

PULMONARY HYPERTENSION ASSOCIATION OF CANADA

L'ASSOCIATION D'HYPERTENSION PULMONAIRE DU CANADA

Clinical Trials: What matters to you?

Introduction

Why do people with pulmonary arterial hypertension participate in clinical trials? Why might they not wish to participate? Since clinical trials are often conducted through clinics, how much effort and cost is associated with clinic visits? This online survey, conducted in Canada in July 2024, sought to examine these issues.

These results will help researchers in Canada and internationally design new clinical trials that are more relevant to patients and that minimize the burdens of participating.

Acknowledgements

PHA Canada conducted this survey with Principal Investigator Dr. Jason Weatherald, in partnership with Pulmonary Hypertension Association (PHA) UK.

PHA UK, who conducted a similar survey and published their report in 2022 (https://www.phauk.org/clinical-trials-what-matters-to-you/), kindly let us reproduce their question set and general report format.

Suggested Citation

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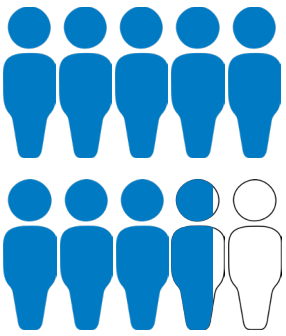
Who responded to the survey?

73

people with pulmonary hypertension (PH) completed this survey



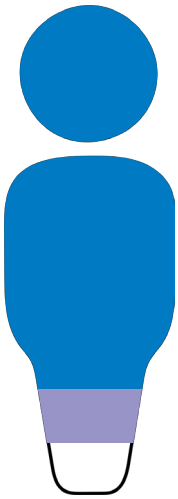
2/3 were **over 55 years of age**



88% were **female**

81% described themselves as **white**

8% described themselves as **other**



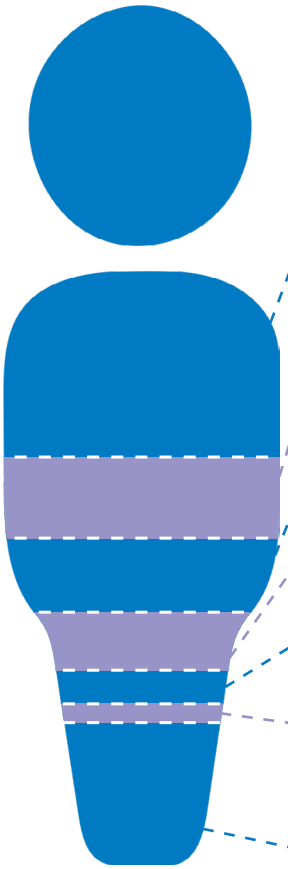
11% described themselves as **Asian**



74% had their PAH diagnosis for **over three years**



10% had their PAH diagnosis for **less than 1 year**



53% have idiopathic pulmonary arterial hypertension (IPAH - WHO Group 1)

11% have pulmonary hypertension in association with congenital heart disease (WHO Group 2)

8% have pulmonary hypertension in association with systemic sclerosis (WHO Group 5)

7% have chronic thromboembolic pulmonary hypertension (CTEPH - WHO Group 4)

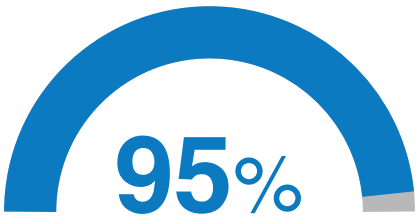
4% have pulmonary hypertension due to lung diseases (WHO Group 3)

1% have heritable pulmonary arterial hypertension with an identified genetic mutation (WHO Group 1)

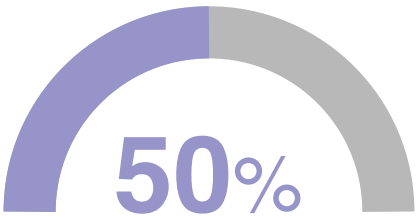
16% The remaining 16% stated “other” or that they do not know what type of PH they have



Technology use



of respondents have a smartphone (57% have an iPhone, and 38% have an Android phone)



use technology to track their activity (38% use a smartwatch, and 12% use their phone)



The most common smartwatch brands reported were Apple Watch, Garmin, Fitbit, Apex Fit and Amazfit

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100%

of those who do not currently use a wearable activity tracker said they would be willing to wear one for most of the day if it was provided free as part of a research trial

