



Living with PH | 2016 Survey

1. Before diagnosis

The early symptoms of pulmonary hypertension can often be mild and are common to many diseases so that it is often a difficult and lengthy process to arrive at the diagnosis. We would like to ask you about your experiences.

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

Less than 3 mths 3-6 mnths 6-12 mnths 1-2yrs 2-3yrs 3+yrs

B. Were you admitted to hospital as an emergency because of your symptoms which led to you being diagnosed with pulmonary hypertension?

Yes (go to Section 2) No (please answer the next three Questions)

C. 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?

Less than 3 mths 3-6 mnths 6-12 mnths 1-2yrs 2-3yrs 3+yrs

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

Not referred Less than 3 mnths 3-6 mnths 6-12 mnths 1-2yrs 2-3yrs 3+yrs

E. Which one of these Specialist Pulmonary Hypertension Centres where you referred to?

Freeman Hospital, Newcastle <input type="checkbox"/>	Papworth Hospital NHS Trust, Cambridgeshire <input type="checkbox"/>
Golden Jubilee National Hospital, Glasgow <input type="checkbox"/>	Royal Brompton Hospital, London <input type="checkbox"/>
Great Ormond Street Hospital, London <input type="checkbox"/>	Royal Hallamshire Hospital, Sheffield <input type="checkbox"/>
Hammersmith Hospital, London <input type="checkbox"/>	Royal Free Hospital, London <input type="checkbox"/>
Mater Misericordiae University Hospital, Dublin <input type="checkbox"/>	

2. Diagnosis

Please tell us a little more about your experience of diagnosis.

A. Overall how long was it from the time you first noticed symptoms until you were diagnosed with pulmonary hypertension?

Less than 3 mths 3-6 mnths 6-12 mnths 1-2yrs 2-3yrs 3+yrs

B. How many doctors did you see before getting the diagnosis of pulmonary hypertension?

1 2 3 4 5 6 7 More than 7

C. Who gave you your diagnosis?

GP Local Hospital Consultant Specialist PH Centre Consultant Other

D. I understood the explanation of what was wrong.

Agree Disagree

E. I felt the information was given in a sensitive manner.

Agree Disagree

3. Treatment

We'd like to hear more about how your treatment options were handled at your PH specialist centre.

A. The choice of treatments were explained to me.

Agree Disagree

B. I felt involved in the treatment decisions.

Agree Disagree

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

Agree Disagree

D. Hospital staff gave me information about:

Support groups Agree Disagree

Effect of PH on work and education Agree Disagree

Getting financial support Agree Disagree

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

Agree Disagree

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

Agree Disagree

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

Agree Disagree

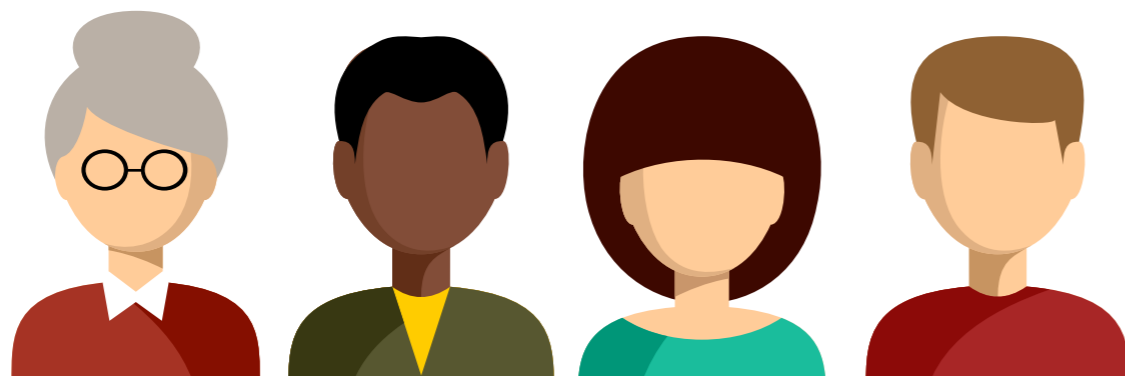
H. Information was given to my GP.

