

Creating a Hybrid Heart

Thoughts from the UK pulmonary hypertension community



OVERVIEW

In May 2021, the Pulmonary Hypertension Association (PHA UK) carried out an online survey to understand how much people affected by PH would value the proposed creation of the 'Hybrid Heart', a soft robotic heart that researchers hope will provide a solution to heart failure.

Responses were overwhelmingly positive, with **100%** stating they think the potential development of the Hybrid Heart is 'very important' or 'important'.

99% stated they are 'very interested' or 'interested' in its development.

COMMENTS INCLUDED:

“
I'm so impressed by this. It's the first time I've felt actual hope around the disease
”

“
[The] future suddenly seems brighter
”

“
I'd take this hybrid heart tomorrow if I could.
”

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ABOUT THE SURVEY

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

The survey was open to PH patients over the age of 16 and their carers / loved ones too.



ABOUT THE RESPONDENTS

199

people responded to the survey

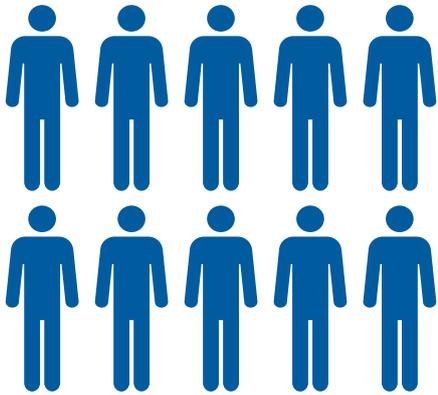
82%

have a diagnosis of pulmonary hypertension

18%

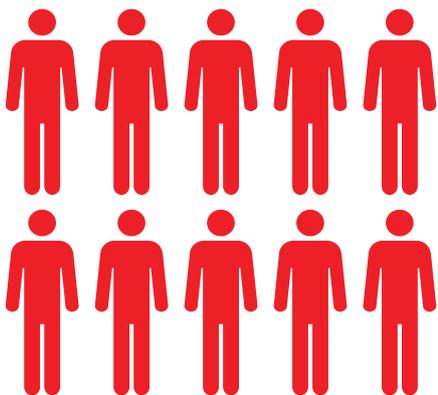
know or care for someone with a diagnosis of pulmonary hypertension

The findings



100%

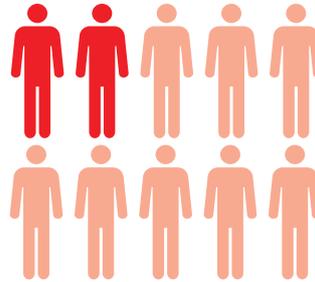
of respondents said they think the potential development of the Hybrid Heart is **'very important'** or **'important'**



99%

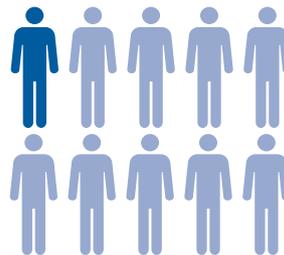
of respondents say they are **'very interested'** or **'interested'** in its development

17%



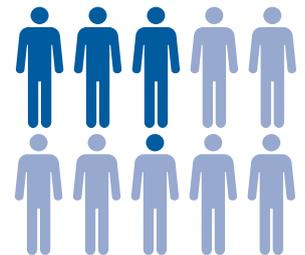
of respondents with PH said they would be interested in receiving the heart, if it was made available, **as soon as they were able to** – regardless of what stage their illness may be at.

14%



said they would want it when their PH symptoms became **difficult** to live with

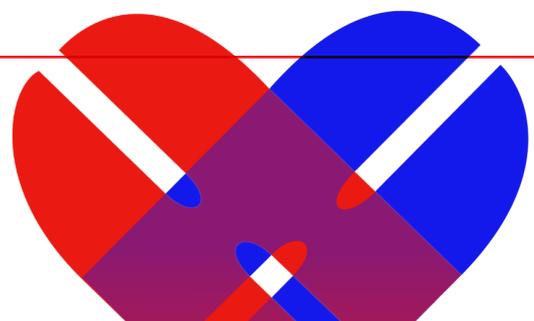
30%



said they would want it when their PH symptoms became **very difficult** to live with

39%

said they would want it when it is their only option for survival (when they have been told they need a lung and / or heart transplant)



The findings

Priorities of potential benefits

33%

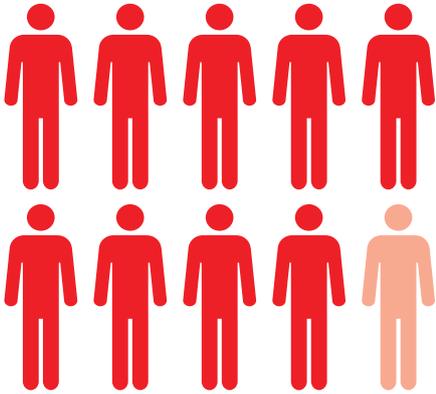
said the possibility that the Hybrid Heart may **improve quality of life by reducing the symptoms of PH** was most important to them.

