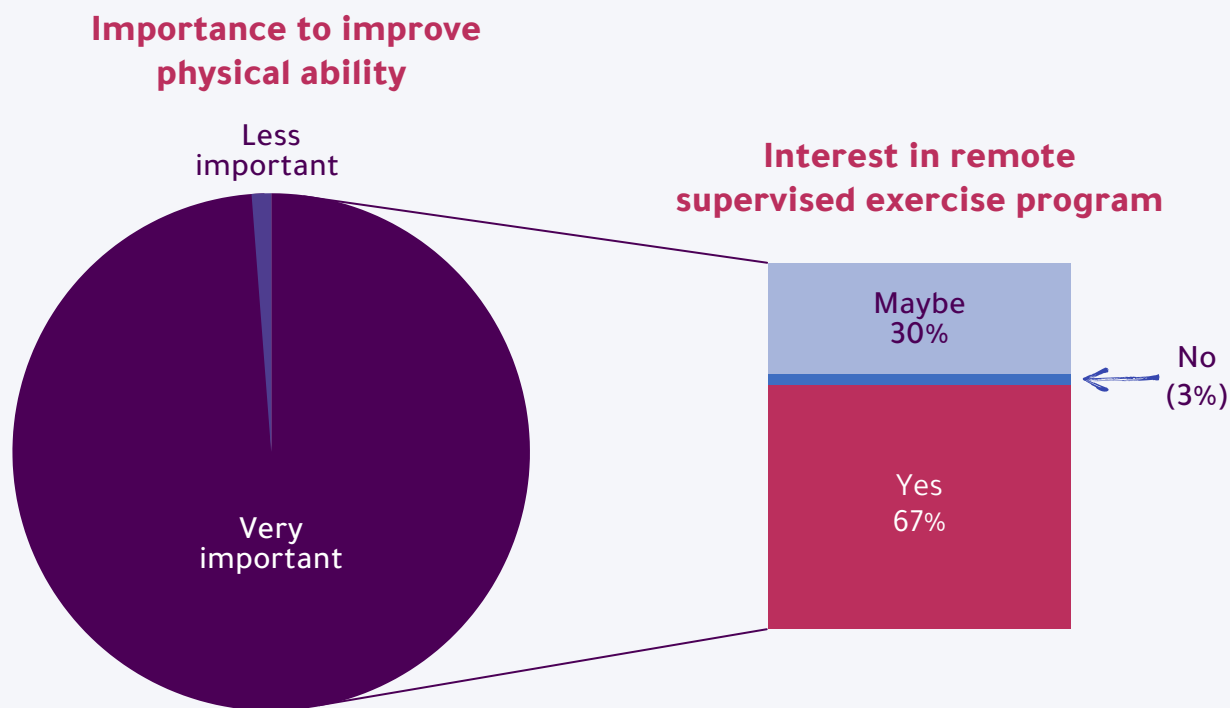
NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Almost all respondents (98.76%) stated the importance of improving their physical ability. it was noted that of these respondents, 66% were interested in a remote supervised exercise program.

About 96% of respondents stated that they would be interested in receiving help and guidance to manage their Bronchiectasis/NTM through a remote supervised exercise/lifestyle program.

About 91% of respondents stated that with appropriate guidance they would then be confident to exercise independently.

Of the respondents (67%) that were interested in the remote supervised exercise program, 42% would participate in a program twice a week and for a duration of 2 to 3 months.



***Question:**

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

"17. Would you be interested in receiving help and guidance to manage your Bronchiectasis/NTM through a remote supervised exercise/lifestyle program?"

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

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

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

Mental & Physical Health

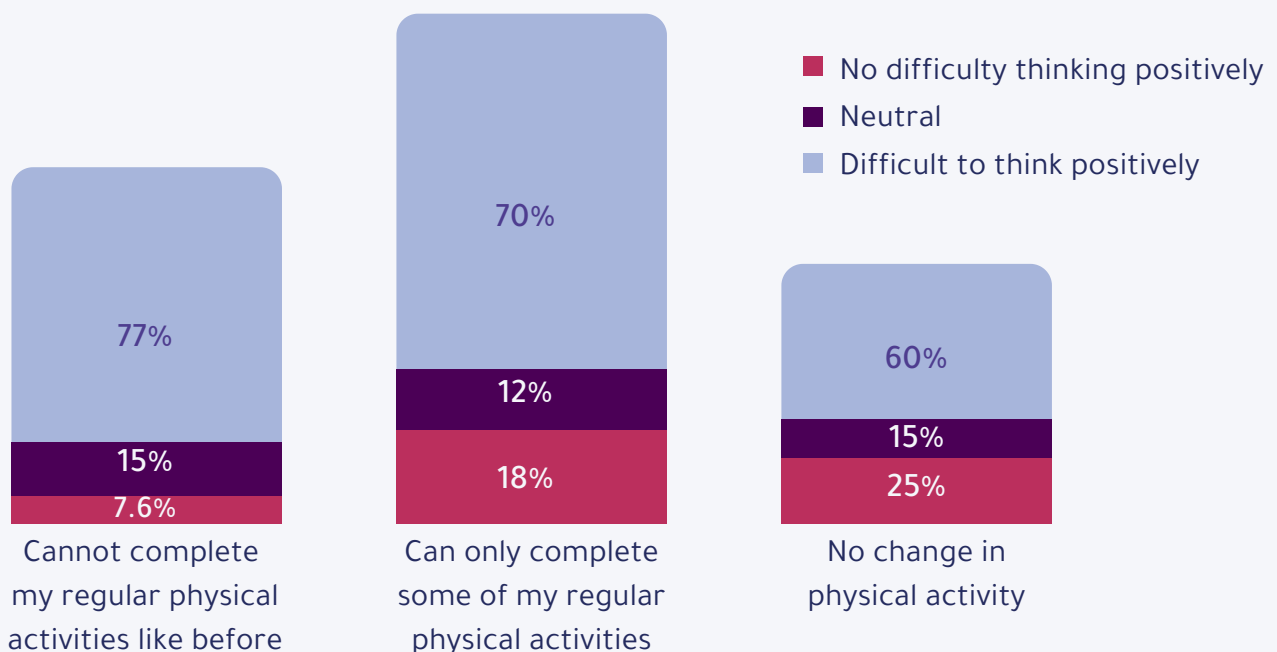
NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Data was combined from questions regarding lifestyle change and physical and mental health during the pandemic. It was found that 69% of respondents had some difficulty thinking positively about their health during the pandemic. From this group, 45% of respondents didn't have much change in their physical activity in comparison to before the pandemic and 75% cared strongly about improving their physical ability.

However, from the respondents that care strongly about improving their physical ability, 62% find it difficult to maintain their physical health during the pandemic.

From this, it can be noted that many individuals have had their regular physical activity routines disrupted and are finding it challenging to maintain their physical health during the pandemic.

