LIVE BETTER WITH PH

FULL REPORT | Sept 2017

What it means to live with PH today

The results of the UK's largest study into the lived experience of pulmonary hypertension.

pha UK
Influence.
Hope.
Integrity.

Registered Charity No. 1120756

Breathless not voiceless.

In 2016, 563 people affected by pulmonary hypertension shared their voices in our third major survey into what it's like to live with the serious condition.

Although PH is a rare disease, with just 7,000 people diagnosed in the UK, the results show just how much it ***impacts upon the lives of patients and their loved ones****.*

Illness can structure someone's entire life. But it can, and often does, recede into the background in a way that's hard for someone with full health to imagine. This report helps people to both imagine and understand the lived experience of PH from an individual's perspective.

Many things are assumed about pulmonary hypertension and how it affects people's lives, but this survey has provided ***concrete evidence*** *which can be used to address the crucial need for targeted treatment and specialist care.*

The understanding of the vulnerability that often accompanies life-threatening illnesses such as pulmonary hypertension, and the complexity and uncertainty associated with many decisions having to be made, is the art of quality healthcare at every stage.

This was a vital piece of research into what it means to have PH in the UK today.

It enabled us to secure robust information about matters such as PH patients' quality of life, control of their symptoms, the effectiveness of drugs, experience of NHS services and other important aspects of living with pulmonary hypertension.

The results of the survey will inform our work far beyond the pages of this publication.

As well as helping us set our own priorities as a support and advocacy organisation, they will also really help us to represent the interests of people with PH in future debates about NHS policy and spending reviews.

And there has never been a more crucial time to make sure we are in a strong position to do this. It is becoming ***increasingly important to make our voice heard*** *as the hard-pressed NHS reviews its spending on drugs and investment in services.*

If we do not speak up loudly, and with the robust evidence this report provides, the potential consequences will be disinvestment, poor and limited access to drugs, and the breaking up of the world-leading service for PH.

The survey results are already informing important work to help people ***live better with PH****. Read about our new advocacy programme, PHocus2021, on p40.*

Thank you to everyone who gave up their time to take part in the research. Together, we can make our voices heard and help people live better with PH.

Iain Armstrong

Iain Armstrong
Chair, PHA UK,
Nurse Consultant, Royal Hallamshire Hospital

> *PH is what I have,*
> ***not who I am.***
>
> **Keziah**

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We'd love to hear your thoughts about the research.

Please contact us on 01709 761450
or email office@phauk.org

You can also tweet us @PHA_UK
or find us on Facebook @PULHAUK

Use the hashtag #BreathlessNotVoiceless
to join the conversation online.

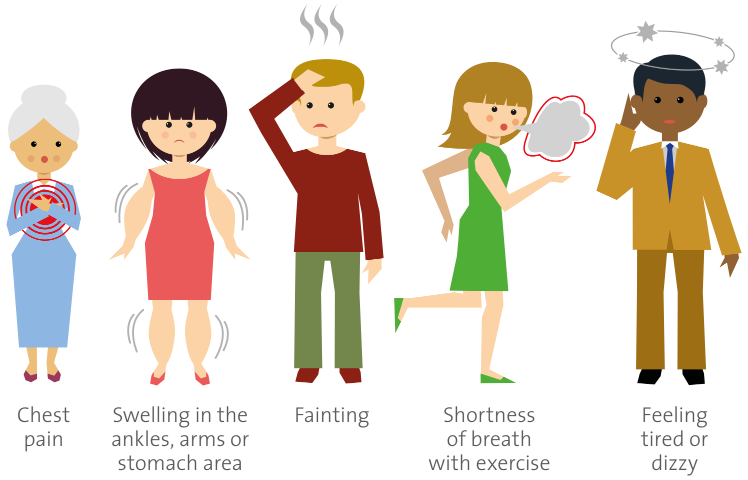
About pulmonary hypertension

Pulmonary hypertension - PH for short - is a serious condition that causes high blood pressure in the blood vessels connecting the heart and lungs (the pulmonary arteries).

In a healthy cardiovascular system, the right side to the heart pumps blood into the lungs to pick up oxygen and this oxygen-rich blood is then pumped around the body by the left side of the heart.

When a person develops PH, the walls of the pulmonary arteries become stiff and thickened, or partially blocked by chronic blood clots. This makes it difficult for them to expand; and trying to pump blood through these tightened, narrowed or scarred arteries puts increasing strain on the right side of the heart as it tries to do its job. The essential task of pumping blood into the lungs to pick up oxygen which can then be circulated to every cell in the body becomes much harder.

PH affects people's abilities to carry out basic tasks and get around. People with this condition often look well at rest and it's only through a simple activity such as climbing the stairs, washing or dressing, that they may experience symptoms:



Pulmonary hypertension is rare. Around 7,000 people are diagnosed with PH in the UK. It can affect anyone, regardless of age or ethnic background. It affects more women than men.

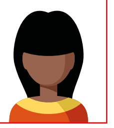
About PHA UK

The Pulmonary Hypertension Association (PHA UK) is the only charity in the UK dedicated to supporting those affected by PH.

PHA UK provides information, support and advice to people with pulmonary hypertension. It funds research, educational programmes and activities to promote better understanding, diagnosis and treatment of the disease and to raise awareness.

Set up in 2000 by a small team of volunteers - patients, family members, friends and frontline NHS health professionals, PHA UK is now at the heart of a nationwide PH community, providing a network of mutual support; and a voice for those affected by the disease.

> *People find it hard to believe that my condition is life-limiting, because I don't look ill.*



About the research

The ***2016 Living with PH Survey*** was the third major piece of research conducted by the PHA UK into the impact of pulmonary hypertension on patients and their families and loved ones. It followed similar research, the ImPHAct survey, conducted in 2007 and 2010.

The Living with PH survey asked about experiences of diagnosis, treatment and care, and the wider impact of the condition on issues like family life, finances and mental health.

It was available to complete online via the PHA UK website, and hard copies were sent to all PHA UK members and to patients on PH-specific targeted therapy though a network of home care delivery services.

The survey was open to every adult diagnosed with pulmonary hypertension, not only members of PHA UK. Respondents could choose to remain anonymous.

The results showed patient characteristics very similar to those found in the UK National Audit of Pulmonary Hypertension, representing patients normally seen in a clinical setting. The results of the survey are therefore a true reflection of patient experiences within the UK.

The research aimed to:

- Find out what it means to live with PH today
- Gather important statistical evidence about issues affecting PH patients
- Give patients a voice by providing a platform to share their experiences
- Help PHA UK identify its own future priorities as a research organisation
- Represent the interests of people with PH in future debates about NHS policy and spending reviews

563 *responses were received which is the biggest response ever to a PHA UK survey*

10% *filled in online surveys and the rest were sent through the post.*

"Research and its evidence translated into practice is vital in transforming services and improving patient outcomes across the NHS. The NHS Research Strategy calls for every patient to be offered the opportunity to take part in research where practicable." **(NHS England)**

> *Without our help as patients, research will flatline. There is only so much that the professionals can do without our input.*

Living with PH: *the key findings*

QUALITY OF LIFE

60%

of respondents said pulmonary hypertension has a 'major impact' on their overall quality of life.

Life expectancy has a big impact on quality of life, along with emotional and mental wellbeing and relationships and family.

45% said their PH treatment and management improves their overall quality of life 'a lot'.

> *PH has left a massive hole in my life.*

TIME TO DIAGNOSIS

48%

of patients waited over a year after first experiencing symptoms before being diagnosed.

40% saw four or more doctors before being diagnosed.

For 10% of patients, it took over 3 years to be diagnosed.

> *It felt like every time I went somewhere I was told there was nothing wrong – and there clearly was.*

FINANCIAL IMPACT

63%

of those surveyed said that financial worries had an impact on their lives.

26% said it had a 'major impact'

63% said PH affects their ability to attend work or education.

> *I'm having to fight to prove that I'm too ill to work.*

TREATMENT AND SPECIALIST CENTRES

87%

of survey respondents said their PH treatment and management has improved their overall quality of life.

62% think the support they receive from their specialist centre is excellent.

92% think it's better to travel to a specialist centre than be under the care of a non-PH specialist at a more local hospital.

> *The care I've received has been exceptional.*

For the full survey results, see pages 9 to 38

What does a PH patient look like today?

The *Living with PH survey* asked for information about gender, age at diagnosis, age now, and co-existing conditions. The results show that the survey population closely represents the real clinical environment.

70%
of PH patients are female

The average age of a PH patient in this study is
59 YEARS

The average age at diagnosis is
53 YEARS

30%
of PH patients are male

59%
of patients have conditions that may have contributed to the development of PH.

They include **15%** with congenital heart disease...

...and **11%** with connective tissue disease.

The Findings

Pulmonary hypertension and...

Quality of Life

Pulmonary hypertension has a major impact on the lives of many patients.

*Almost everyone who responded to the survey (**98%**) said the condition impacts on their overall quality of life, and **60%** reported a major impact.*

Concerns about life expectancy and the future, relationships with family and friends and mental and emotional wellbeing are all affected by PH.

***56%** of patients ranked improvement in overall quality of life as the most important improvement they hoped to gain from treatment.*

Enhancing quality of life for people with long term conditions is a key service outcome for the NHS.