Agree Disagree

I. What do you most hope to gain from treatment? Rank most important (1) to least important (4)

Improvement in overall QOL Control of symptoms

Increased life expectancy Lack of side effects



4. Living with Pulmonary Hypertension

Pulmonary hypertension can affect many areas of your life. We would like to ask you what the impact on your life has been.

A. How big an impact does PH have in these areas of your life?

	Major impact	Some impact	No impact
Overall quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns about life expectancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General mental/emotional well being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationships/family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ability to attend work/education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial situation/financial worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B. How has your PH treatment and management affected these areas of your life?

	Improved a lot	Improved a little	No Improvement
Overall QOL	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns about life expectancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General mental/emotional well being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationships/family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ability to attend work/education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial situation/financial worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C. Since being diagnosed how frequently do you see a pulmonary hypertension specialist doctor or nurse about your PH?

Every month or more Every 1-2 mnths Every 3-4 mnths
Every 6-12 mnths Once a year Never

D. Do you regularly attend a Specialist Pulmonary Hypertension Centre?

Yes No

E. Do you see your specialist doctor or nurse often enough?

Yes No

F. How many miles do you have to travel to see your specialist doctor or nurse?

0-20 miles 20-50 miles 50-100 miles More than 100 miles

G. Do you have difficulties with travelling because of:

Age Yes No

Condition Yes No

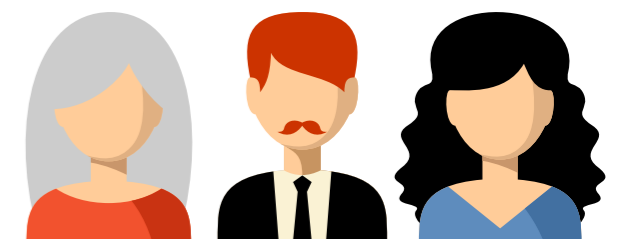
Cost Yes No

H. 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?

Yes No

I. How satisfied are you with the support you receive?

Poor Fair Good Excellent



J. I feel I can get support to:

Help me cope with family life and work Agree Disagree
 Help me cope with my feelings Agree Disagree

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

Agree Disagree

5. About you

We would like to know a little more about you. All information will be kept confidential.

A. What is your current age?

_____ Years

B. What was your age at diagnosis?

_____ Years

C. Are you:

Male Female

D. Which of the following PH drugs are you currently on?

Nifedipine <input type="checkbox"/>	Diltiazem <input type="checkbox"/>	Nicardipine <input type="checkbox"/>
Amlodipine <input type="checkbox"/>	Ambrisentan (Volibris) <input type="checkbox"/>	Bosentan (Tracleer) <input type="checkbox"/>
Macitentan (Opsumit) <input type="checkbox"/>	Sildenafil (Viagra or Revatio) <input type="checkbox"/>	Tadalafil (Adcirca) <input type="checkbox"/>
Riociguat (Adempas) <input type="checkbox"/>	Epoprostenol (Flolan) <input type="checkbox"/>	Iloprost (Ventavis) <input type="checkbox"/>
Treprostinil (Remodulin) <input type="checkbox"/>	Veletri <input type="checkbox"/>	

E. Have you had any of the following surgery?

Pulmonary endarterectomy Atrial septostomy Transplant surgery

F. Do you have any of the following conditions?

Connective tissue disease Portal hypertension Congenital heart disease
 Sickle cell anaemia HIV infection (Human Immunodeficiency Virus)
 Lung disease (e.g, COPD, pulmonary fibrosis)

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

Yes No

H. It is very important to ensure the patient voice continues to be heard. Would you be happy to be contacted in the future by email or mail to allow us to hear your views on topics that are of important to patients with pulmonary hypertension?

Yes No (If Yes, please provide your details)

Name _____

Address _____

_____ Email _____

Thank you! We very much appreciate you taking the time to complete the 'Living with PH 2016' survey. Please check you have answered all sections and then return your completed survey in the envelope provided. If you have any questions about the survey please call the PHA UK office on 01709 761450 or email office@phassociation.uk.com