Level of physical activity during the pandemic



*Question:

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

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

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

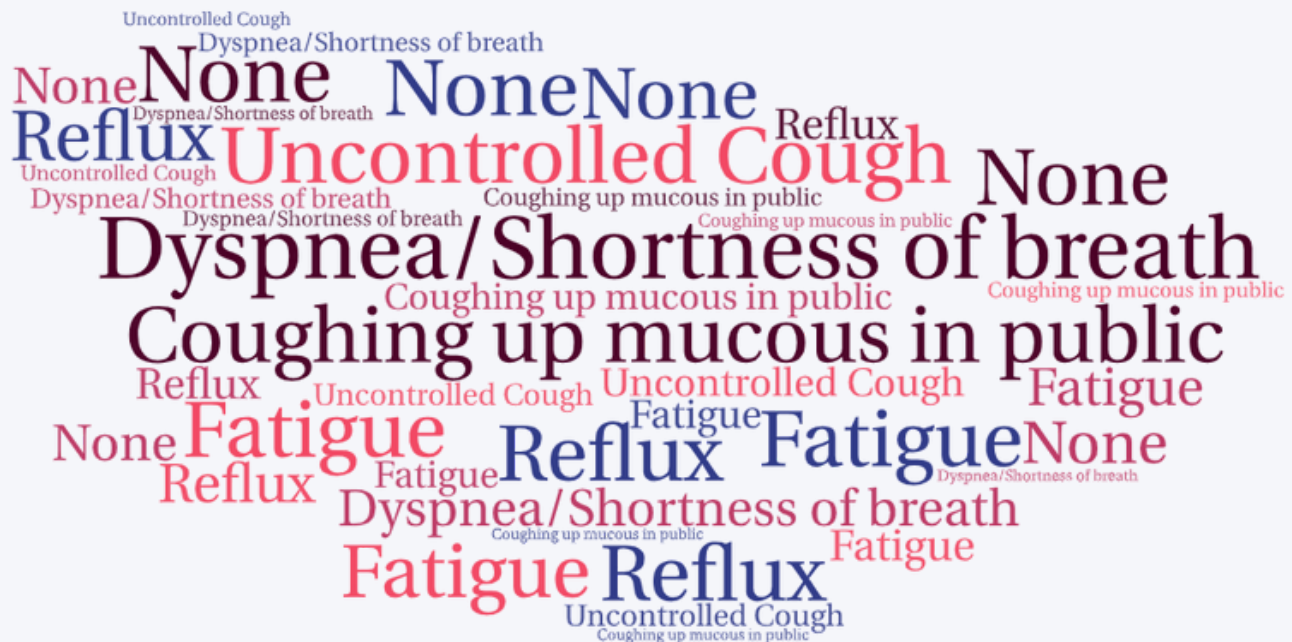
"14. I am having difficulty maintaining my physical health during the COVID-19 pandemic."

Symptoms during exercise

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were asked to state the symptoms they may experience and that possibly limit them when exercising. This will provide a deeper understanding of the limitations these respondents may have when exercising.

Through these results, common symptoms were noted, which are: "Dyspnea/Shortness of breath" (143), "Fatigue" (139), "Coughing up mucous in public" (69), "Uncontrolled Cough" (46), "Reflux" (41), and "None" (52).



Barrier for participation

NTM/B ConnEx | HCP- Needs Assessment Survey 2021 - 2022

The HCP group was asked to state what barriers a patient with Bronchiectasis/NTM may have to NOT want to participate in an at-home exercise program. The most frequently occurring terms have been compiled in the form of a keyword cloud.

Through these results, it can be noted that the terms “Computer & Technology” (10), “Limited Knowledge” (6), “Insurance Reimbursement” (2), and “Fatigue” (2) are those most frequently used by respondents regarding this question.

It must be noted that, respondents from the non HCP group do not have a similar level of concern regarding use of technology. The pandemic has been instrumental in improving confidence in seeking and receiving information and services online (see page 29).



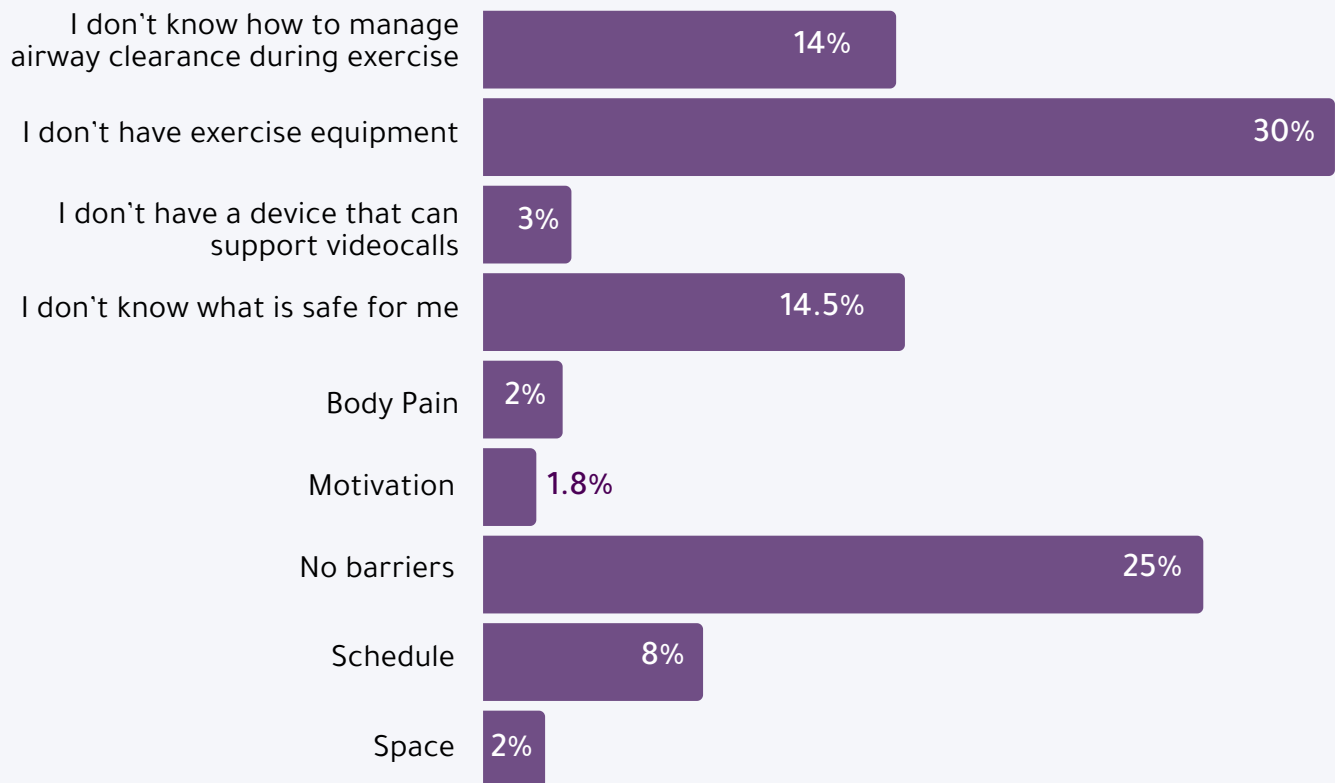
Barriers to Program Participation

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were asked to state what barriers they may have to begin exercising remotely. It was noted that 30% were worried about not having the proper exercise equipment. An exercise intervention for this group should consider this finding. For example, beneficial functional exercise would not need gym equipment and can use bodyweight exercises.

It was highlighted that the respondents either don't know how to manage airway clearance during exercise or don't know what exercises are safe for them, 14% and 14.5% respectively. When creating a program, it should be ensured that there is appropriate education on airway clearance to support and facilitate an increase in activity level.

8% of respondents mentioned their schedule would be a barrier. Any program for this group needs to be mindful of the participants' current schedule and commitments.



*Question:

"21. What barriers would you have to begin exercising remotely?"

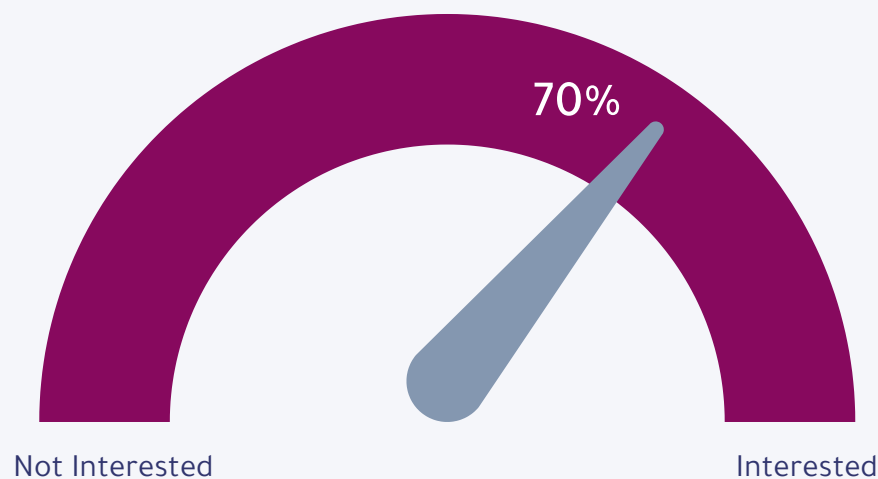
Interest in Help/Support

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Almost all respondents were either “interested” (70%) or “maybe interested” (28%), demonstrating acceptability for a remote exercise and lifestyle program of this type. As demonstrated on page 12, they would be interested in having appropriate guidance to manage their symptoms.