> *Everyone deals with life with pulmonary hypertension in different ways. Some struggle to accept and live with a diagnosis, while others cope better. But the number of people reporting a major impact on many areas of their lives shows that although PH may be rare, **it's a serious condition that urgently demands more recognition and resources.***

Iain Armstrong
Chair, PHA UK,
Nurse Consultant, Royal Hallamshire Hospital

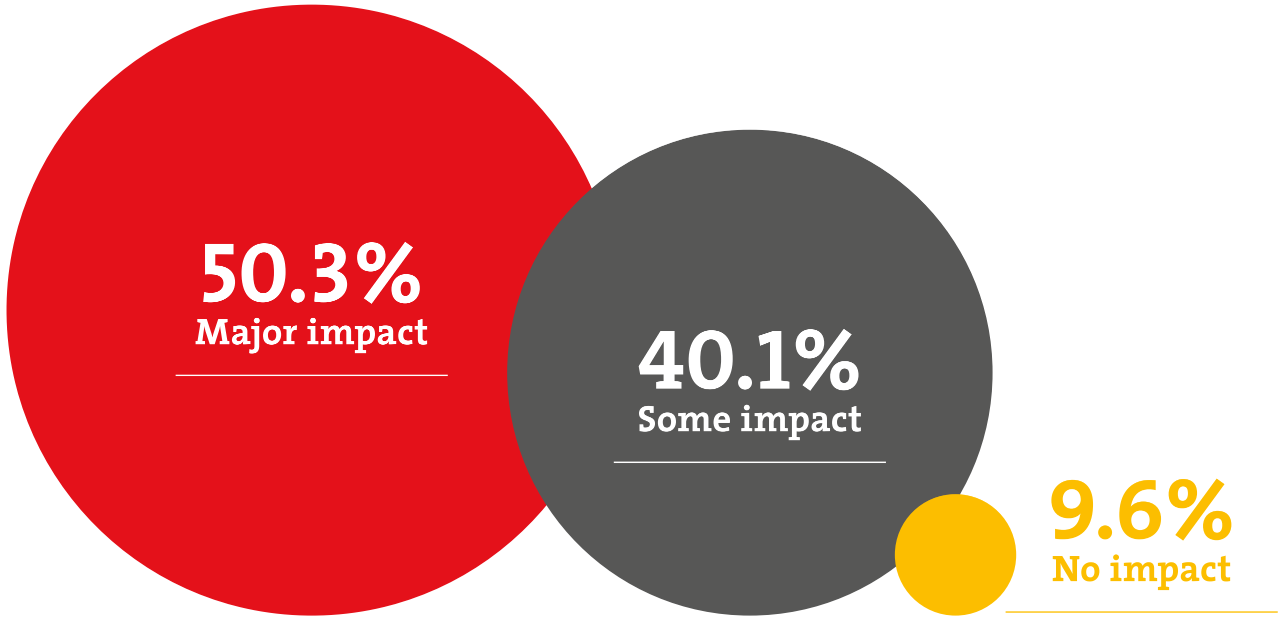
1 How big an impact does PH have on your ***overall quality of life?***

59.7% Major impact

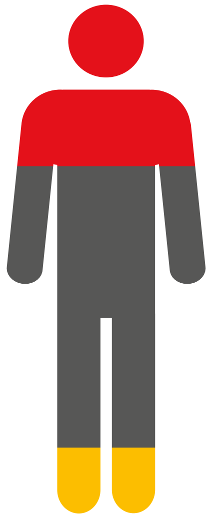
38.1% Some impact

2.2% No impact

2 How big an impact does PH have on your ***concerns about life expectancy?***



3 How big an impact does PH have on your ***general mental and emotional wellbeing?***

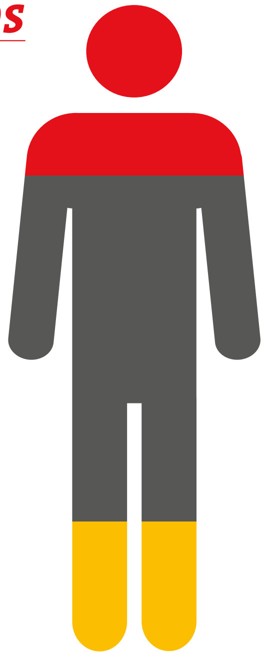


31.9% Major impact

55% Some impact

13.1% No impact

4 How big an impact does PH have on your ***relationships and family?***



26.2% Major impact

53.2% Some impact

20.6% No impact

> *There hasn't been more than a few moments in the past three years where I haven't thought about pulmonary hypertension.* ***I am constantly thinking about how it has changed my life, my health, abilities and future.*** *I am constantly worrying about what may or may not happen. I wonder how long other people can go without thinking about their diagnosis, or worrying about their life exploding?*

Serena Lawrence
Diagnosed with PH in 2013

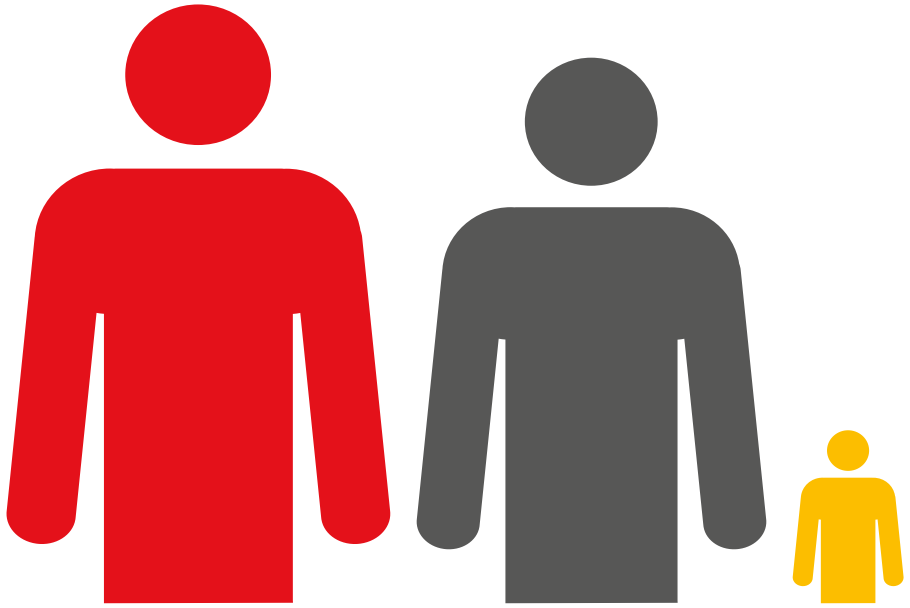
5

How has your PH treatment & management improved your ***overall quality of life?***

45%
Improved a lot

41.7%
Improved a little

13.3%
No improvement



> ***“***
> *PH has given me a new perspective on life. It’s shown me never to settle for the mundane and being miserable, but to focus on being happy and reaching for the stars.* ***I accept what I can’t do and embrace what I can do.*** *It’s taught me to smile at people, to be friendly to everyone, to be kinder to strangers, to enjoy being me and the happiness I can give. In that respect, I am glad I have PH. It makes me think about life in a totally different way.*
> ***”***

Selina Walker

6

How has your PH treatment & management improved your ***concerns about life expectancy?***

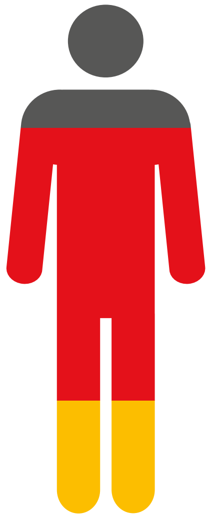
25.1%
Improved a lot

53%
Improved a little

21.9%
No improvement

7

How has your PH treatment & management improved your ***general mental and emotional wellbeing?***



24.1%
Improved a lot

53.4%
Improved a little

22.5%
No improvement

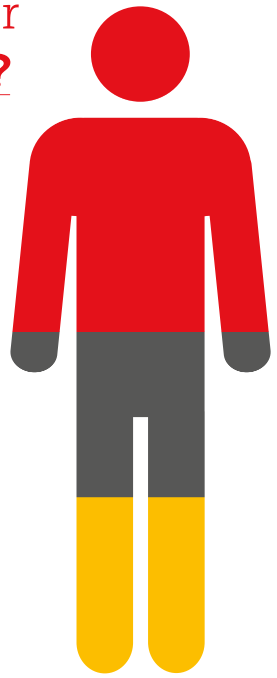
8

How has your PH treatment & management improved your ***relationships?***

48.8%
Major impact

24.5%
Some impact

26.7%
No impact



Pulmonary hypertension and...

