

**SUPPLEMENTARY MATERIAL - TO BE PUBLISHED ELECTRONICALLY**

Manuscript title: Understanding the impact of pulmonary arterial hypertension on patients' and carers' lives

Manuscript ID: ERR-0057-2013.R1

This supplementary material includes the following documents:

Patient questionnaire .....	pg. 2
Carer questionnaire .....	pg. 19

**Thank you for requesting a copy of this questionnaire.** In total we hope to receive feedback from approximately 300 patients and carers, across France, Germany, Spain, Italy and the UK, whose lives are affected by pulmonary arterial hypertension (PAH).

We would like to explore how PAH has affected your life. In particular we would like to know the impact PAH has had on your emotional wellbeing, since your diagnosis, as this is an area that has not been researched widely in the past.

Your responses will be collected with those from the other patients and carers and used to improve our understanding of the impact of PAH. We would like to use these insights to develop new information resources to support patients, carers and healthcare professionals. The findings from the questionnaire will also help us to raise public awareness about the emotional impact PAH has on the lives of both patients and carers.

We will be developing the information resources during 2012. If you would like to know more about their status please contact your local PAH patient organisation, which will be able to update you on progress.

**About the questionnaire**

This questionnaire has been commissioned by Actelion Pharmaceuticals Ltd, Switzerland, and the content has been developed and approved by a team of doctors and nurses who manage patients with PAH. Patient organisations and healthcare professionals at PAH centre in the participating countries are aware that this research is taking place.

**Thank you**

We would like to thank you for agreeing to take part in this survey. Your input to this piece of work as a PAH patient is highly appreciated. If possible, please return your questionnaire by Saturday 31 December.

**When completing the questionnaire, please consider the following:**

- We recommended that you find a quiet and comfortable place to sit by yourself and complete this. If you need to stop and take a break while completing the questionnaire, we suggest that you do this and continue with the remainder of the questionnaire when you are ready. If you are completing this questionnaire on the Internet, you may get an automated reminder to complete the questionnaire. In addition, online administration of questionnaire allows you to complete it either all in one sitting or to complete it a little at a time, logging on and off the questionnaire according to your preference. Our secure platform will automatically keep track of your progress, so when you log back into the questionnaire you will pick up where you left off. This will be the same in case your browser remains inactive for a while. Once you have started the online completion, there is not any time limit to complete the entire questionnaire.
- You will be asked about physical, practical, social and emotional impact of the PAH from the patient perspective. **We understand that it must be difficult for you to talk about these life aspects and you have the possibility to not answer to a specific question should you not want to disclose such information.** The content has been developed and approved by a team of doctors and nurses who manage PAH patients

**Before completing the questionnaire, we would like to reassure you that:**

- As an independent market research company, we (Harris Interactive) comply with the codes of conduct of market research associations (ESOMAR and EphMRA) and all [insert country] laws in protecting your personal data
- Your responses will be collated with other respondents and presented to the sponsor in aggregated or anonymous form; your identity will not be revealed at any time. Your responses will be confidential and will not be used for any other purposes than the above mentioned or disclosed to any third party without your approval.
- Any personal information you give us is only used for the purposes for which you provide it; e.g. your mail/email address will only be used to send you information you specifically requested. We will never send you unsolicited mails/emails, we will not pass any data you supply to any other party and all employees who process your data are required to respect the confidentiality of your personal data.