From the respondents that were “interested” and “maybe interested”, 97% and 87% respectively, were interested in setting new goals to improve their habits and physical health.

It can be concluded that almost all the respondents are either “interested” or “maybe interested” in a remote at-home supervised program. They are largely interested in setting goals to improve their lifestyle and physical health. When creating goals, the kinesiologist utilizes motivational interviewing techniques that encourage goal setting and adherence.



***Question:**

“15. How interested are you to set new goals and change lifestyle habits to improve your physical health?”

“17. Would you be interested in receiving help and guidance to manage your Bronchiectasis/NTM through a remote supervised exercise/lifestyle program?”

Referring to Exercise Programs

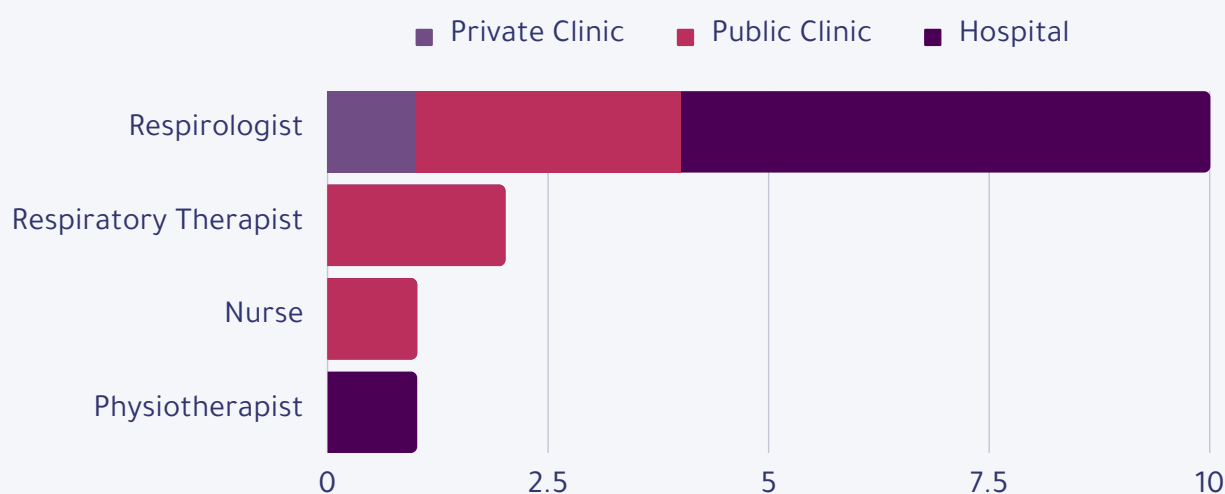
NTM/B ConnEx | HCP - Needs Assessment Survey 2021 - 2022

The majority (77.8%) of the HCPs respondents were respirologists, with 11% being respiratory therapists, 5.5% nurses, and 5.5% physiotherapists. With 50% of the HCPs coming from hospitals and 39% coming from public clinics.

From these respondents, the majority (72%) are likely to refer their patients to a ConnEx style program. A large majority of respirologists would refer their patients to a ConnEx program.

It should be noted that 39% have already referred their patients to an at-home exercise program in the past.

Likelihood to Refer to the NTM/B ConnEx Program



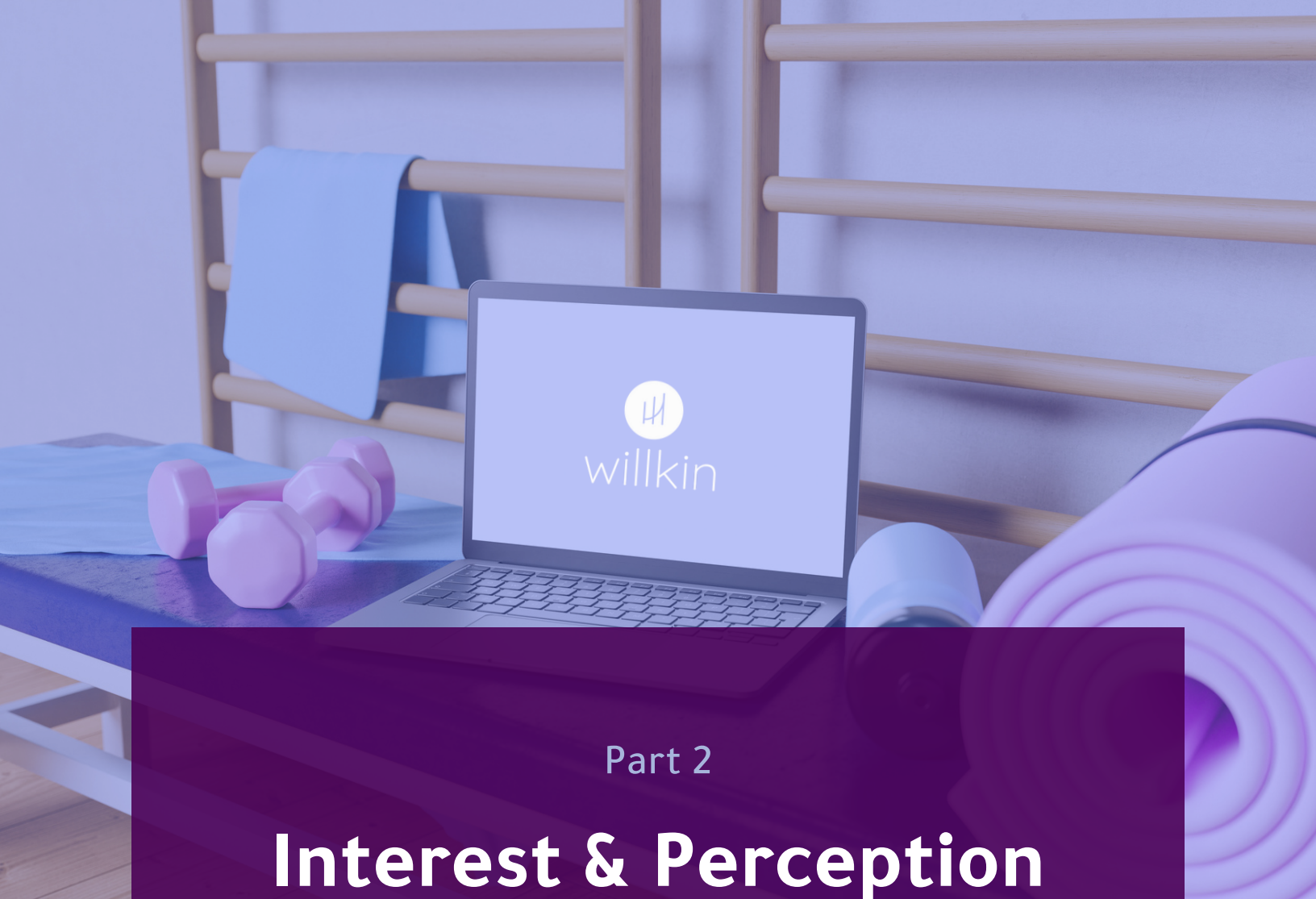
*Question:

"2. What is your professional practice setting?"

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

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

"20. Are you likely to refer your patient to this type of ConnEx program?"