Quality of Life

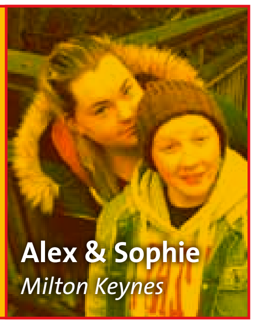
9

I feel I can get support to ***help me cope with family life and work.***

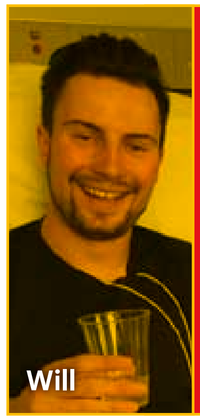
75.6% **Agree**

24.4% **Disagree**

*I think that, if anything, **the diagnosis has brought us closer together.***



Alex & Sophie
Milton Keynes

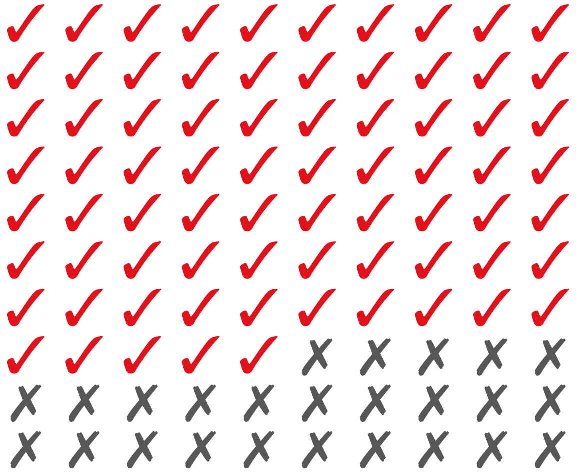


Will

*PH has had a **huge impact on my life**, however I am determined to minimise that impact as much as possible.*

10

I feel I can get support to ***help me cope with my feelings.***



74.7% **Agree**

25.3% **Disagree**

11

I feel I can ***talk about my hopes and fears.***

76.4% **Agree**

23.6% **Disagree**

The Findings

Pulmonary hypertension and...

Experiences of Diagnosis

Patients are still waiting too long to be diagnosed with pulmonary hypertension.

*The survey showed that **48%** waited over a year after first experiencing symptoms before being diagnosed and **40%** had to see four or more doctors. This time to diagnosis has remained unchanged for over ten years and can impact on prognosis, emotional and mental health and wellbeing for PH patients.*

***10%** of respondents said they waited over three years after noticing symptoms before going to see a doctor. **33%** of patients were admitted to hospital as an emergency because of their symptoms, which led to them being diagnosed with pulmonary hypertension.*

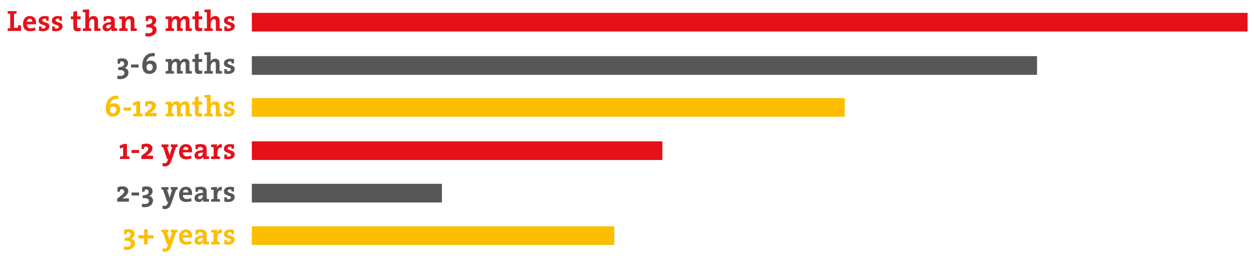
57% strongly agreed that their diagnosis had been explained in a way they could understand.

*The early symptoms of pulmonary hypertension can often be mild and are common to many diseases, so it is often a difficult and lengthy process to arrive at the diagnosis. Late diagnosis can occur when a patient delays going to see a doctor about symptoms they have developed, or a doctor wrongly judges those signs to be of no concern, or believes they indicate another illness. **The delays we are seeing are worrying as earlier diagnosis would result in better treatment and outcomes**, and the process of waiting can cause a lot of emotional distress.*

Iain Armstrong
Chair, PHA UK,
Nurse Consultant,
Royal Hallamshire Hospital

12

How long did you notice symptoms *before going to see a doctor?*



30% less than 3 mths

17.8% 6-12 mths

5.4% 2-3 years

23.5% 3-6 mths

12.4% 1-2 years

10.9% 3+ years

13

Were you admitted to hospital *as an emergency* because of your symptoms which led to you being diagnosed with PH?

66.8% No

33.2% Yes

Alex Walker
Leicester

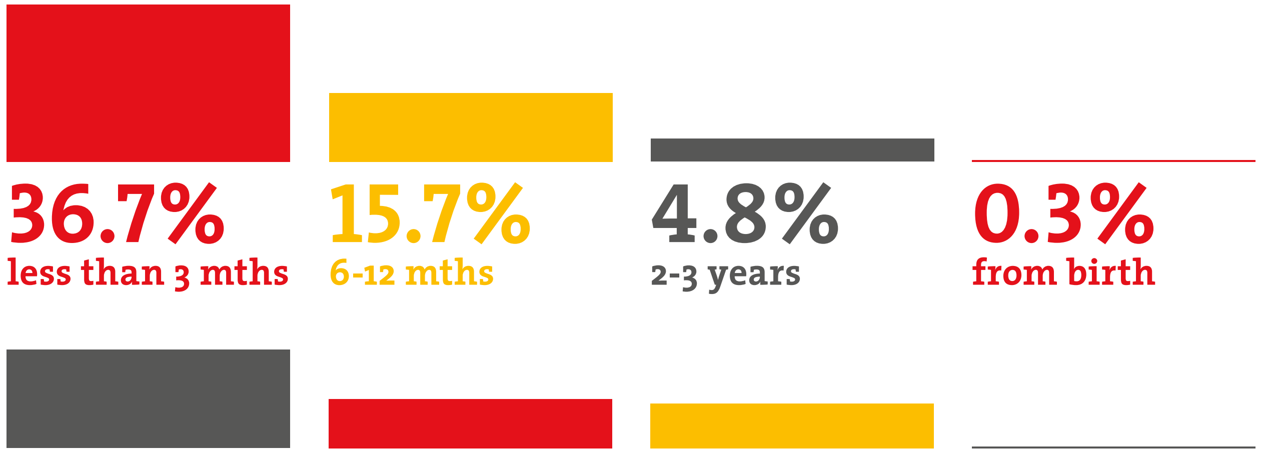
> ***The doctor had told me that he believed I was suffering with anxiety*** *and panic attacks and that I should slow myself down and look into breathing techniques – and that maybe yoga would help!*

> *I was getting more and more breathless. I kept going to my GP and they kept giving me asthma inhalers. It was getting so bad that I was having to go upstairs on my hands and knees, and on my behind coming back down. My wife used to find me sitting on the floor with tears running down my face because I couldn't do anything.* ***It was upsetting and frustrating because it felt like every time I went somewhere I was told there was nothing wrong – and there clearly was.***

Chris Johnson
South Yorkshire

14

If you went first to see your GP with your symptoms (and were not admitted to hospital as an emergency) *how long was it before you were referred to hospital?*



36.7% less than 3 mths

15.7% 6-12 mths

4.8% 2-3 years

0.3% from birth

22.2% 3-6 mths

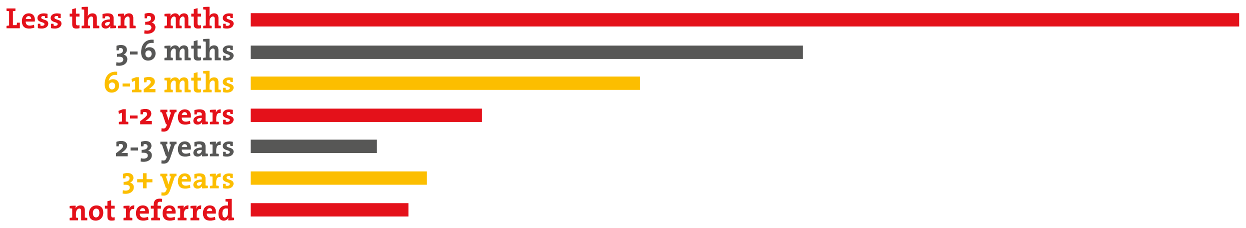
10.8% 1-2 years

9.2% 3+ years

0.3% GP refused to refer

15

If you were referred to a local hospital, how long was it before you were referred to a ***Specialist Pulmonary Hypertension Centre?***



37.6% less than 3 mths

14.9% 6-12 mths

4.8% 2-3 years

6% not referred

21.1% 3-6 mths

8.9% 1-2 years

6.7% 3+ years

> *When I was diagnosed with PH at just nine months old, like most other people, my parents had never heard of the condition.*
> ***As I've grown older, I've learnt how to cope and manage my illness and not let it consume me.***


Shani Fernando
Croydon

> ***It took me eight years to get a diagnosis.*** *I was getting increasingly breathless and I kept on going to the doctor, and kept getting told it was anxiety, or I was getting unfit. I was told there was nothing wrong with me, and no tests were ever done. One day, eight years after first seeing a doctor, I collapsed. My lips were blue, my feet were blue and I couldn't breathe properly. I was taken to hospital and as a result, six months later, I was diagnosed with PH. To be honest it was a relief after so long.*


Sarah Marshall
Oxfordshire

16

Overall, how long was it from the time you first noticed symptoms until you ***were diagnosed with PH?***