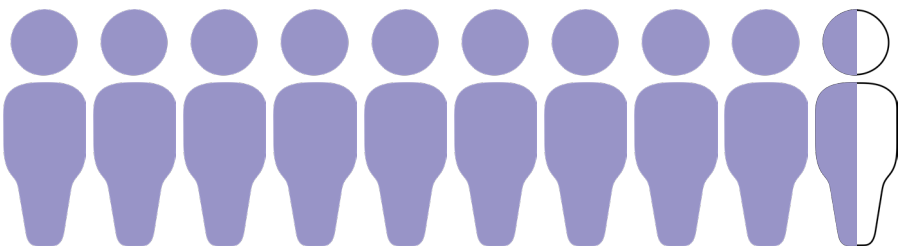
81%

said they feel ‘very’ or ‘quite’ confident using apps on mobile phones or tablets

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95%

have close family, friends, or carers who use apps on a smartphone



54%

of respondents said they share at-home health measurements with their specialist (14% do so ‘regularly’)

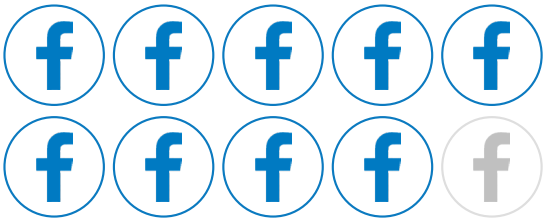
100%

of those who do not currently share these measurements said they would be happy to do so

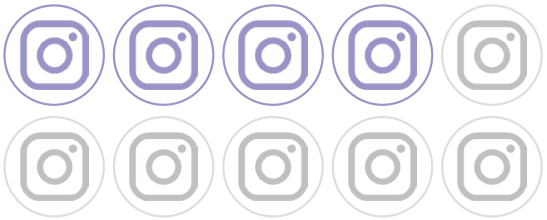
Respondents were asked to list the health apps they used. They included apps for:

- Fitness activity tracking and step counting
- Nutrition and weight
- Sleep
- Apps that track (or connect with devices to record) heart rate, blood glucose, blood pressure, pulse and oxygen levels.

90% of respondents said they use Facebook at least once a week



40% use Instagram at least once a week



12% use X (Twitter) at least once a week



7%

said they do not use social media at all

Taking part in clinical trials

21%



of respondents said they had taken part in a clinical trial which involved taking a drug for pulmonary hypertension