Part 2

Interest & Perception towards the Program

Motivation towards Program

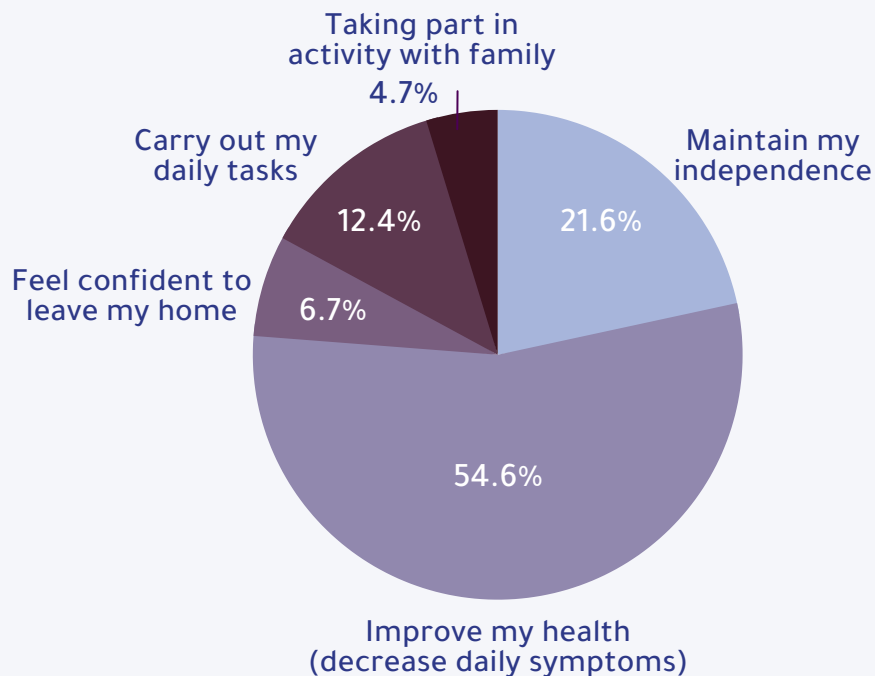
NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

More than half of the respondents (54%) are motivated to improve their health (decrease daily symptoms). This motivation will encourage their adherence to an at-home exercise program. In addition to exercises, a program should include goal setting and motivational interviewing techniques. This will aid in self-efficacy and integrating an exercise program into their life. Of these respondents (54%), about 89% are confident to begin an exercise-based program from home.

About 21% of the respondents are motivated to participate in this program as they want to maintain their independence.

An education and exercise program would allow the participants to increase their independence through their activities of daily living.

Motivation to participate in an at-home exercise program



*Question:

"16. How confident are you to begin an exercise-based program from home?"

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

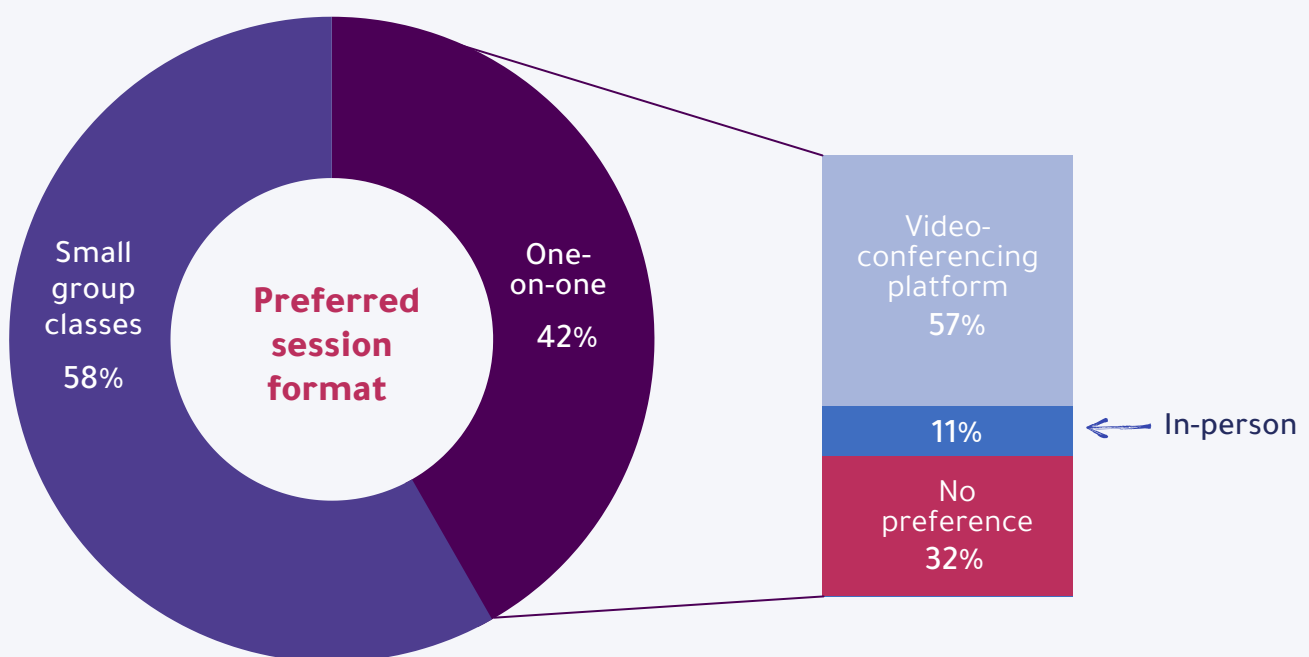
Preferred Delivery for the Program

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Almost half (42%) of the respondents prefer one-on-one and more than half (58%) prefer small group classes.

More than half (57%) of the respondents would prefer to participate in the at-home exercise program through a video-conferencing platform. The other 32% of the respondents don't have a preference in the delivery method of the program. These results indicate that a program that is delivered remotely would be widely accepted by this group.

The majority (59%) of the respondents prefer to participate twice a week. Of the 59% respondents, about half (55%) would like to be a part of small group classes.



*Question:

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

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

"30. Would your preference be in person or on a video-conferencing platform?"

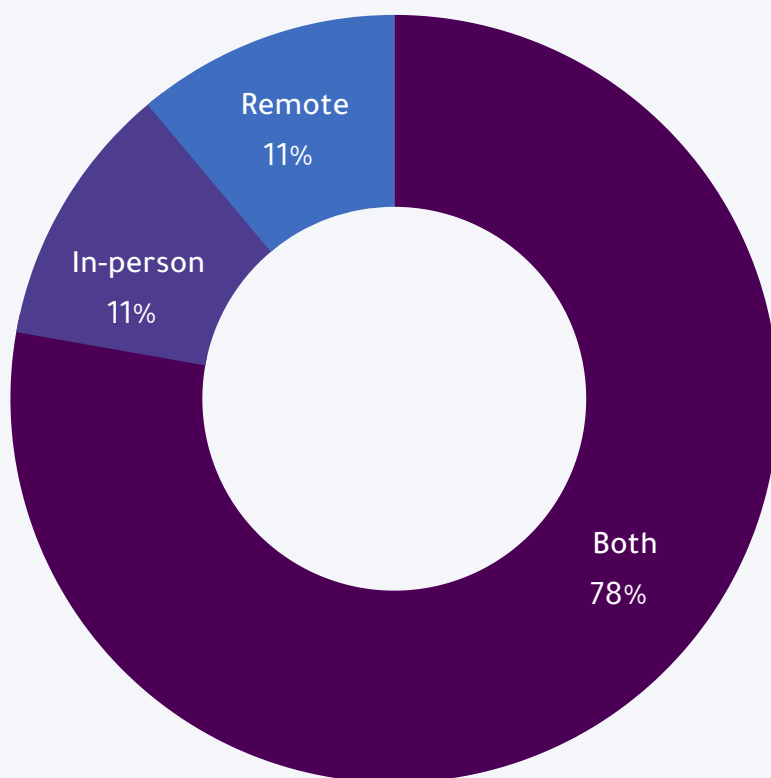
Preferred Delivery of the Program

NTM/B ConnEx | HCP - Needs Assessment Survey 2021 - 2022

The majority (78%) of the HCP respondents said that both in-person and online delivery would be the preferred methods for their patients living with Bronchiectasis and/or NTM.

Of the 22% remaining respondents, there was an equal divide in preference for in-person or remote delivery.

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



*Question:

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

Understanding the Benefits of a Kinesiologist

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were asked to describe what their understanding was of a Kinesiologist. The most frequently occurring terms have been compiled in the form of a keyword cloud.