14.6% less than 3 mths

18.1% 3-6 mths

19.6% 6-12 mths

15.3% 1-2 years

12.1% 2-3 years

20.3% 3+ years

Cynthia Croughton
Hertfordshire

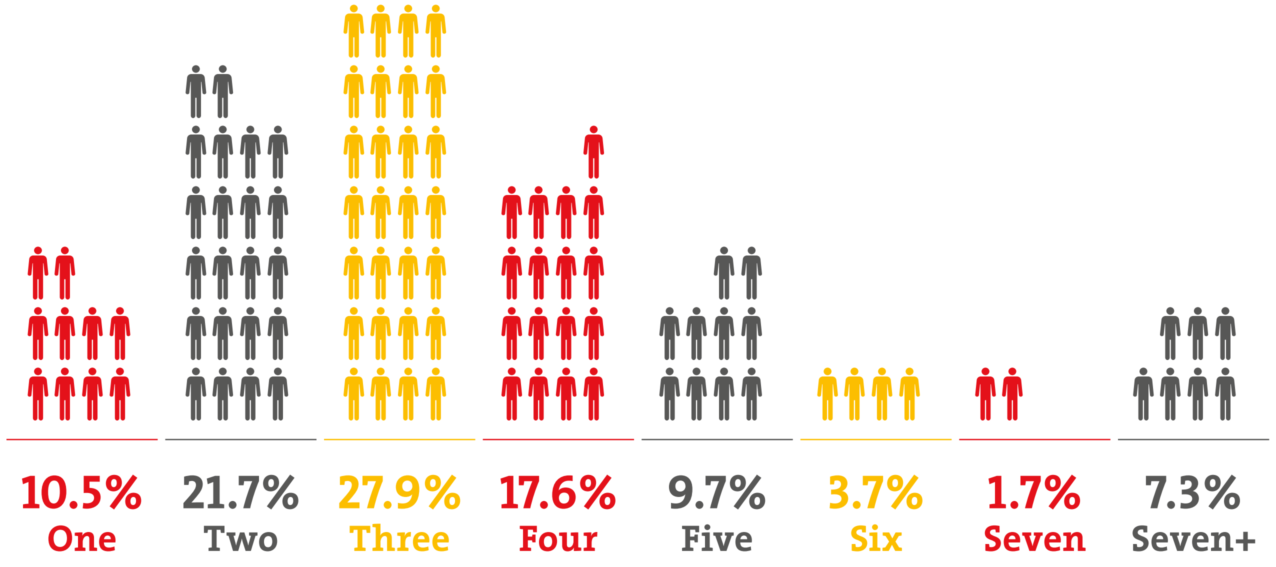
> *It had taken five doctors two-and-a-half years to properly diagnose my PH.*

> *When the consultant first told me I had PH, it was a lot to take in.*

Victoria Sant
Sussex

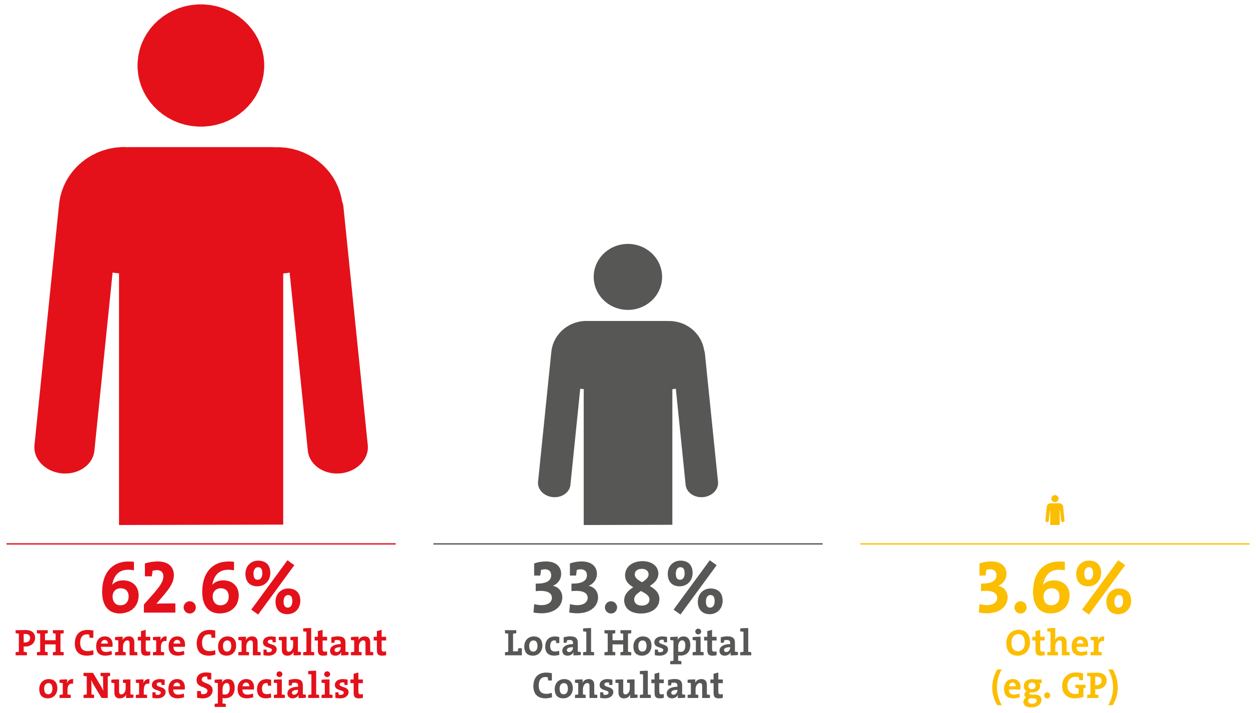
17

How many doctors did you see before getting the diagnosis of PH?



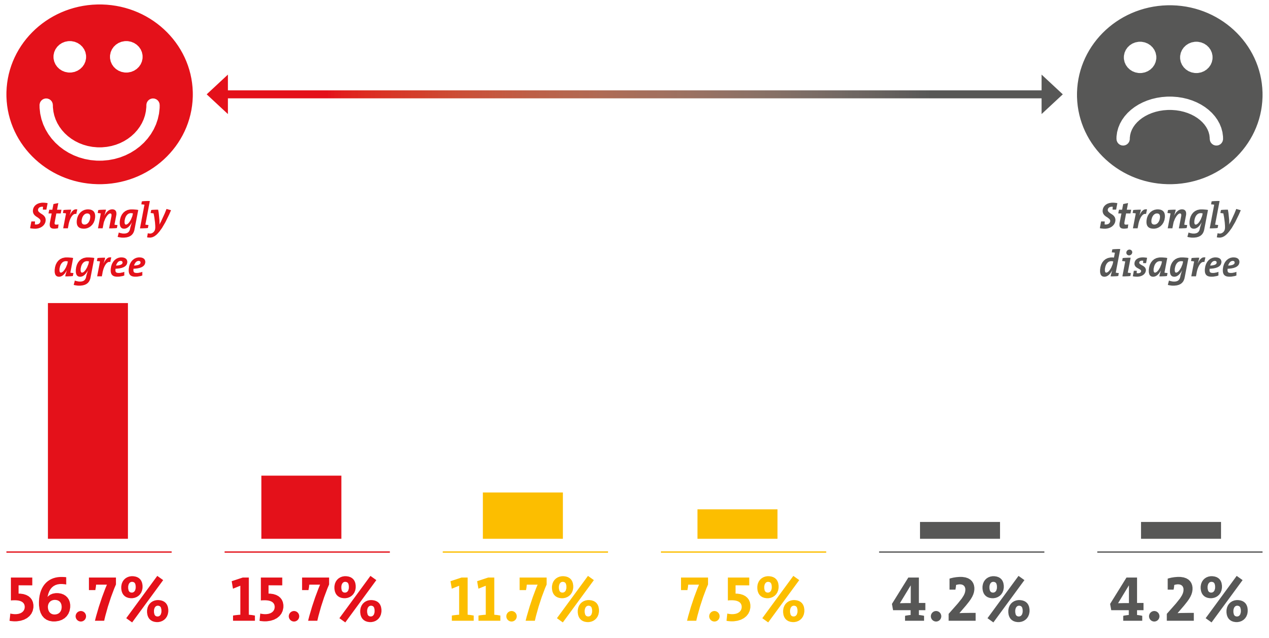
18

Who gave you your diagnosis?



19

I understood the explanation of what was wrong.

