

Diagnosing PH earlier in people with systemic sclerosis: Study proposal findings

In December 2020, the PHA UK conducted an online survey to find out how interested people with PH would be in a study aimed at diagnosing the condition earlier in those with systemic sclerosis.

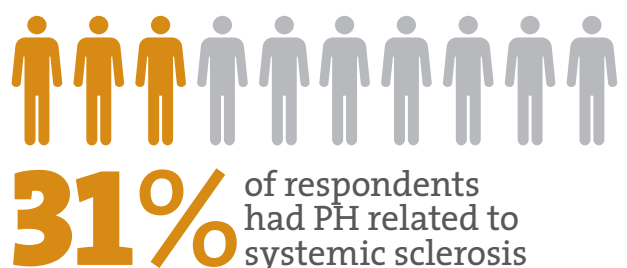
Researchers are aiming to set up the study looking at the use of cutting-edge magnetic resonance imaging (MRI) scans and new disease markers in the blood to help PH be detected earlier. The technologically advanced MRI scans have recently been used in the diagnosis of lung scarring and researchers want to

see if they can also be used for earlier diagnosis of pulmonary hypertension. The survey was conducted in collaboration with **Dr Ashraful Haque**, Rheumatology Registrar and Clinical Research Fellow at the Royal Hallamshire Hospital.



HOW THE SURVEY WAS CARRIED OUT

Online survey tool
SurveyMonkey was used to carry out the research. Participants were recruited via the PHA UK's social media channels and via an e-newsletter. The survey consisted of 10 multiple choice questions, with space for additional comments too. It was open for three weeks, to anyone with a diagnosis of pulmonary hypertension (regardless of whether they have systemic sclerosis too).



The findings



100%

deem the study important
(95% said 'very important')



97%

would be interested in the results
(64% said 'very interested')



80%

would be interested in taking part
in the study (50% 'very interested')



92%

would be happy for additional
bloods to be taken for the purpose
of the study



Only
18%

said they have had a bad
experience with an MRI scan.
Most selected 'neutral'



68%

said they would be happy
to have an MRI scan for the
purpose of the study

COMMENTS FROM PATIENTS WHO COMPLETED THE SURVEY

■ ■ I was diagnosed with limited systemic sclerosis in 2020. It was in 2014 that I was diagnosed with PH. The initial tests were inconclusive, and it took another visit for a right heart catheterisation to diagnose it. I feel I was fortunate that my rheumatologist was good at monitoring me for this. ■ ■

■ ■ Earlier detection is key to being able to treat this condition. ■ ■

■ ■ I have annual/biannual MRI scans as well as regular blood tests and would be happy to share the findings of the tests. ■ ■

■ ■ I think taking part in study is a good thing. Scleroderma is rare and PH is rare. I am happy to take part because if I don't then doctors won't learn. ■ ■

WHAT NEXT?

The results of this research show people with PH would be very interested in a study using MRI technology and new disease markers in the blood to detect PH earlier in those with systemic sclerosis. They would be willing to undergo additional scans and blood tests to support the study.

The findings from this survey will be used as evidence to support the application for approval and funding of the proposed study. The PHA UK will keep members updated with progress and opportunities to enrol in the study if approved. Thank you to everyone who completed the survey.

If you have any questions about this survey, please contact office@phauk.org