Through these results, it can be noted that the terms “Movement” (107), “I don’t know” (77), “Exercise” (68), “Health Professional” (25), “Muscle” (9), and “Holistic” (4) are those most frequently used by respondents regarding this thematic.

These results indicate that it would be important to explain the professional scope of practice of a Kinesiologist / Exercise physiologist when communicating any program to this demographic.

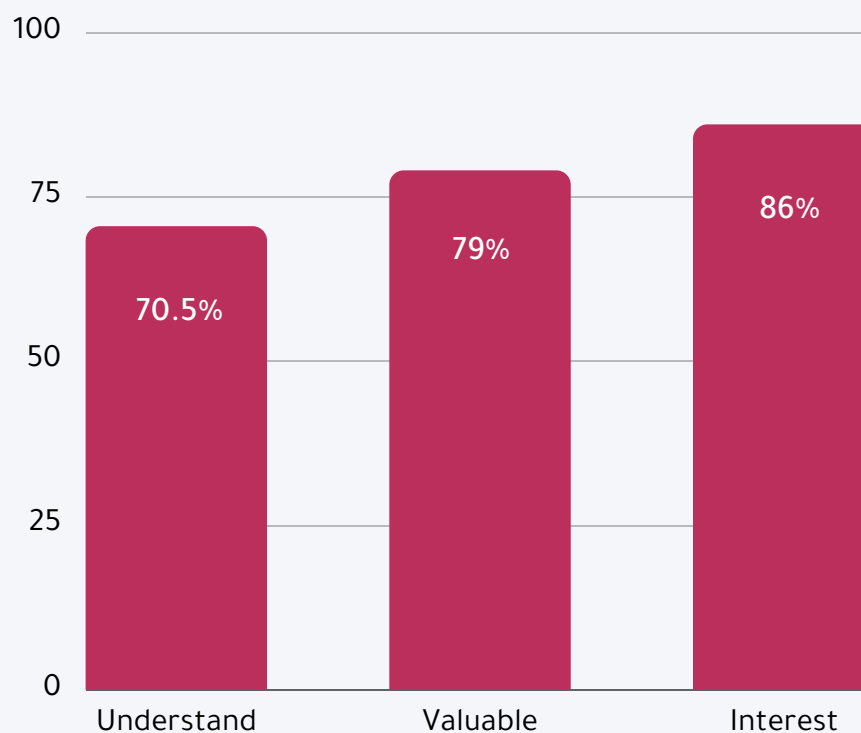


Acceptability of the Program

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were questioned on several items to learn more about the acceptability of a potential NTM/B ConnEx program. From these items, it was seen that the respondents, living with NTM and/or bronchiectasis, had a 70.5% understanding of the program. 79%, acknowledge the value of the program and 86% are interested in the program.

These findings demonstrate a high acceptance of an exercise and lifestyle program amongst this demographic



*Question:

"31. In general, I understand what the NTM/B ConnEx program can do for me"

"32. The NTM/B ConnEx program would be of value to me"

"33. In general, I have an interest in the NTM/B ConnEx program"

Perceived Usefulness of the Program

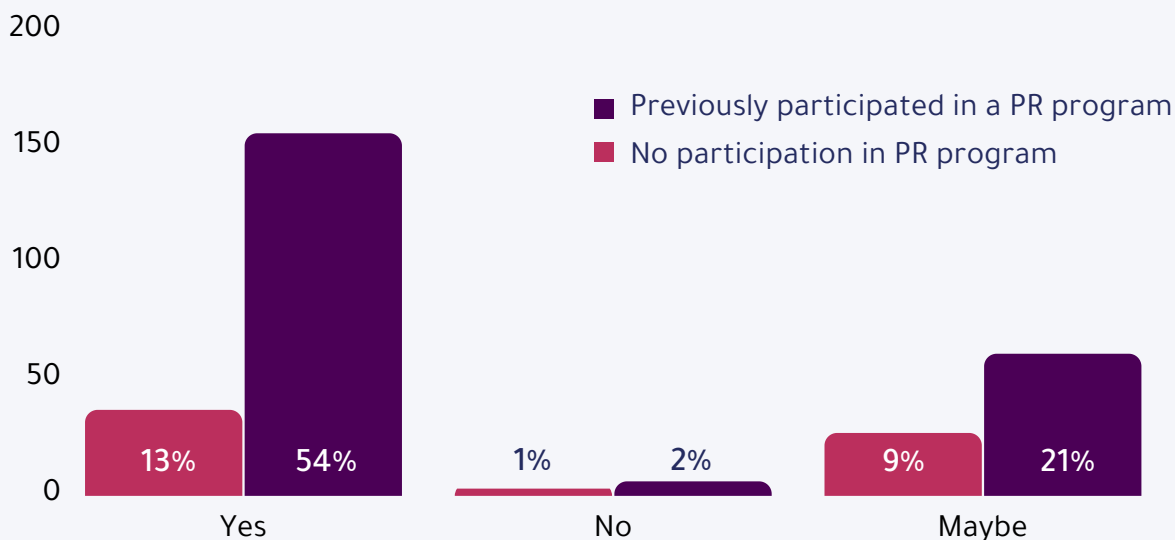
NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were asked about their perception of the usefulness of the program. In addition to the fact that the majority (67%) would be interested in receiving help and guidance to manage their Bronchiectasis/NTM, most of the respondents actively participated in supervised physical activity sessions 3 to 4 times a week prior to the pandemic. It can be assumed that interest in participating in these sessions weekly is correlated to the respondents' activity levels prior to the pandemic. Most of these respondents would be interested in having sessions twice a week.

Though the majority of the respondents are interested in receiving help and guidance to manage their Bronchiectasis/NTM, only a small segment have participated in pulmonary rehabilitation in the past. Lack of knowledge about a PR program and its benefits and not having access to such a program might be the reason for some hesitation.

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.

Interest in receiving help and guidance to manage their Bronchiectasis/NTM



*Question:

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

"17. Would you be interested in receiving help and guidance to manage your Bronchiectasis/NTM through a remote supervised exercise/lifestyle program?"

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

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

Willingness to Pay

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were asked what they would be willing to pay for a remote program. Approximately one-third (36%) would be willing to pay more than \$15 per session for this program. From the 36%, approximately 23% is in CAD currency. A session would be 45 minutes in length.

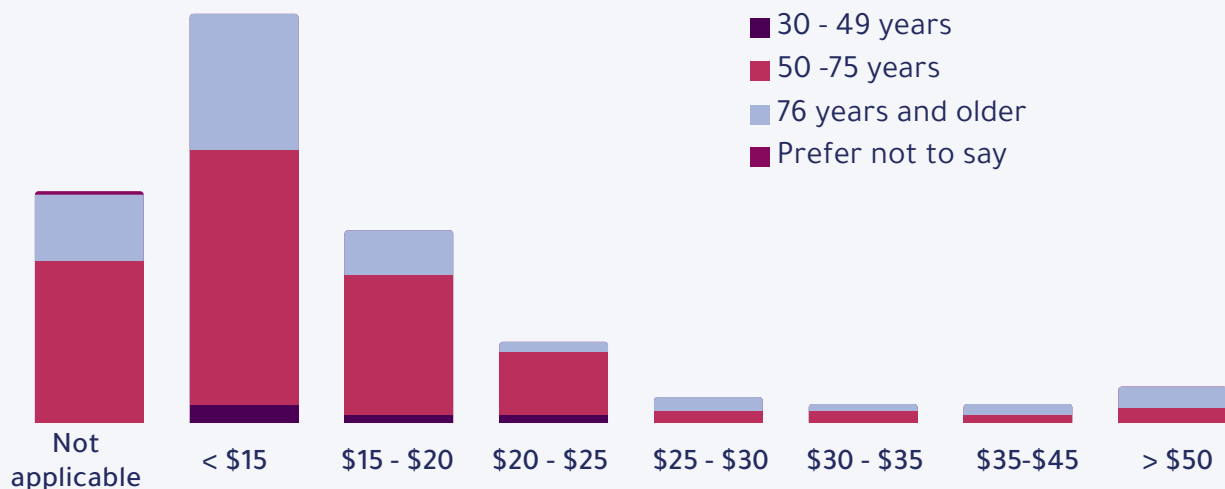
Approximately 40% of the total respondents are willing to pay less than \$15 per session. From the 40%, about 15% is CAD currency. Of this group (CAD and USD), 52% are between the age of 65-75 years old.

