

# Helping people get the most from their **PH treatments:** *Phoenix study proposal findings*



**In March 2021, the Pulmonary Hypertension Association (PHA UK) carried out an online survey to understand how much people with PH would value the proposed Phoenix study.**

## **ABOUT THE SURVEY**

**The survey was conducted via the online survey tool Suvey Monkey and promoted via social media. It consisted of ten questions; most of which were multiple choice. There was also space for additional comments.**

# 119

people responded  
to the survey

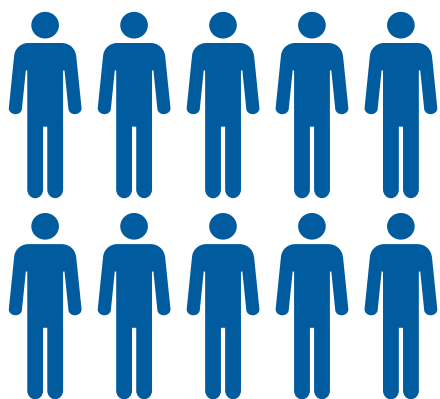
## **ABOUT THE RESPONDENTS:**

**72%**  
**have PAH**  
(43% have idiopathic PAH)

**77%**  
**are aged  
between 31 & 70**

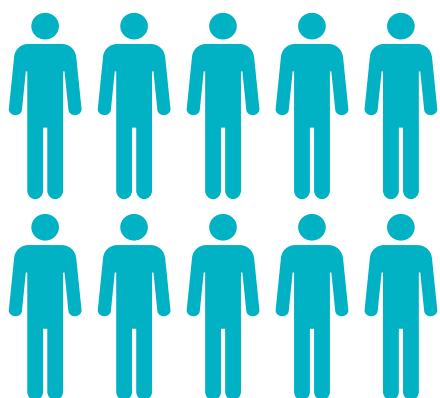
**92%**  
**are female**

# The findings



# 100%

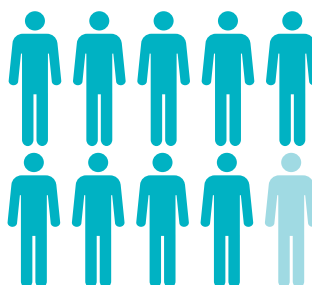
of people with PH think the study is **important**. (84% think it is very important)



# 99%

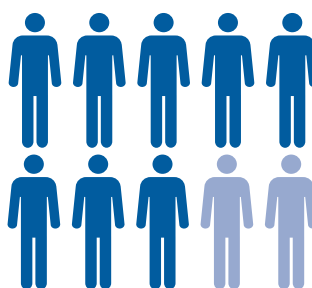
of people with PH would be **interested** in the findings. (79% would be very interested)

# 89%



of people with PH think the study's aim of helping patients benefit from the right mix of treatments for them, balancing clinical benefit and side effects, is **very important**. 11% believe it to be **important**.

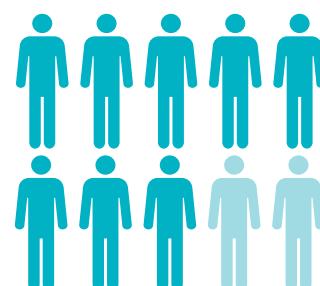
# 79%



of people with PH think the study's aim of minimising visits to specialist centres by enabling data to be sent directly to specialists from patients' homes is **very important**. 19% believe it to be **important**.

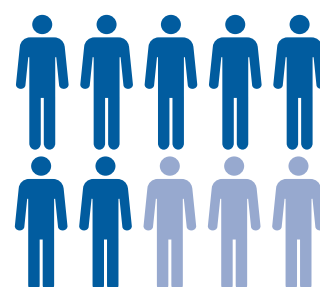
# 81%

of respondents said they would be interested in taking part in the study. Of these, 84% have PAH.



# 66%

of respondents (78 individuals) provided their contact details for researchers to contact them should the study be approved.



# Comments from respondents

*It sounds like this could be the start of something as significant for PH as insulin pumps for diabetes, and that is massive! I know it just sends info, but knowledge is power, and it's a first step to who knows what increased personalisation in treatment."*

*This could give a better picture of how the patient is in daily life in comparison to clinic.*

*I think that monitoring is key to treatment and keeping patients stable, detecting changes before things become too bad.*

*Anything that would enable a better understanding of PH and treatment would definitely be worth it.*

*Many patients live a long distance from the specialist centres so this type of monitoring could reduce unnecessary visits but flag patients who need to be seen more often.*

*Anything that gives insight into management, treatments and monitoring progression/deterioration has to be of benefit.*

*This is the next step to personalisation of therapy to improve our condition or monitor it. So, it has to be beneficial to us all.*

*The concept of personalised medicine is a breath of fresh air for someone like me with an autoimmune condition where everyone has different symptoms and different problems.*

*Being able to live a less 'interrupted' life [due to less specialist centre visits] would be incredible.*

*How fantastic that you are including people's views who actually have this disease.*

*This is very exciting.*

*Anything that makes our lives easier and aids research is good for the PH community.*

*The study seems to be progressive and a real step forward.*

*This is a brilliant move forward.*

If you have any questions about the findings of this survey, please contact [office@phauk.org](mailto:office@phauk.org)