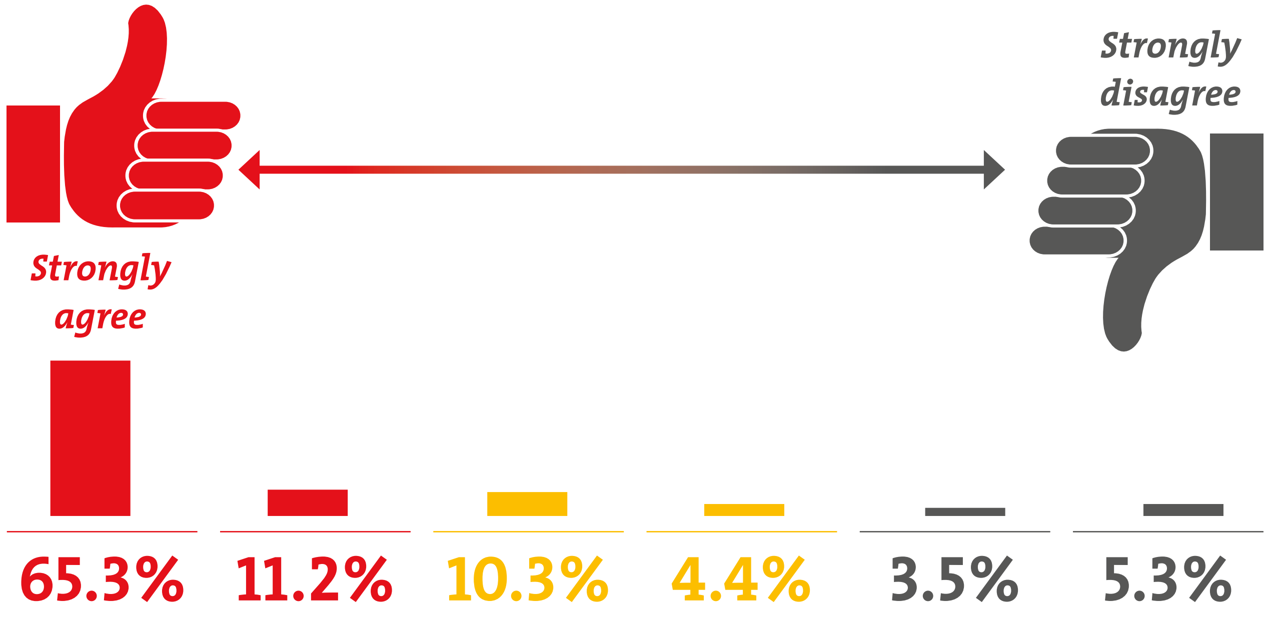


> *I was diagnosed with PH when I was seven months pregnant. I knew there was something wrong right from the beginning but each time I went to see a doctor about my symptoms they told me it was a normal part of pregnancy.* ***It felt like I was banging my head against a wall*** *and at times it felt like I was going crazy. I was so frustrated.*

Pauline Harrison
Inverness

20

When I was diagnosed, I felt the information was given ***in a sensitive manner.***



The Findings

Pulmonary hypertension and...
Financial Impact

Over half of patients say that having PH affects their finances.

Many people with PH are forced to give up work or reduce their working hours due to the impact of their condition, having a significant knock-on effect to their financial situation.

Although the treatment and management of their condition has improved the ability to work or eased financial worries for some people, over half of respondents said it had not.

Building on the results of this study, the PHA is conducting further research into the financial consequences of pulmonary hypertension, to find out which elements of people's financial stability are affected the most, and to understand the impact that has on their lives.

The results of this important research will be available in 2018.

> *For people already struggling with the physical and emotional impact of a condition like PH, financial hardship can have a debilitating effect on their quality of life and mental health. At the PHA UK we are often contacted by members trying to access support through the welfare system, but who have been refused what they are entitled to.* ***To improve quality of life for people with PH, this is an area that needs increasing focus*** *- which is why we are carrying out further research.*

Iain Armstrong
Chair, PHA UK,
Nurse Consultant, Royal Hallamshire Hospital

21

How big an impact has PH had on your ***ability to attend work/education?***

40.8%
Major impact

22.4%
Some impact

36.8%
No impact

Some of those who answered 'Some impact' or 'No impact' may be retired, semi-retired or not working for other reasons.

> ***I've had to reduce my working hours because of my PH.*** *It costs me £50 in petrol to travel to my hospital appointments in London and takes nearly three hours. My appointments range from one a month to one every three months. If I'm kept in, it costs my husband £55 per night to stay in hospital accommodation.*

Manda

22

How big an impact has PH had on your ***financial situation/financial worries?***

26.3%
Major impact

37.1%
Some impact

36.6%
No impact

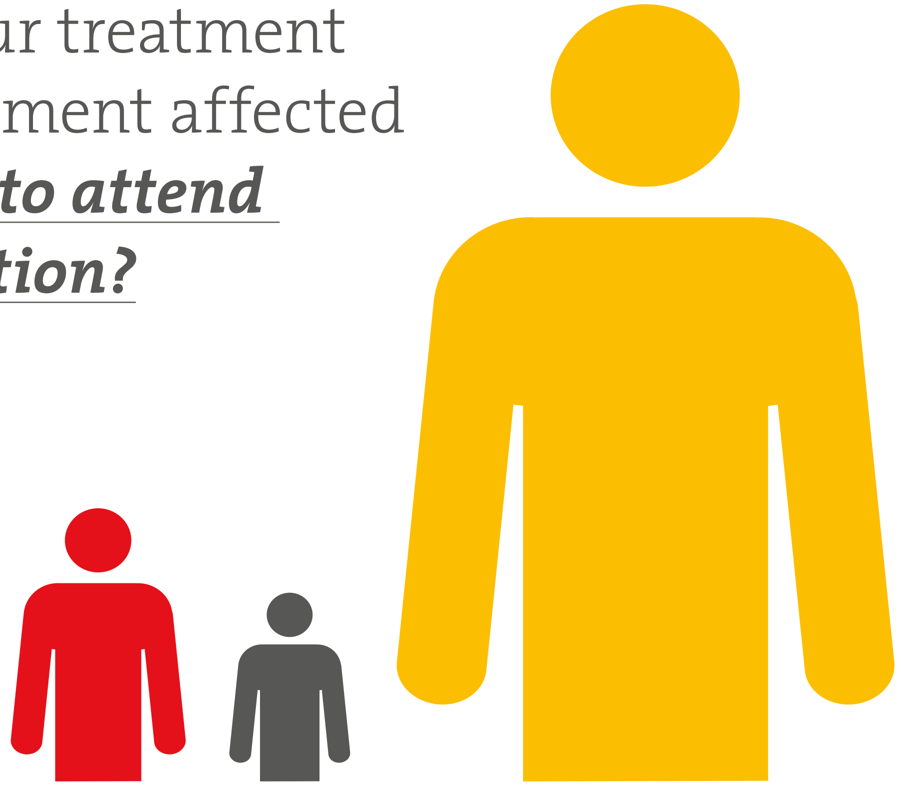
23

How has your treatment and management affected your ***ability to attend work/education?***

22.1%
Improved a little

15.2%
Improved a lot

62.7%
No improvement



Pulmonary hypertension and...

Financial impact

24

How has your treatment and management affected your ***financial situation/financial worries?***

32.2%
Improved a little

10.4%
Improved a lot

57.4%
No improvement


Tracy

> ***My electricity costs me more*** *because I have my oxygen machine on all the time, plus a fan because the machine heats up.*

> ***Having PH has massively affected our financial situation.*** *We've gone from two full-time salaries, to none, to relying on the benefits system, which is even more difficult with something* ***the DWP don't understand****, like PH.*


Jayne Venables

The Findings

Pulmonary hypertension and...

Treatment & Specialist Centres

Pulmonary hypertension services in the UK are, overall, providing very good patient centred care.

*The vast majority of people being treated for pulmonary hypertension (**89%**) think their care is either excellent or good, and **87%** said their treatment and management has improved their overall quality of life. Patients rate improvement in quality of life to be equally as important as increased life expectancy when it comes to what they hope to gain from their treatment.*

78% of patients regularly attend a PH specialist centre and even amongst those who have to travel more than 100 miles, 94% would prefer to attend a specialist centre than be under the care of a more local hospital.

> ***The specialist centres in the UK are the envy of the world*** *and this research highlights the key role they play in improving the lives of those affected by pulmonary hypertension. It's positive to see that so many patients feel involved in decisions about their treatment – which is line with NHS England's Shared Decision Making process.*


Iain Armstrong
Chair, PHA UK,
Nurse Consultant, Royal Hallamshire Hospital

25

The choice of treatments ***were explained to me.***

93% Agree

7% Disagree

26

I felt involved in the treatment decisions.

88.3% Agree

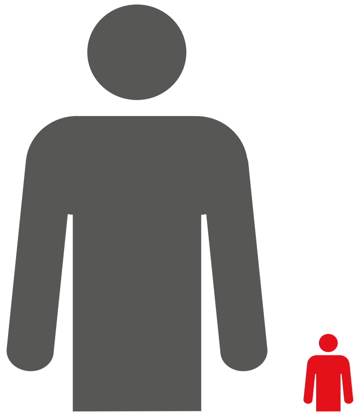
11.7% Disagree

> *Since my diagnosis at my specialist centre* ***I feel like I've had an angel watching over me****. The care and treatment is beyond words - they keep me updated with regular check-ups and informed about research and studies they are carrying out. I truly feel that without the support and treatment I am receiving I wouldn't be here to share my story. I am forever grateful to all of the staff there.*

Asha Sagoo
Leicester

27

The side effects of treatments ***were explained to me.***



84.3% Agree

15.7% Disagree

28

Hospital staff gave me information about ***support groups.***

68.4% Agree

31.6% Disagree

29

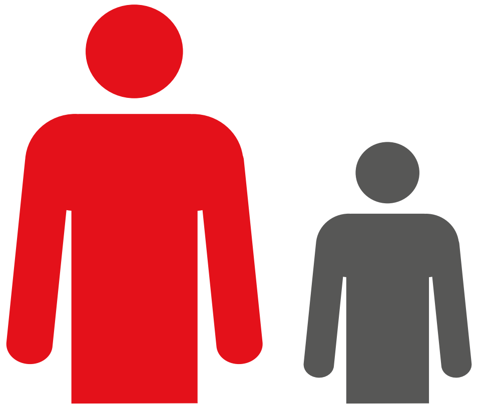
Hospital staff gave me information about the ***effect of PH on work and education.***

58.8% Agree

41.2% Disagree

30

Hospital staff gave me information about ***financial support.***

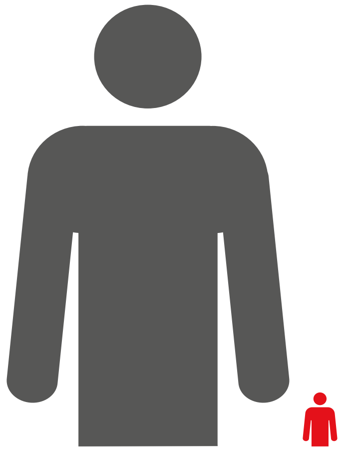


60.4% Disagree

39.6% Agree

31

I was told who to contact if I need advice on ***coping with symptoms or side effects.***



89.3% Agree

10.7% Disagree

32

I was ***given written information*** about my treatment plan.