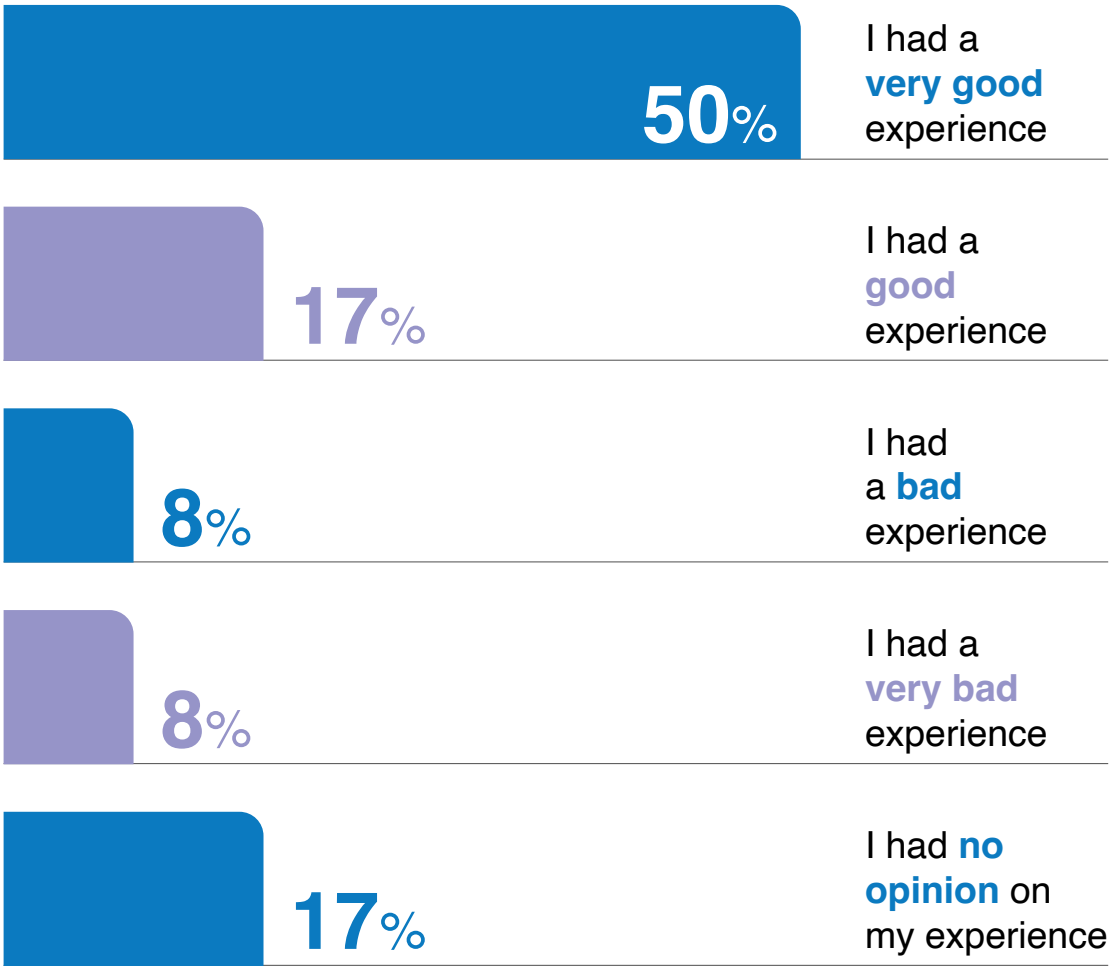
84%



of those who have taken part in a clinical trial that involved taking a drug for pulmonary hypertension would definitely or probably do so again

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Those who had taken part in a clinical trial said this about their overall experience:



The top 5 reasons people gave for **wanting to take part** in clinical trials were:

1. To help other people with PH in the future
2. Because the drug treatment I would get in the trial may help me
3. To advance science
4. As a patient with a rare condition, I am a useful 'resource' for science
5. To give a patient's perspective to a trial.

Top 5 reasons people gave for **being discouraged from taking part** in clinical trials:

1. I would be worried about side effects from medication
2. The cost that may be associated – e.g. travel to hospital, parking, or time off work
3. It wouldn't be worth it if I ended up getting a 'dummy' or placebo treatment instead of the drug being tested
4. I would be worried about taking a new drug
5. I wouldn't want to travel a long way, or frequently, to a specialist hospital.

The emPHasis-10 questionnaire

The survey asked respondents to look at the emPHasis-10 questionnaire, the quality of life measure used by researchers and doctors to find out how patients feel and whether their treatments are helping.

Respondents were asked to identify ways that PH affects their life that are **not covered** by the emPHasis-10 questionnaire. They included:



Mental health
Including depression, anxiety, memory, and isolation



Relationships
Including intimacy



Physical symptoms
Including shortness of breath, nausea, dizziness, and swollen legs



Work
Including the ability to maintain employment or pursue a career



Mobility
Including daily activities, social/work participation, and driving ability



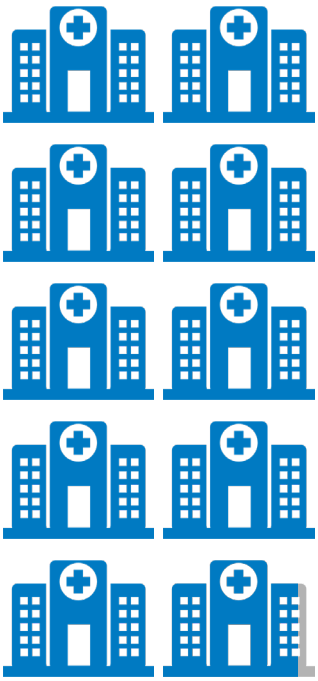
Oxygen use
And the limitations it can cause



Financial effects
Including strain from medical costs, reduced income, and daily living expenses