**PLEASE NOTE:**

***If you experience any distress while taking part in this survey please stop the survey immediately and seek assistance from either your PAH patient organization or your healthcare professional.***

**Do you agree to participate in this survey under the above conditions and that you will be asked to provide information on your health and how you are living with PAH?**

Yes	1. <input type="checkbox"/>
No	2. <input type="checkbox"/>

***If you do not feel comfortable answering a particular question please leave it blank and if you feel distress at any point please stop the survey immediately and seek assistance from your PAH patient organization or your doctor*** 1

**GENERAL INFORMATION**

**S1. Please specify your gender**

Male	1. <input type="checkbox"/>	Female	2. <input type="checkbox"/>
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**S2. Please specify your age: |\_\_\_\_\_| years old**

**S3. What is your marital status?**

Single answer

Married	1. <input type="checkbox"/>
Living with a partner	2. <input type="checkbox"/>
Widowed	3. <input type="checkbox"/>
Divorced	4. <input type="checkbox"/>
Separated	5. <input type="checkbox"/>
Single, never married	6. <input type="checkbox"/>
Other, please specify	7. <input type="checkbox"/>

**S4. Currently, how many children are there in your household?**

Single answer

0	1. <input type="checkbox"/>	<b>→ GO TO QUESTION S6</b>
1	2. <input type="checkbox"/>	
2	3. <input type="checkbox"/>	<b>→ PLEASE FILL IN THE QUESTION S5</b>
3	4. <input type="checkbox"/>	
4	5. <input type="checkbox"/>	
5 or more	6. <input type="checkbox"/>	

**S5. Please specify the age for each of these children?**

Child N# 1	Child N# 2	Child N# 3	Child N# 4	Child N# 5
_____  years	_____  years	_____  years	_____  years	_____  years

**S6. What is your level of education?**

Single answer

Up to high school	1. <input type="checkbox"/>
Up to university	2. <input type="checkbox"/>
Technical/non-university	3. <input type="checkbox"/>
Post-graduate education	4. <input type="checkbox"/>
Other	5. <input type="checkbox"/>

**S7. What is the annual income of your household?**

Single answer

Under £10,000	1. <input type="checkbox"/>
£10,000 – £14,999	2. <input type="checkbox"/>
£15,000 – £19,999	3. <input type="checkbox"/>
£20,000 – £24,999	4. <input type="checkbox"/>
£25,000 – £29,999	5. <input type="checkbox"/>
£30,000 or more	6. <input type="checkbox"/>

**Background information on PAH**

**S8a. Would you please indicate the year of your first symptoms and the year of PAH diagnosis?**

Please indicate the year in the following boxes using this date format: yyyy.

First symptoms	First diagnosis
1	2
_ _ _	_ _ _

**S8b. What were these first symptoms?**

Several answers possible. Please select all that apply.

Breathlessness/dyspnoea	1. <input type="checkbox"/>
Tiredness/fatigue	2. <input type="checkbox"/>
Chest pain	3. <input type="checkbox"/>
Fainting/loss of consciousness	4. <input type="checkbox"/>
Irregularities in heart beat	5. <input type="checkbox"/>
Anxiety	6. <input type="checkbox"/>
Other, please specify	7. <input type="checkbox"/>

**S9. PAH can have no known cause, run in the family or be associated with one or more related conditions. Do you know what type of PAH you have?**

Single answer

No known cause	1. <input type="checkbox"/>
Family history of PAH	2. <input type="checkbox"/>
Associated with connective tissue disease (such as scleroderma or lupus)	3. <input type="checkbox"/>
Associated with congenital heart disease	4. <input type="checkbox"/>
Associated with HIV	5. <input type="checkbox"/>
Associated with other condition	6. <input type="checkbox"/>
Not sure	7. <input type="checkbox"/>

**S10. Which of the following statements best describes the impact of your PAH on your current level of activity?**

Single answer

I have no symptoms and no limitations in ordinary physical activity (e.g. when walking, climbing stairs, running errands etc)	1. <input type="checkbox"/>
I experience mild symptoms and slight limitations during ordinary activity (e.g. I get breathless when walking, climbing stairs, running errands etc).	2. <input type="checkbox"/>
I experience significant limitation in ordinary physical activity due to my symptoms. I am comfortable only when resting/not active.	3. <input type="checkbox"/>
I am not able to carry out any physical activity without symptoms and symptoms may even be present at rest. My discomfort is increased by any physical activity (e.g. I feel breathless all the time and/or I find it difficult to sleep)	4. <input type="checkbox"/>