78.6% Agree

21.4% Disagree

> *I have permanent nerve damage (from my pulmonary endarterectomy) but I can do almost everything I used to be able to do, and am back at work.* ***If I had not had the surgery, I would have died.*** *I now play sports and lead a full and active life. I will take Warfarin forever but I consider this a small price to pay.*

Elizabeth Cullen
Republic of Ireland

> *Our sincere thanks go to the specialist team for all their expertise and support and making us feel like we matter.* ***It's of great comfort to us to know that should we have a problem, we can pick up the phone and someone will be there*** *with words of wisdom and reassurance.*

Bunty and Bobby Cloy
Dumfries and Galloway

33

Information about my care was ***given to my family/carers.***

63% Agree

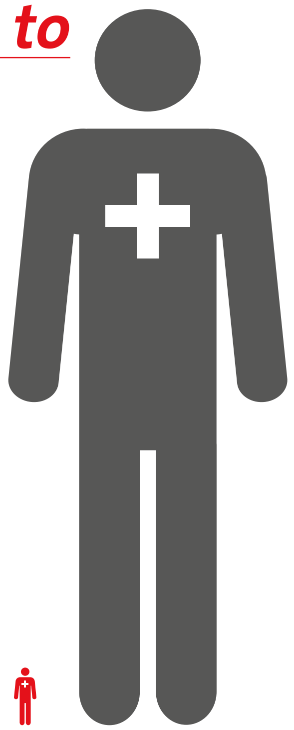
37% Disagree

34

Information was ***given to my GP.***

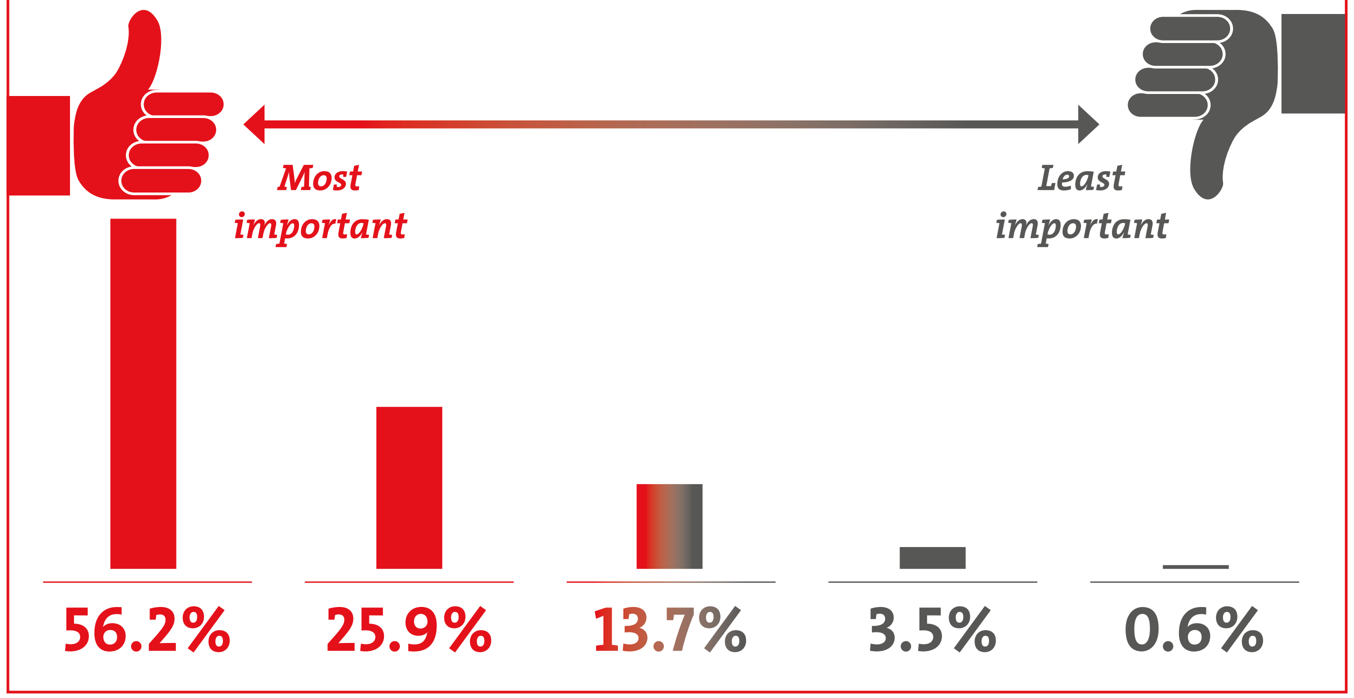
92.6% Agree

7.4% Disagree



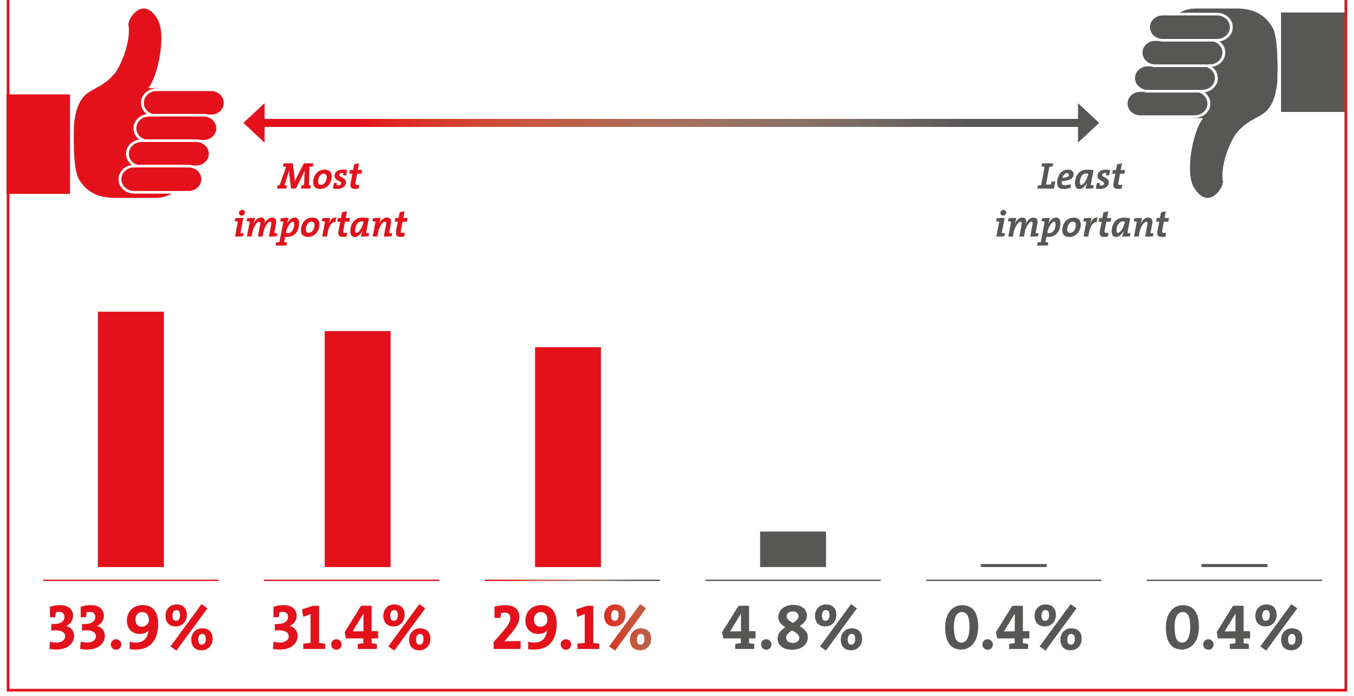
35

What do you hope to gain most from treatment? ***A. Overall Quality of Life.***