Visiting specialist PH centres

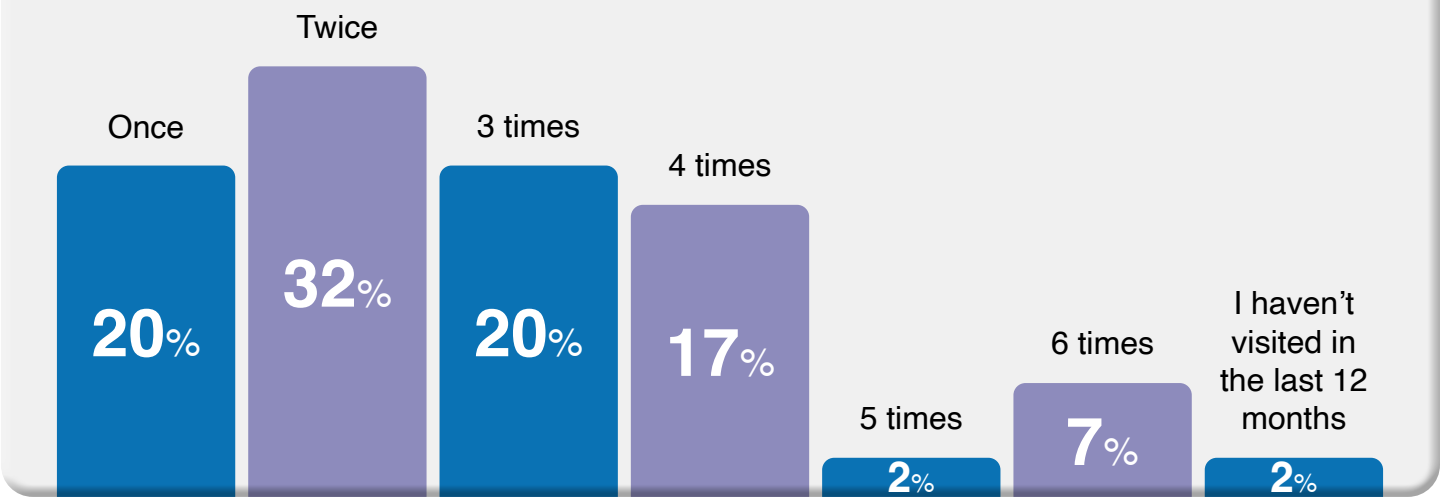


98%

of patients attended their PH centre at least once in the last 12 months

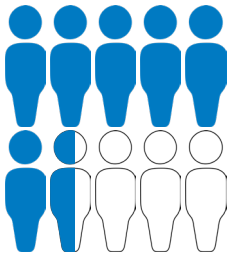


Frequency of visits to your specialist PH hospital in the last 12 months:



66%

of respondents said they are usually accompanied by a partner, family member, or friend for their specialist PH centre visits