**Background information on PAH**

**S11a. Have you heard of the term “World Health Organization (WHO) or New York Heart Association (NYHA) Functional Class” with regard to PAH? Single answer**

Yes	1. <input type="checkbox"/> → PLEASE ANSWER QUESTION S11b
No	2. <input type="checkbox"/> → GO TO QUESTION S12

**S11b. Which of the following sentences best describes your level of understanding of this term? Single answer**

I understand what it means	1. <input type="checkbox"/> → PLEASE ANSWER QUESTIONS S11c AND S11d
I partially understand what it means	2. <input type="checkbox"/> → PLEASE ANSWER QUESTIONS S11c AND S11d
I don't understand what it means, I only know it by name	3. <input type="checkbox"/> → GO TO QUESTION S12

**S11c. What relevance does it have for you? Select the most relevant one. Single answer**

It helps me to understand my condition	1. <input type="checkbox"/>
It allows me to better know what I can do/cannot do	2. <input type="checkbox"/>
It can show how effective my treatment is	3. <input type="checkbox"/>
It reassures me	4. <input type="checkbox"/>
It does not help me	5. <input type="checkbox"/>
It frightens me	6. <input type="checkbox"/>
It helps me plan for the future	7. <input type="checkbox"/>

**S11d. Has your PAH specialist/doctor or a/your nurse told you your WHO or NYHA Functional class?**

Several answers possible. Please tick all that apply

Yes my PAH doctor	1. <input type="checkbox"/> → PLEASE ANSWER QUESTION S11e
Yes a/my nurse	2. <input type="checkbox"/> → PLEASE ANSWER QUESTION S11e
None	3. <input type="checkbox"/> → GO TO QUESTION S12

**S11e. What is your current WHO or NYHA Functional class? Single answer**

WHO/NYHA Functional Class I	1. <input type="checkbox"/>
WHO/NYHA Functional Class II	2. <input type="checkbox"/>
WHO/NYHA Functional Class III	3. <input type="checkbox"/>
WHO/NYHA Functional Class IV	4. <input type="checkbox"/>
I am not sure / I do not remember	5. <input type="checkbox"/>

**S12. Do you suffer from any other disease(s) or condition(s) requiring regular visits to a doctor or regular drug treatment?**

Several answers possible. Please select all that apply.

High blood pressure	1. <input type="checkbox"/>
Other heart & blood vessel disease	2. <input type="checkbox"/>
Asthma	3. <input type="checkbox"/>
Other lung disease	4. <input type="checkbox"/>
Psoriasis or other skin conditions	5. <input type="checkbox"/>
Kidney disease	6. <input type="checkbox"/>
Diabetes	7. <input type="checkbox"/>
Obesity	8. <input type="checkbox"/>
Depression	9. <input type="checkbox"/>
Anxiety	10. <input type="checkbox"/>
Panic attacks	11. <input type="checkbox"/>
Sleep disorders	12. <input type="checkbox"/>
Cancer	13. <input type="checkbox"/>
Systemic sclerosis / scleroderma	14. <input type="checkbox"/>
Another chronic disease or problem	15. <input type="checkbox"/>
Other conditions, please specify :	16. <input type="checkbox"/>
None	17. <input type="checkbox"/>
Don't know	18. <input type="checkbox"/>

**S13a. Who would you say is your main carer (the person who supports you and takes care of you and your needs the most)?**

Single answer

My spouse/partner	1. <input type="checkbox"/>	
My son/daughter	2. <input type="checkbox"/>	
My mother/father	3. <input type="checkbox"/>	
Other family member	4. <input type="checkbox"/>	
A friend	5. <input type="checkbox"/>	
A colleague	6. <input type="checkbox"/>	
A neighbour	7. <input type="checkbox"/>	
Other, please specify	8. <input type="checkbox"/>	
None	9. <input type="checkbox"/>	→ GO TO QUESTION S14a

**S13b. On scale from 1 to 10, how much do you believe/estimate that your main carer has contributed to your quality of life?**

Please use the following scale where 1 means "no contribution at all" and 10 means "very significant contribution".