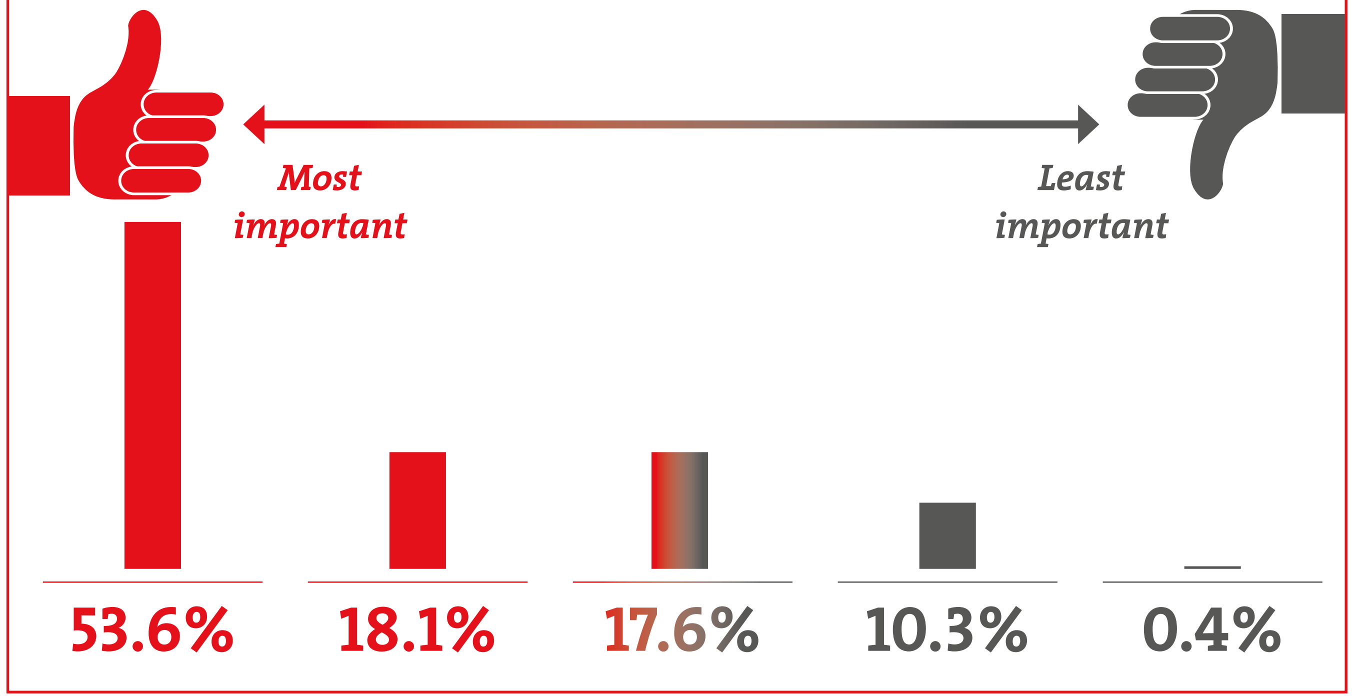
36

What do you hope to gain most from treatment? ***B. Control of Symptoms.***



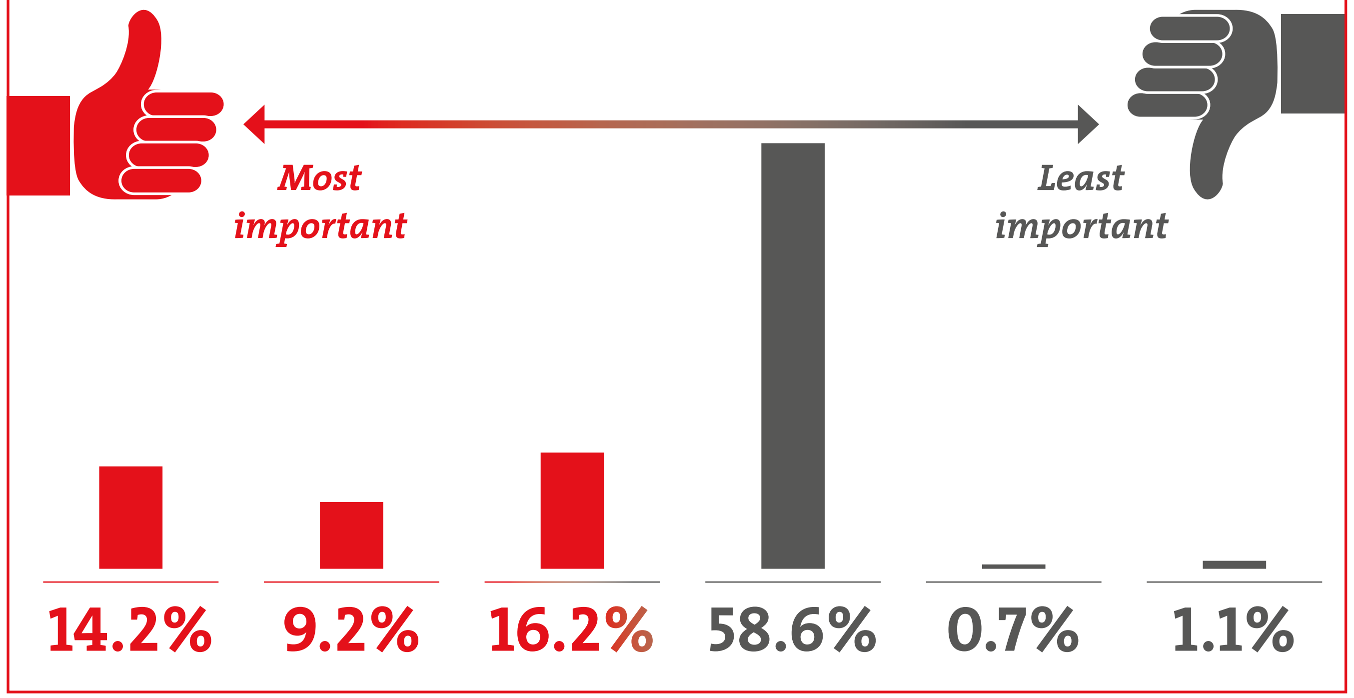
37

What do you hope to gain most from treatment? ***C. Increased Life Expectancy.***



38

What do you hope to gain most from treatment? ***D. Lack of Side Effects.***



39 Since being diagnosed how frequently do you see a ***PH specialist doctor or nurse about your PH?***

1.4% Every month or more

6.1% Every 1-2 months

41.5% Every 3-4 months

38.7% Every 6-12 months

8.5% Once a year

3.6% Never

40 Do you regularly attend a ***specialist PH Centre?***

77.5% Yes

22.3% No

0.2% Satellite Centre

41 Do you see your specialist doctor or nurse ***often enough?***

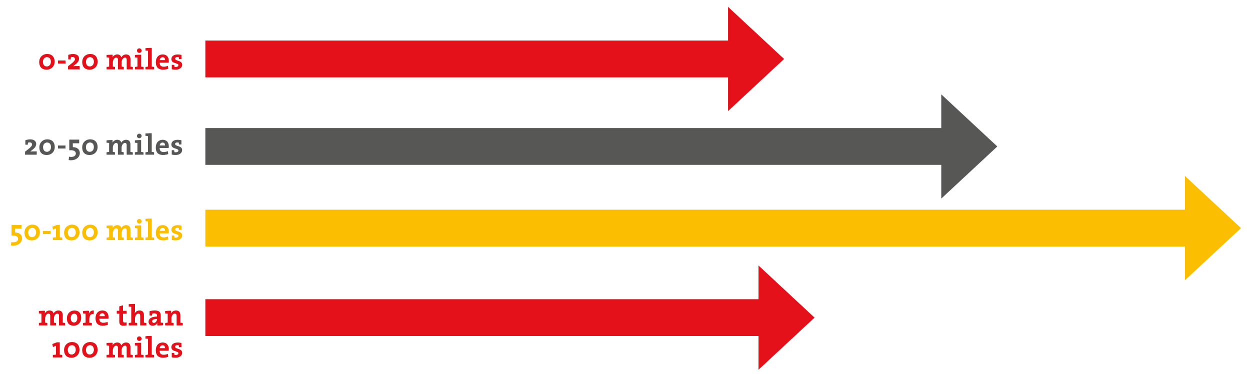
84.6% Yes

15.4% No

Mary Jane Lomer
Hampshire

> *I can't thank everyone at my specialist centre enough* ***for extending my life*** *and helping me to continue enjoying my retirement and family life.*

42 ***How many miles do you have to travel*** to see your specialist doctor or nurse?