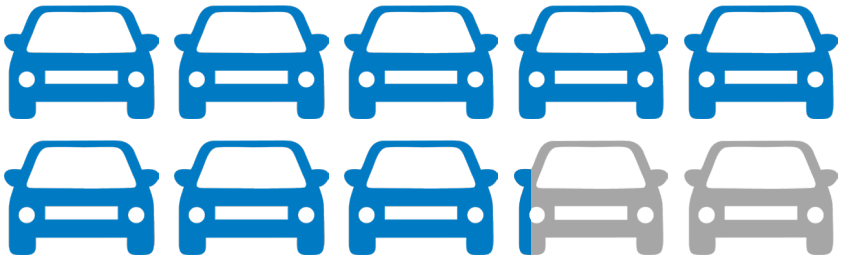


32%

of the time, that person has to take time off work to accompany them

81%

of patients travel to their specialist centre by car

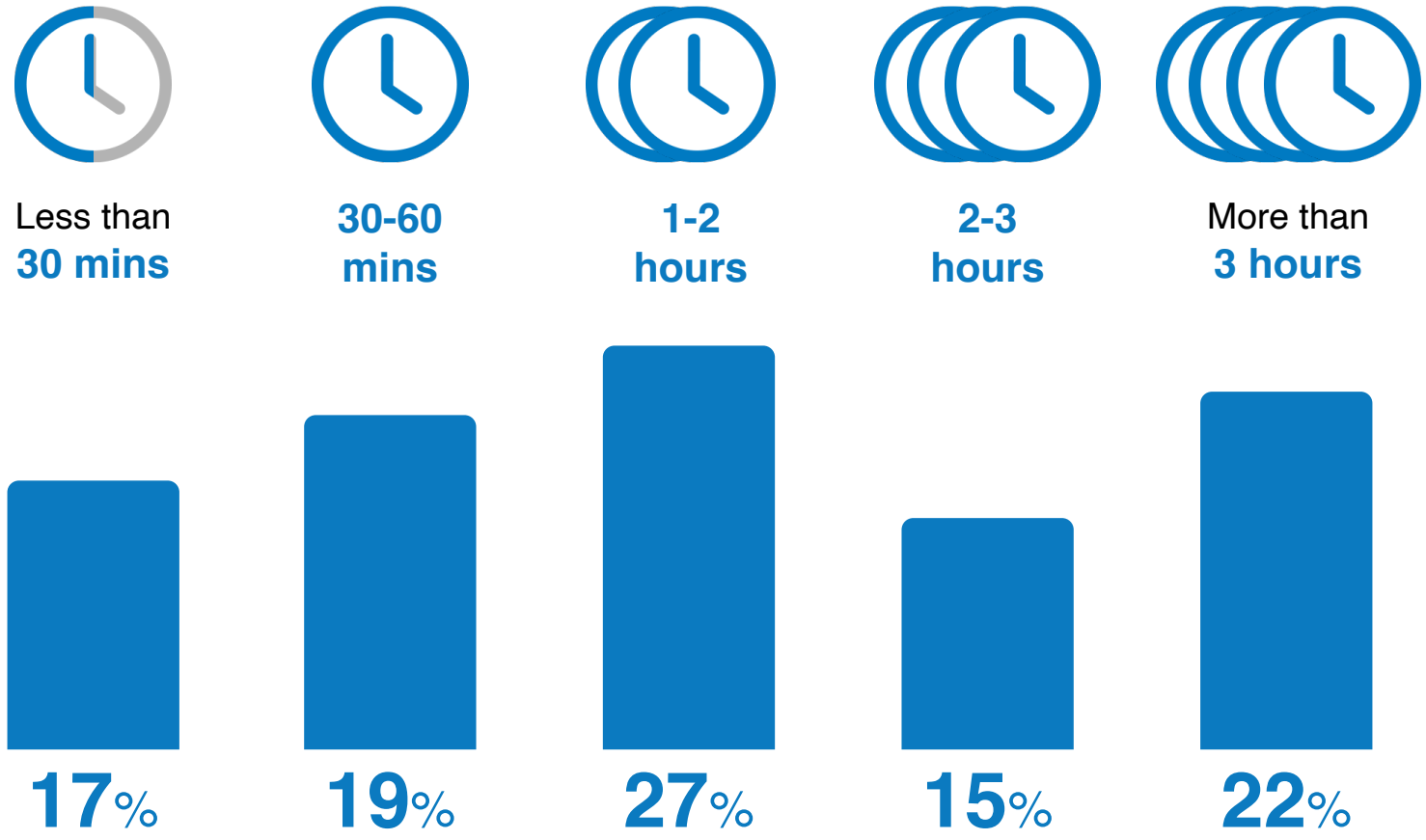


5% by bus or train

2% hospital transport

12% other

For **64%** of patients, the journey takes **more than an hour each way**



Half of respondents pay more than **$65** per clinic visit

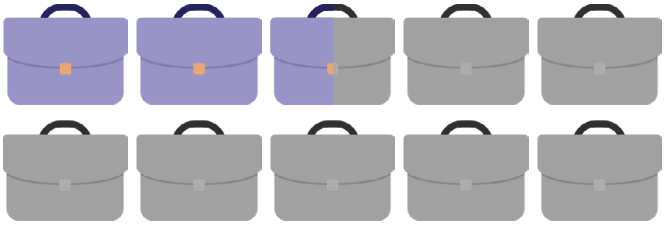


The average cost of the journey is about **$237**. It is higher if people must stay overnight



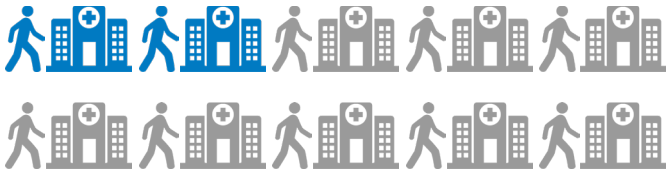
Some respondents had costs as high as **$2,000 - $3,000**





25%

of all respondents indicate that they are **currently working**



20%

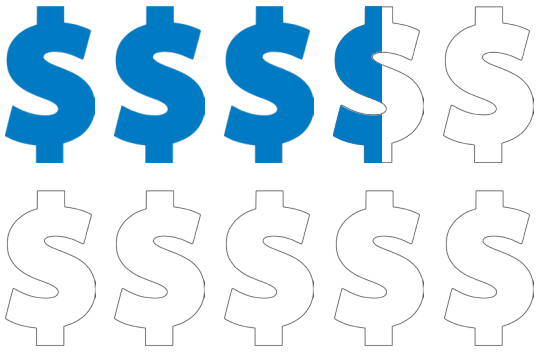
of them said it was **quite difficult** for them to **take time off work** to attend appointments

> *"Work usually accommodates my appointments as they are currently only 2x per year"*