23% of the total respondents were not able to put a price on the session. From this group, about 30% were "maybe" interested in receiving guidance to manage their Bronchiectasis/NTM.

From the small cohort of men (4.3%) about 46% of this group would be willing to pay less than \$15 per session.

About 19% of the respondents are willing to pay \$15-\$20 per session. From this group, about 40% are between the ages of 65-75 years old.

Willingness to pay per session for the program, per age



*Question:

17. Would you be interested in receiving help and guidance to manage your Bronchiectasis/NTM through a remote supervised exercise/lifestyle program?

"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"

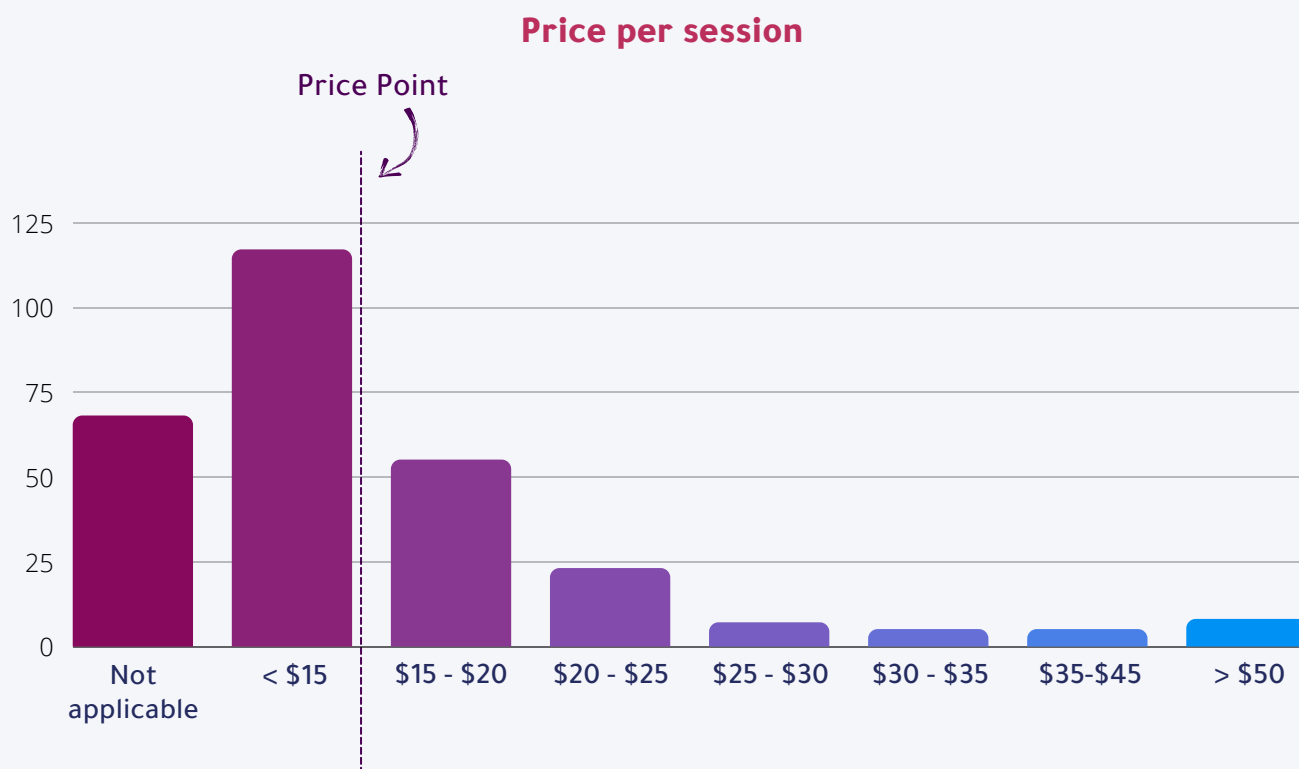
"31. Please indicate your gender"

Price Point

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Of the respondents that are willing to pay for this program, approximately 40% of the total respondents are willing to pay less than \$15 per session.

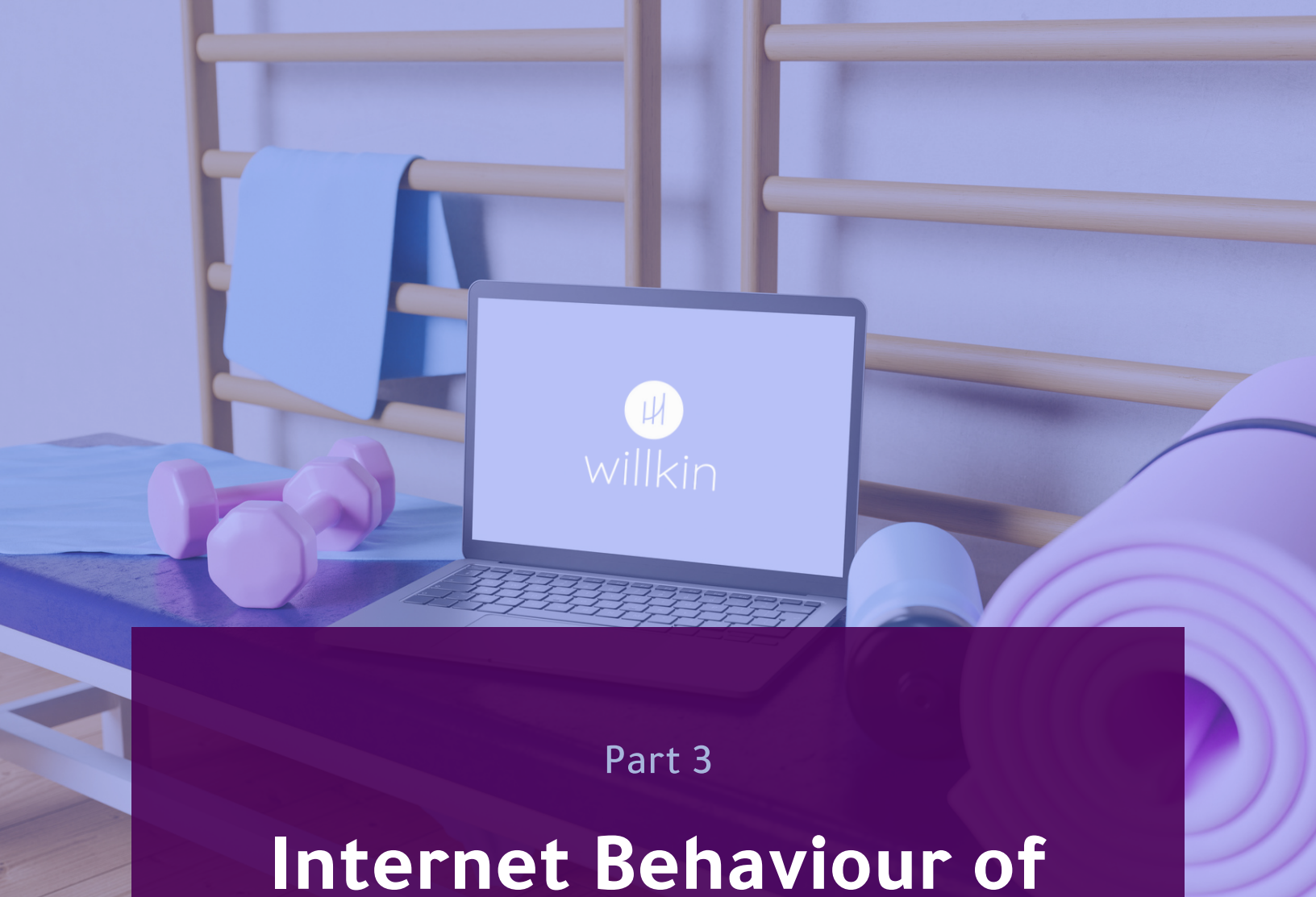
From this group, willing to pay less than \$15 per session, 43% of the participants are interested in receiving guidance to manage their Bronchiectasis/NTM. This information is important when considering the price per session for this program.