19% 0-20 miles

26.2% 20-50 miles

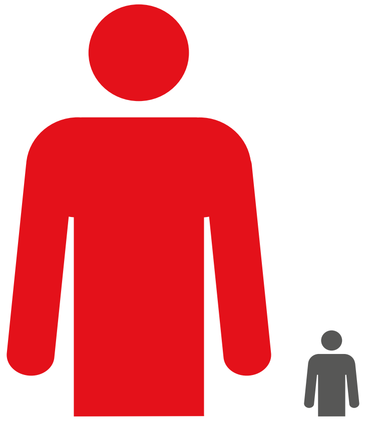
34.4% 50-100 miles

20.4% more than 100 miles

Treatment & Specialist Centres

43

Do you have difficulties travelling ***because of age?***



84.4%
No

15.6%
Yes

44

Do you have difficulties travelling ***because of your condition?***

60.3%
No

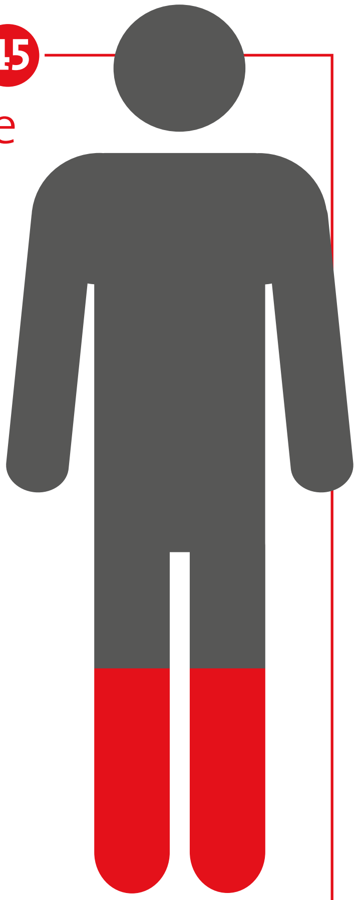
39.7%
Yes

Patricia Higgins
Tyne and Wear

> *Overall, I would say my PEA surgery was a partial success, as I still have to take Sildenafil and I continue to be looked after by the brilliant team at my specialist centre. However,* ***I live a full independent life and am always grateful for that.***

45

Do you have difficulties travelling ***because of cost?***



74.7%
No

25.3%
Yes

Toby Pettifor
East Sussex

> *My amazing specialist nurses taught me everything about how to care for my line and how to make up my drugs, and quite frankly* ***had the patience of saints.***

46

Do you think it is better to travel to a ***Specialist PH Centre*** rather than to be under the care of a non-PH specialist at a more local hospital?

91.6%
Yes

8.4%
No

47

How satisfied are you with ***the support you receive?***

62.3%	26.3%	7.6%	3.8%
Excellent	Good	Fair	Poor

> *I have come across endless people who make the NHS tick, from porter staff who have happily chatted to me about random topics making me forget which theatre room they are wheeling me off to this time, through to blood takers, specialist nurses, doctors, consultants, professors and paramedics. Each have ensured I am well cared for and looked after; some have consoled me when the future looked particularly bleak; others have saved me from death; and others have given me hope. **I am eternally grateful for each and every one of them**, as without them I don't think my future would look anything like it does now.*

Gemma Cousins
Manchester

48 Have you been asked to take part in *research looking at new tests or drugs?*

Does this survey tell us anything new?

In the summer of 2010, the PHA UK commissioned two pieces of research to look at the impact of PH on the lives of people affected by the condition.

The *ImPAHct Survey* and the *Lived Experience of Pulmonary Hypertension Survey* asked similar questions to the *Living with Pulmonary Hypertension Survey* conducted in 2016.

Comparisons between the two time periods show little has changed when it comes to life with PH.

PH is still having a *major impact* on overall quality of life.

In 2010, ***60%*** of people said pulmonary hypertension has a 'major impact' on their overall quality of life. In 2016, this figure was the same.

Little progress has been made when it comes to *earlier diagnosis*.

In 2010, ***53%*** of people waited a year or more for a diagnosis of PH. In 2016, that fell only slightly to ***48%***.

In 2010, ***34%*** of people waited more than two years for a diagnosis. In 2016, it was ***32%***.

In 2010, ***47%*** of people saw four or more doctors before being diagnosed. In 2016, it was ***40%***.

Treatment is still making a *big difference* to people's lives.

In 2010, ***94%*** of patients said PH treatment and management improved their quality of life. In 2016, it was ***87%***.

In 2010, patients said improvement in quality of life was equally important as increased life expectancy and this was the same in 2016.

The overall support from hospitals treating people with PH *is still excellent*.

In 2010, ***nine out of ten*** said that the overall support they receive is 'good' or 'excellent'. In 2016 this was the same, with ***62%*** reporting it to be 'excellent'.

Specialist treatment and support continues to be excellent, despite the number of people being treated for PH increasing. In 2015/16, PH centres managed 7035 patients, compared to 5478 in 2009 /2010.*

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*The National Audit of Pulmonary Hypertension, April 2015 – March 2016 and April 2009 – March 2010

Our call to action

The results of the Living with PH Survey show just how much pulmonary hypertension affects the lives of those it touches. It also shows the dramatic difference that the right treatment and management can make.

The results of the research form the backbone of a new advocacy programme, spearheaded by the PHA UK, to ensure pulmonary hypertension receives greater attention from Government.

Putting a PHocus on pulmonary hypertension

PHocus2021 is a five-year programme with the aim of pushing for the changes to public policy that PH patients really want to see.

The group behind the programme is made up of representatives of PHA UK, plus leading medical professionals in the field of PH, academia and general practice and a special ‘patient panel’ made up of patients, carers and family members. Political relations experts are supporting *PHocus2021* to achieve its strategic objectives and make an impact.

The *PHocus2021* programme has four main objectives, based around reducing time to diagnosis, emphasising the importance of patient quality of life, unblocking new treatments, and reducing financial hardship incurred by living with pulmonary hypertension. All of these aims are backed up by the results of the Living with PH survey.

> *Research such as the Living with PH Survey is just one of the ways that the PHA UK works to improve the lives of people affected by pulmonary hypertension. With over 3500 members, and more joining us every month, we will continue our support, research and advocacy* ***- helping to ensure the voices of patients are heard.***

Shaun Clayton
Director of Membership Support, PHA UK

To find out more about the work of **PHocus2021**, visit www.phocus2021.org

1

Reduce the time to diagnosis.

We want to reduce the time to diagnosis for pulmonary hypertension by educating colleagues in primary and secondary care about the condition, its signs and symptoms, and when to appropriately refer to specialist care.

“The longer that PH is allowed to progress, the harder it becomes to restore the patient to a good quality of life, which is why it’s so important to reduce the time it takes to diagnose the condition. Early diagnosis makes for a better prognosis.”

Dr Simon Gibbs
Lead Clinician and Honorary Consultant Cardiologist
for the National Pulmonary Hypertension Service
at Hammersmith Hospital, London

2

Improve the health, wellbeing and quality of life of patients with PH and their kinship.

PHocus2021 will work to ensure that NHS England and relevant health authorities update national commissioning guidelines so that these appropriately reflect the importance of patient quality of life, as well as appropriate self-care, as measures for service quality and patient outcomes.

This will be achieved through establishing an engagement programme with key stakeholders to draw attention to PH and the risks associated with decreasing funding of its services, and developing a strategy for growing the membership of PHA UK.

3

Ensure equity of access in the UK to evidence-based treatments for all

An urgent review is needed on decisions regarding new therapies available for PH currently blocked or deferred by national funders, so that PH patients receive the best quality care for this debilitating, terminal disease.

There is a clear need to reinvest in new treatments and the specialised service which is so vital for, and relied upon by, PH patients. But there are indications that PH might become de-prioritised, and the service may face more challenges in engaging efficiently with NHS England.

4

Reduce financial hardship incurred by living with PH

For people already struggling with the physical and emotional impact of a life-limiting condition like PH, financial hardship can have a debilitating effect on their quality of life and mental health.

We are currently conducting further research into the financial impact of PH, to identify priority areas and, once this has been completed, will commence a campaign calling for reforms to the welfare system and other areas, such as insurance provision, to ensure PH is appropriately recognised and patients no longer experience unfair treatment and exclusion.

I am constantly thinking about how pulmonary hypertension impacts my life.

Serena

Pauline Harrison
Inverness

I feel angry *as I have lost my role in life as a mother, wife and grandmother.*

Tyana

Fatigue is the hardest thing. It does sometimes get the better of me, and it does affect my quality of life. ***I do still have a fear of 'oh my god, I can't leave my son behind'.*** *But I'm positive that one day there might be a cure for PH.*

My children help me manage my condition *by making me smile more than anything or anyone can – even when I don't feel able to.*

David
Preston

People tend to judge me because I don't look ill and it drives me mad. When I park in a disabled space, ***I'm often tackled about it because I don't look a 'typical' disabled driver.***

Tess
Essex

It's very painful being a mum of a three-year-old *with PH, but my daughter fights it and doesn't let it define her. It has put restrictions on our way of life but I'm very grateful that she is still here and that treatment is slowing progression.*

Mariella

Kathryn
Hertfordshire

The thing I struggle with the most is walking. *I live in a hilly area so without my car, I'd be housebound.*

Claire
South Wales

Often your mind and your emotions are left playing 'catch up' later after all the physical stuff has been dealt with. I count myself as being extremely lucky, as from the very outset of my illness, ***I had very solid emotional support from my close family and friends.***

LIVE BETTER WITH PH

pha UK | Influence. Hope. Integrity.

Should I be feeling any better now?
I've had a cough and some antibiotics
And its all cleared up
Except I'm still feeling a little breathless

Should I be feeling any better now?
I've had blood tests and breathing tests
And they've all come back as normal
And I've seen the nurse and the GP
And they're not quite sure what's wrong
Apart from the fact I'm still feeling breathless.

Should I be feeling any better now?
I've had a heart tracing which isn't quite right
And been referred to the hospital and had an X-ray
And more blood tests and had a scan of my heart
And seen the consultant and I'm due another test
And to see another consultant in another hospital
And they all seem to know what they're doing
But all I know is I'm still feeling really breathless.

Should I be feeling any better now?
I've had my diagnosis
I know what it is.
So yes, I will be breathless
And things will change.
One breath at a time,
I begin to take back control
so that, in my own way,
I can start to feel a little better now.

Poem by *Helen Knight*, based on conversations
with people living with pulmonary hypertension.

#BreathlessNotVoiceless

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