Single answer

No contribution at all										Very significant contribution
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>	

**S14a. Do you currently belong to any patient association/support group?**

Single answer

Yes, I belong to a patient association <u>and</u> I am an active member	1. <input type="checkbox"/> → PLEASE ANSWER QUESTION S14b, S14c AND S14d
Yes, I belong to a patient association <u>but</u> I am not an active member	1. <input type="checkbox"/> → PLEASE ANSWER QUESTION S14b, S14c AND S14d
No, I do not belong to / I am not in contact with a patient association	2. <input type="checkbox"/> → GO TO QUESTION S14e

**S14b. Which of the following patient associations do you belong to?**

Several answers possible. Please select all that apply

HTAP France <b>(FR only)</b>	1. <input type="checkbox"/>
Association des Sclérodermiques de France <b>(FR only)</b>	2. <input type="checkbox"/>
pulmonale hypertonie ev <b>(GER only)</b>	3. <input type="checkbox"/>
Associazione Malati Ipertensione Polmonare (AMIP) <b>(IT only)</b>	4. <input type="checkbox"/>
Associazione Ipertensione Polmonare Italiana Onlus (APII) <b>(IT only)</b>	5. <input type="checkbox"/>
Asociacion Nacional de Hipertension Pulmonar <b>(SP only)</b>	6. <input type="checkbox"/>
Fundación Contra la Hipertensión Pulmonar <b>(SP only)</b>	7. <input type="checkbox"/>
Pulmonary Hypertension Association UK <b>(UK only)</b>	8. <input type="checkbox"/>
Other association(s) please specify <b>(ALL COUNTRIES)</b>	9. <input type="checkbox"/>
<hr/>	
Patient Organisations outside your country <b>(ALL COUNTRIES)</b>	10. <input type="checkbox"/>

**Background information on PAH**

**S14c. How did you learn about the above organisation(s)?**

Several answers possible. Please select all that apply.

From family doctor or General Practitioner (GP)	1. <input type="checkbox"/>
From specialists involved in the management of PAH	2. <input type="checkbox"/>
From nurses	3. <input type="checkbox"/>
From other PAH patients	4. <input type="checkbox"/>
Internet search	5. <input type="checkbox"/>
The association approached me	6. <input type="checkbox"/>
Media (press, TV, etc)	7. <input type="checkbox"/>
Other, please specify	8. <input type="checkbox"/>

**S14d. Why did you decide to join the above patient organisation(s)?**

Several answers possible. Please select all that apply.

I have not been satisfied with the information I have received so far	1. <input type="checkbox"/>
I wanted to hear about/meet other patients and how they were coping	2. <input type="checkbox"/>
I needed practical help (with disability, insurance, pensions etc.)	3. <input type="checkbox"/>
I heard about the association from other patients and was curious	4. <input type="checkbox"/>
My family suggested I contact a patient association	5. <input type="checkbox"/>
My doctor told me about the association	6. <input type="checkbox"/>
I wanted to know all about the condition	7. <input type="checkbox"/>
Other, please specify	8. <input type="checkbox"/>

**If you do not currently belong to any patient association / support group**

**S14e. We are trying to understand why patients do not join patient/support groups. Which of the following best describes your reasons for not joining patient/support groups?**

Select the most relevant one. Single answer

I didn't know a PAH related patient organisation/support group existed	1. <input type="checkbox"/>
I don't see what benefit belonging to a patient organisation/support group would have	2. <input type="checkbox"/>
I don't want to be associated with/around other people with PAH	3. <input type="checkbox"/>
I used to be involved with a patient association/support group but did not see the benefit	4. <input type="checkbox"/>
I used to be involved with a patient association/support group but it became emotionally too difficult	5. <input type="checkbox"/>
Other, please specify:	6. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q1a. On a scale from 1 to 10, how would you describe the impact of your PAH on your daily life?**

Please use the following scale where 1 means “no impact at all” and 10 means “very significant impact”.