***Question:**

17. Would you be interested in receiving help and guidance to manage your Bronchiectasis/NTM through a remote supervised exercise/lifestyle program?

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



Part 3

Internet Behaviour of People Living with NTM and Bronchiectasis

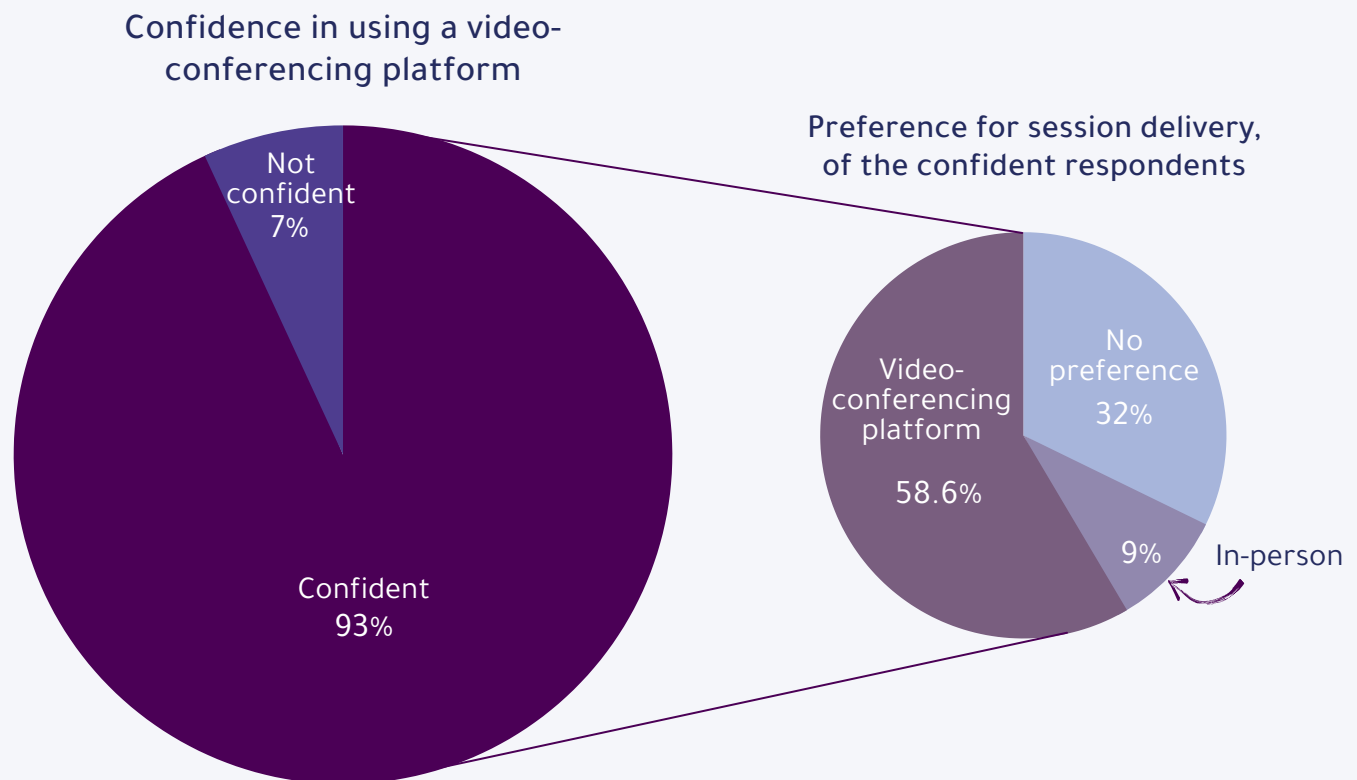
Digital Tools Used

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

The majority of the respondents (93%) are confident in using a video-conferencing platform for a remote supervised exercise session.

Of the respondents that were confident in using this platform, 90% would either prefer remote sessions through a video conferencing platform or have no preference. This survey indicates that people have significant online experience and are more comfortable in online sessions.

Increased awareness and confidence using the internet due to necessity through the pandemic has led to a greater acceptance of using online platforms to seek and receive information and services.



*Question:

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

"30. Would your preference be in person or on a video-conferencing platform?"

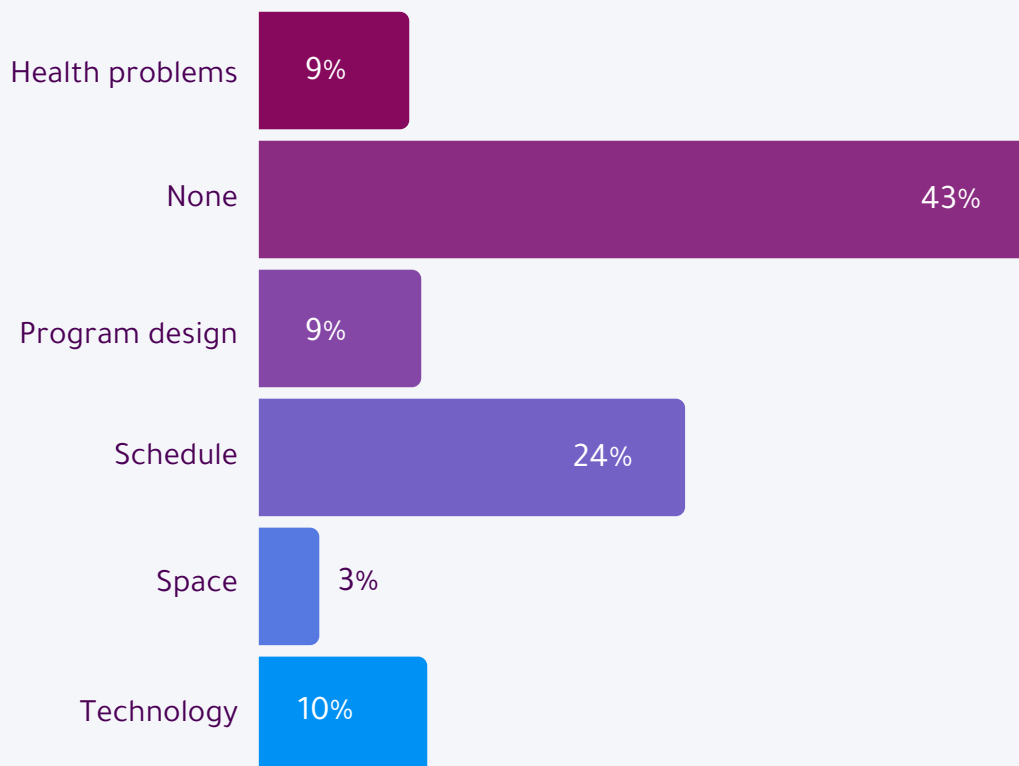
Barriers to Stop Program Participation

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

Respondents were asked about potential barriers that may stop them from participating in a remote-supervised exercise session, using a video-conferencing platform. The survey indicates that a majority (43%) of respondents do not have barriers to participating.