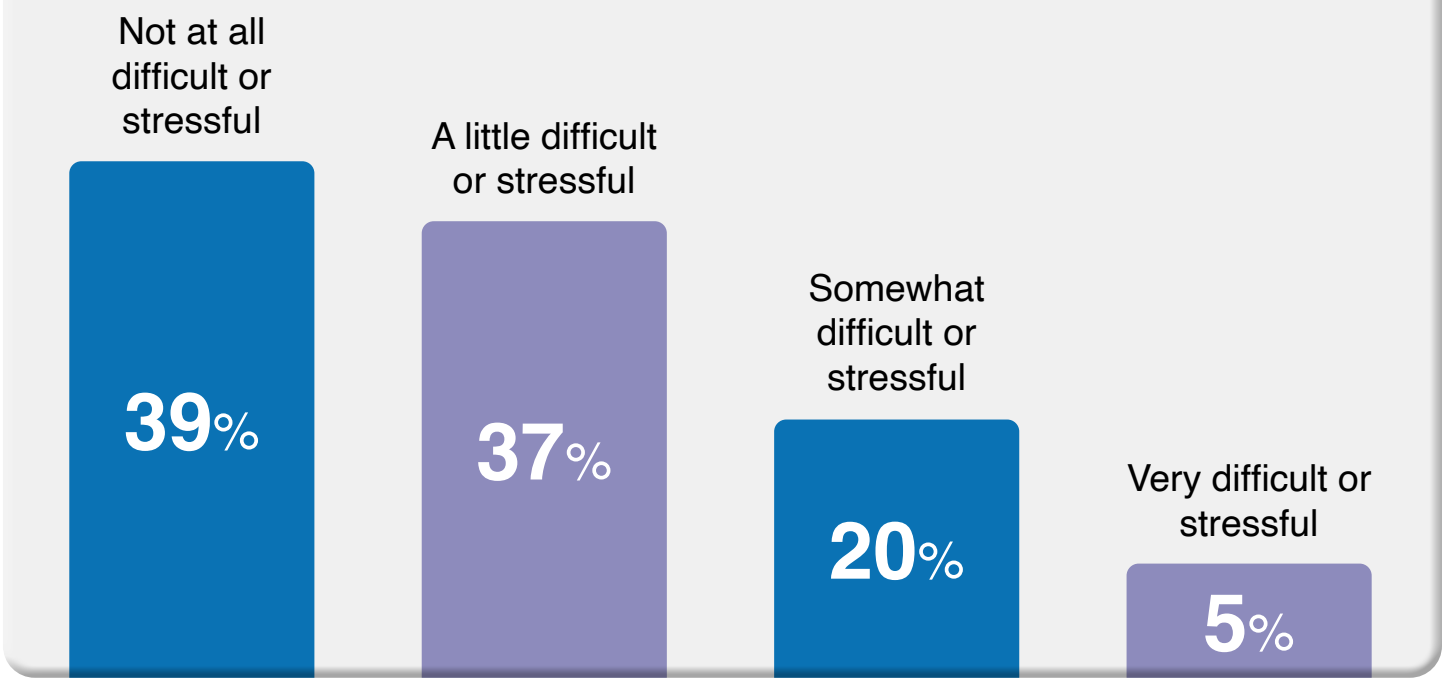
> *"I have a child that I have to get to daycare for a certain time"*

36%

of those who work said they **lose income** from attending specialist centre appointments



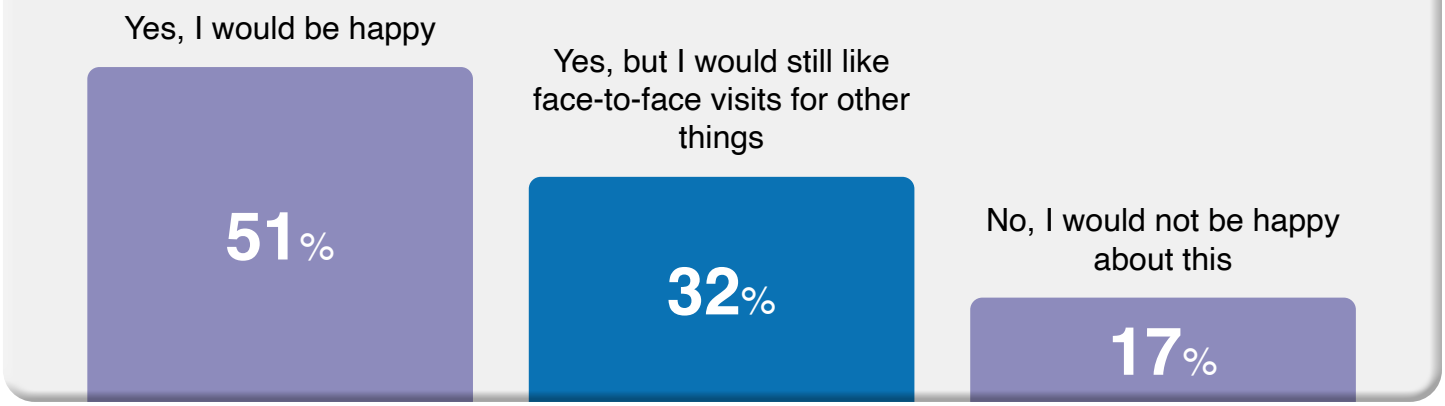
Many patients find that visiting their specialist centre comes with some level of stress or difficulty



"Not the appointment itself. It's just a stressful drive to the city for the appointment."

"Always afraid something may change."

83% of patients said they would be happy for at least **some aspects of their healthcare to be remote**



If some things that normally take place during your visit could be done from home, such as answering questions about your symptoms, would you be happy for this to happen via telephone / video call instead?

"My preference is for face to face for all"

"As I see my PH Specialist only once per year currently I would hesitate to lose that contact"

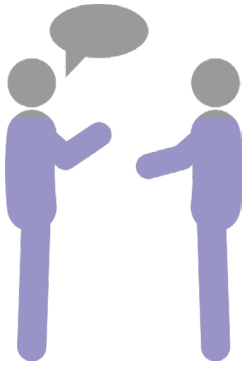
"I tried a few calls during COVID. I missed the body language and I felt rushed, even though I'm sure I wasn't rushed. In person for me made more sense. My walk test and such."