67%

said the possibility that the Hybrid Heart may **extend life** was most important to them.

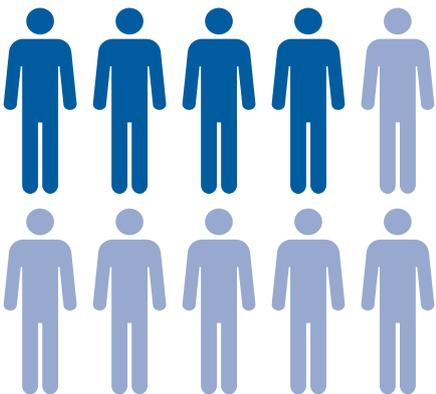


The findings



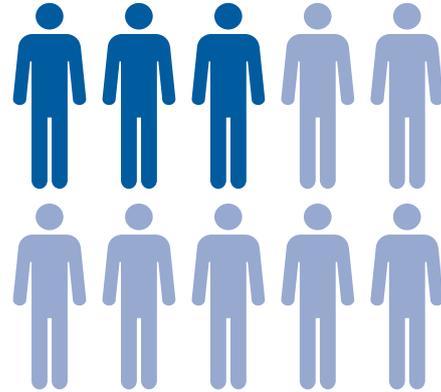
88%*

of respondents said if the Hybrid Heart was developed, they would like to follow its progress via the PHA UK (*member magazine, website, social media etc*)



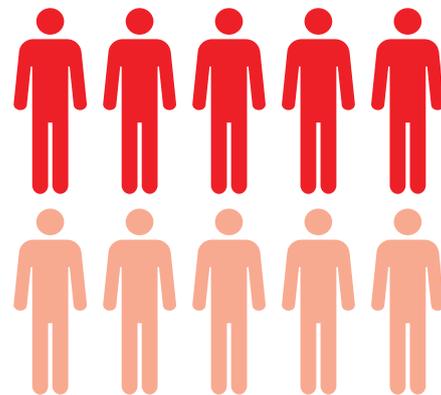
44%*

would like to watch an online presentation by the researchers to find out more about the project



27%*

would be interested in being part of an online patient / carer panel to share their thoughts around the project



47%*

of respondents (94 individuals) said they would be happy to be contacted in the future about this project, for example to be invited to be part of an online panel, and provided their contact details for this purpose.

*respondents were able to select more than one answer to this question

Comments from respondents

“
This sounds like the most important development in terms of benefit to PH sufferers that I've heard of to date.
”

“
The future has always talked about artificial hearts being a real thing. This could make the fiction become reality. If you never push forward, you will only fall back.
”



“
I'm so impressed by this. It's the first time I've felt actual hope around the disease
”

“
As a PH patient who also has uncorrected congenital heart defects, this sounds as if it could be life changer.
”

“
It's so scary to think that my heart could fail. I'd take this hybrid heart tomorrow if I could.
”

“
As a user of both a pump to deliver Veletri infusion to my lungs and an insulin pump (I have Type 1 diabetes as well as PH) my big worry at all times is power failure. It's not immediately fatal with my current pumps, but if my hybrid heart suddenly stopped, that's a death sentence. It would make me very nervous about accepting a hybrid heart.
”

“
“Many with PH also have congenital heart disease as I do and therefore the condition of the heart is of more concern. The thought of a possible option is very encouraging.”
”



Comments from respondents

“
Obviously living longer is good if you have quality of life, but living longer while suffering could well be a trial rather than a benefit.

“
I don't want a long but miserable life. If the hybrid heart just meant that I carried on for years housebound and dependent, that is not my idea of a good life. I would rather have fewer but better years!

“
This could give so many people hope!

“
Any scientific developments in the field of pulmonary hypertension are to be welcomed. It is distressing to know that one has a serious, progressive disease which affects all aspects of life.

“
[The] future suddenly seems brighter

“
Until we have a cure, or even better prevention, for PH, heart failure is going to continue to be a major cause of death among patients and there just aren't enough real hearts available for transplant (plus some people can't accept those for ethical or other reasons).

“
It feels entirely too futuristic in some ways to contemplate an idea of a robotic heart - I think seeing how it works, marketing it so it feels like a natural evolution to medical science as to me it's a little terrifying!