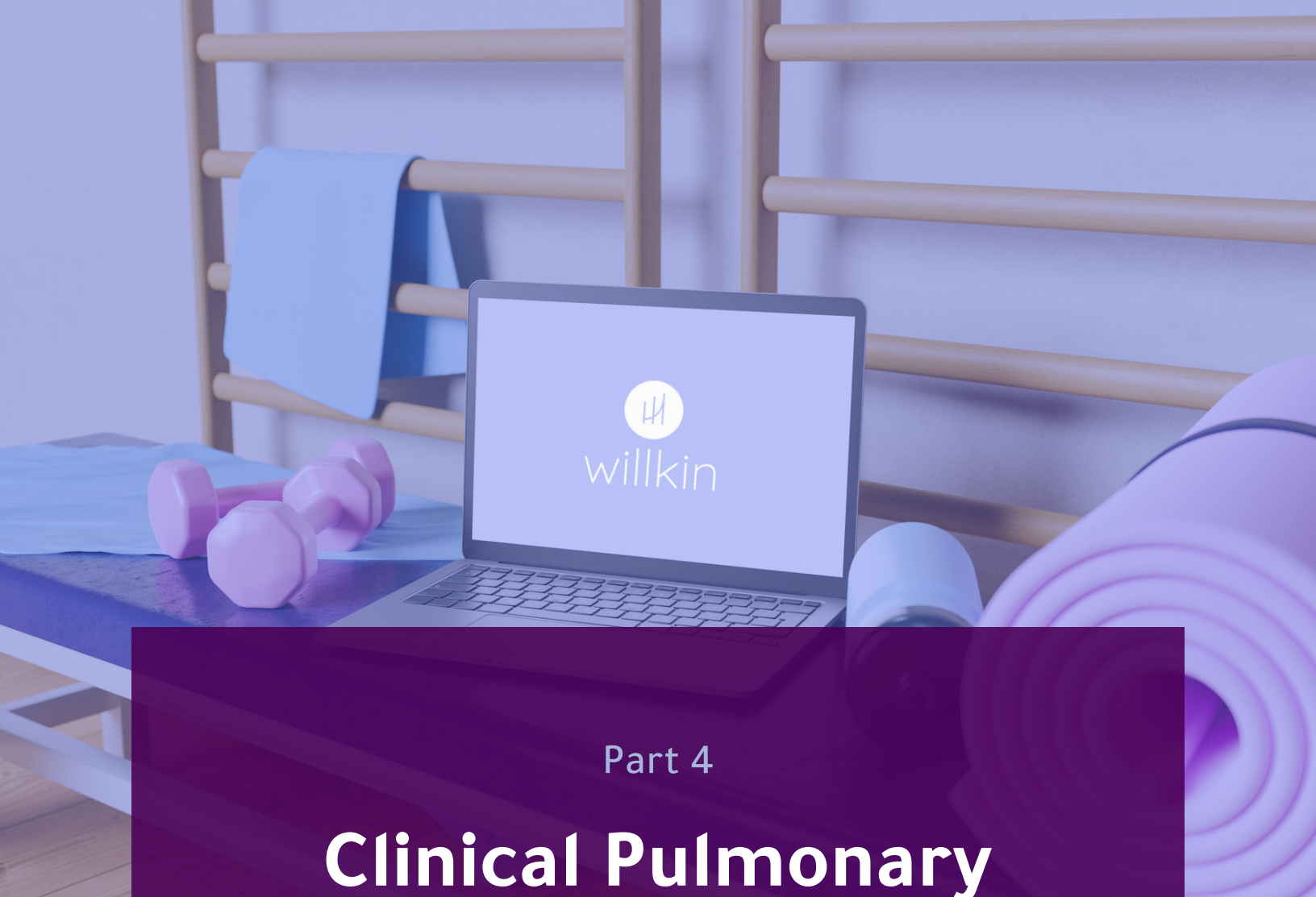
Approximately one quarter of respondents (24%) mentioned scheduling would be a barrier. As mentioned, this would need to be a consideration, but an online delivery format is less disruptive due to no travel time or environmental barriers.

About a tenth (10%) of the respondents mentioned that technology would be a concern or barrier for them. Therefore, any program designed needs to have consideration for this group, and a full onboarding session with guidance on the technology would be required.



*Question:

"24. What barriers would stop you from participating in a remote supervised exercise session, using a video-conferencing platform?"



Part 4

Clinical Pulmonary Rehabilitation

Accessibility to Clinical PR

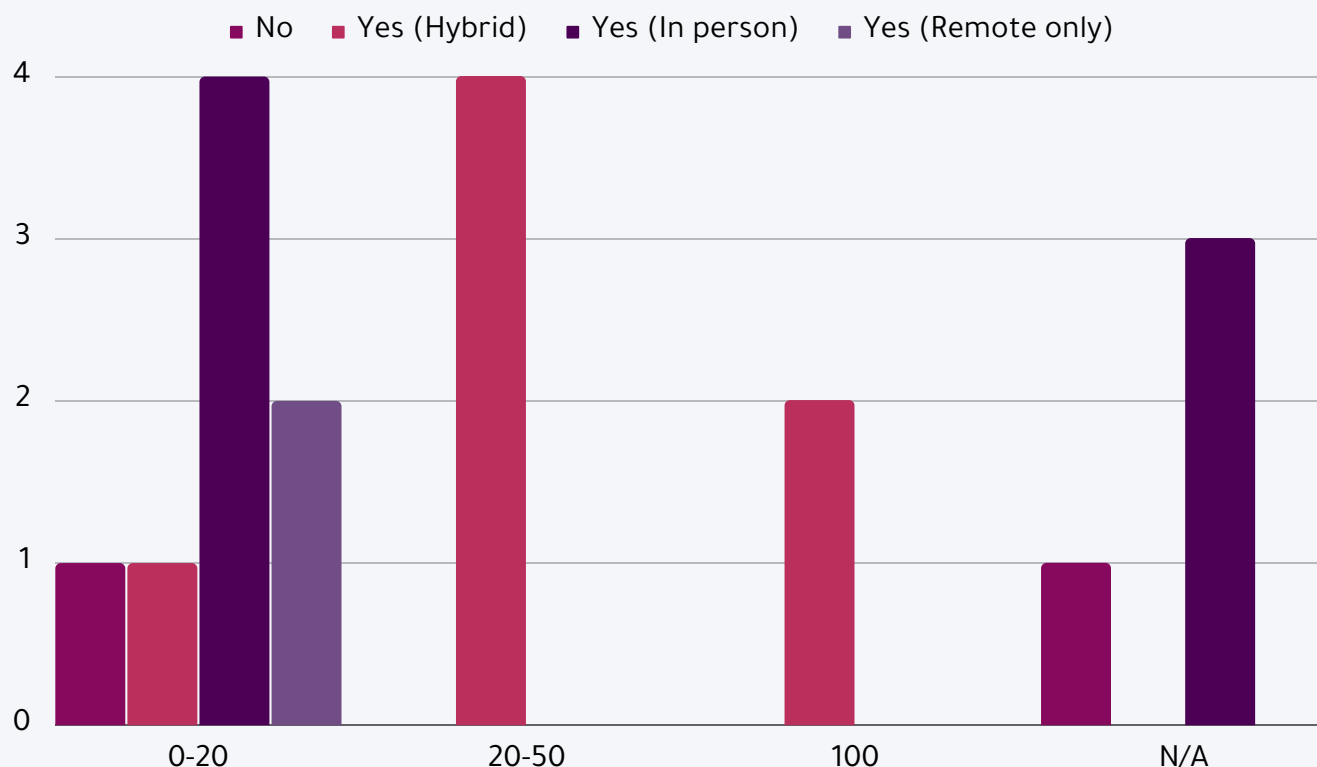
NTM/B ConnEx | HCP - Needs Assessment Survey 2021 - 2022

The HCP group was asked about access to clinical pulmonary rehabilitation programs in their area. A majority of the respondents (89%) said that they have pulmonary rehabilitation in their city. From these respondents, about half (44.4%) report having a wait list of between 0-20 patients.

One-third of the respondents (33%) have wait times that are less than 3 months long.

The data here raises a key issue on the importance of having a program, that is accessible and available to those that are on a waiting list.

Number of Patients on PR Program Waitlist



*Question:

"8. Is there a pulmonary rehabilitation program in your city?"

"10. To the best of your knowledge, at your facility, how many patients are on a waiting list for pulmonary rehab?"

"11. What is the average pulmonary rehab waiting time for a patient with Bronchiectasis/ NTM?"

Report Details

NTM/B ConnEx | Needs Assessment Survey 2021 - 2022

An initiative of:



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