"Preference for video calls"



76%

of respondents said they don't talk to other patients during their specialist centre visits



70%

of those who do talk to other patients said they find it helpful or enjoyable

"I never see other patients. I would love to chat with them"

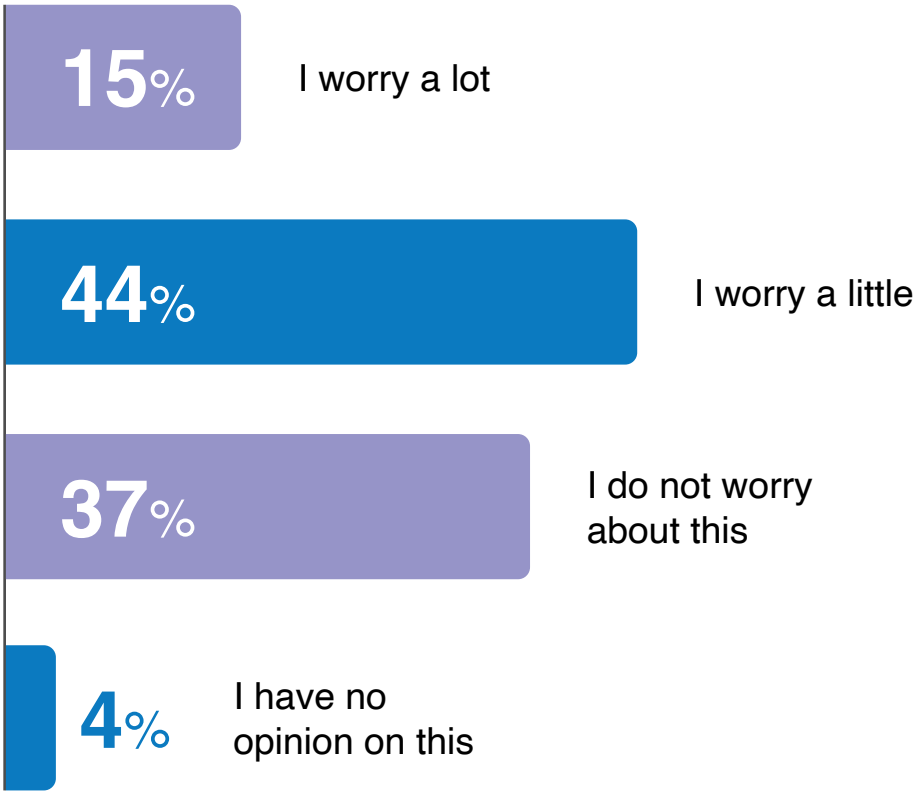
"I don't even know if there are other PAH patients there"

"There is normally no one else there when I have an appointment"



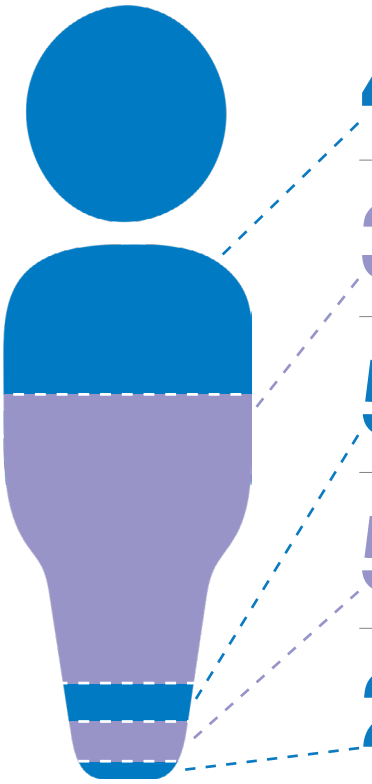
59%

of patients worry about their health **in between specialist centre visits**





Respondents were asked whether the results they get from hospital tests generally reflect how they feel their PH affects them:



49% They sometimes reflect how I feel

39% They always or often reflect how I feel

5% They often do not reflect how I feel

5% They never reflect how I feel

2% Other (“I don’t generally get information re: results of my tests”)

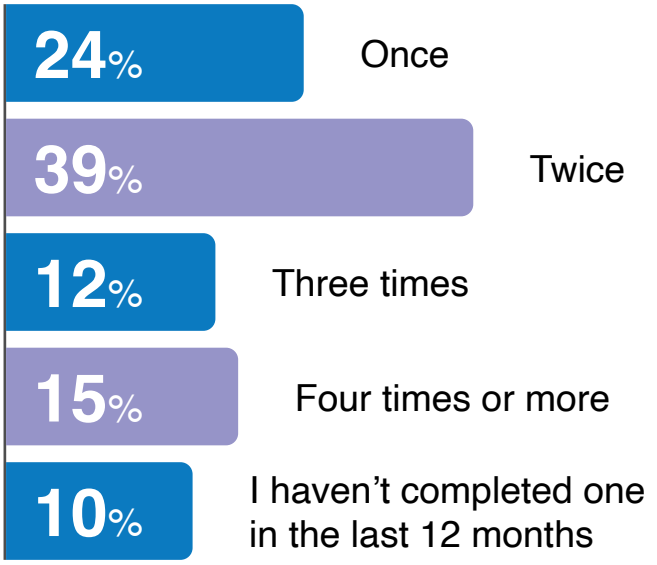
The 6-Minute Walk Test



98%

of respondents said they have completed a 6-Minute Walk Test **at their specialist hospital**

90% have completed one in the last 12 months:



90% said they understood why they were asked to complete a 6-Minute Walk Test

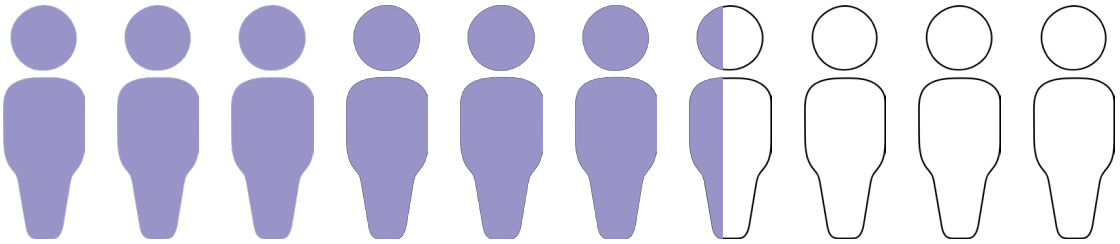


Respondents were asked to explain how they usually feel after completing a 6-Minute Walk Test. Responses included:

“Very short of breath but refreshed after I rest”

“Like I’m lucky I didn’t die. Ready to collapse, exhausted, chest tightness, etc.”

“I normally feel good. I walk a good distance so I always feel good about that”

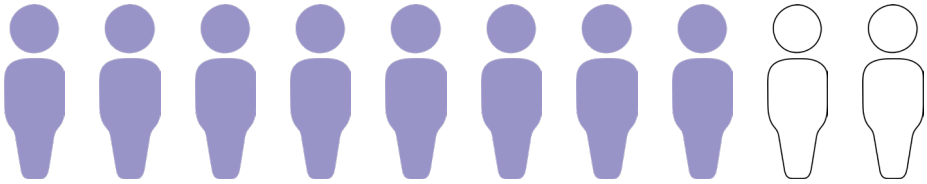


63% said they felt the results reflected how they feel. Additional comments included:

“Don't reflect normal routine activities, e.g. carrying groceries or a laundry basket”

“I don’t push myself to walk same speed/distance in my regular activity as I’m required for a 6MWT”





80% of respondents said that if they were trained to measure distance using an app on a smartphone or digital device, they would feel able to complete a 6-Minute Walk Test outside their house



90% said they have a safe, flat, and fairly straight surface they could walk on outside their home

Respondents were asked if anything would concern them about doing a 6-Minute Walk Test outside their home in their local community. Answers included:

"Only with moderate air temperature and low humidity"

"Couldn't manage the oxygen tanks"

"I currently do a loop in our open concept home"

"No, I could do it quite easily and it would save the drive"

"As long as I had someone to support me and be there while I did it I would be fine"

"Falling or having something happen and there would be no help available"

"If it rained or the weather was not great I would have to find somewhere inside to do it, and that would take extra effort to get to"

Future research

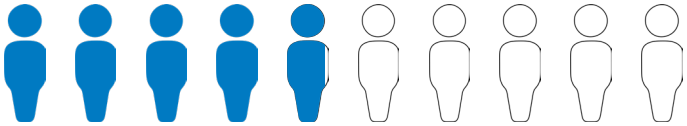
Respondents were asked if they would be happy to take part in further research related to the questionnaire:



88% would be happy to help test a new 6-Minute Walk Test app at home



90% would be happy to fill in more online surveys



49% would be happy to take part in online focus discussion groups with other patients



68% would be happy to take part in online/telephone interviews with a researcher

Additional comments about clinical trials included:

"For me being part of a study would depend on how much work I would miss. As well I live in the country so winter months are more difficult to travel (never know when a storm will hit)"

"I would want to know that there is a support team always there for me when I need them. I need a contact person or team that will answer the phone if there is an emergency."

"The more trials that are opened up to more of us, the more data can be compiled. You can't test for trials for PH on healthy people. You need PH / PAH patients to do the trials."



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