Single answer

No impact at all										Very significant impact
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>	

**Q1b. In the last month how often have you experienced the following?**

Single answer per item

	Never	Rarely	Sometimes	Often	Very often (almost every day)
1. Breathlessness	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Fatigue	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. Dizziness	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. Chest pain	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. Sleep disorders	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. Depression (or related symptoms)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. Lack of concentration	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. Little energy	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. Poor appetite	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
10. Over-eating	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
11. Fidgety/restless	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
12. Stress	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
13. Difficulty with remembering things	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
14. Talking more slowly than usual	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
15. Thinking more slowly than usual	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
16. Loss of libido/interest in sex	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**IF YOU INDICATED THAT YOU HAVE EXPERIENCED “LOSS OF LIBIDO/INTEREST IN SEX” PLEASE ANSWER THE QUESTION Q2, OTHERWISE GO TO THE QUESTION Q3**

**Q2. If you have experience loss in libido/interest in sex since your diagnosis, what has caused it?**

Several answers possible. Please select all that apply.

I have low self-esteem/negative body image	1. <input type="checkbox"/>
I am afraid of getting more ill	2. <input type="checkbox"/>
I am physically not able due to PAH	3. <input type="checkbox"/>
I have lost interest since having PAH	4. <input type="checkbox"/>
I am afraid of pregnancy	5. <input type="checkbox"/>
It was due to the presence of one or more serious diseases or conditions in addition to PAH (or due to the effects of such additional disorders)	6. <input type="checkbox"/>
Other	7. <input type="checkbox"/>



**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q3. Please indicate your ability to perform or carry out the following activities compared to your ability prior to your diagnosis**

*Single answer per item*

	I can manage it without difficulty	I can manage it but with some difficulty	I can manage it but with a lot of difficulty and may need help	I cannot do it anymore and need help
1. Getting dressed	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
2. Taking a shower	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
3. Walking a short distance	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
4. Climbing a flight of stairs	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
5. Leisure and cultural activities such as going to movies, museum etc	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
6. Cooking	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
7. Dealing with domestic work/household chores	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
8. Visiting relatives/friends	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
9. Being visited by friends/relatives	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
10. Playing with my children or grandchildren/helping them do their homework (FOR PARENTS/GRANDPARENTS ONLY)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
11. Fulfilling the role of spouse/partner within my personal relationship	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
12. Being fully intimate with my spouse/partner	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
13. Going on errands e.g. shopping for food	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
14. Having a telephone conversation	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
15. Travelling/going on holiday	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
16. Sport activity/doing exercise	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>
17. Employment / work	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>

**Q4. For which three activities are you most concerned or frustrated regarding the impact PAH had on your ability to perform them?**

*Single answer per column*

	Most concerned	2 <sup>nd</sup> most concerned	3 <sup>rd</sup> most concerned
1. Getting dressed	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
2. Taking a shower	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
3. Walking a short distance	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
4. Climbing a flight of stairs	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
5. Leisure and cultural activities such as going to movies, museum etc	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
6. Cooking	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
7. Dealing with domestic work/household chores	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
8. Visiting relatives/friends	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
9. Being visited by friends/relatives	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
10. Playing with my children or grandchildren/helping them do their homework (FOR PARENTS/GRANDPARENTS ONLY)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
11. Taking on the role of spouse/partner within my couple	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
12. Being fully intimate with my spouse/partner	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
13. Going on errands e.g. shopping for food	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
14. Having a telephone conversation	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
15. Travelling/going on holiday	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
16. Sport activity/doing exercise	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>
17. Employment / work	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>

*If you do not feel comfortable answering a particular question please leave it blank and if you feel distress at any point please stop the survey immediately and seek assistance from your PAH patient organization or your doctor*

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q5. On a scale from 1 to 10, how has your role/status in the following changed since your PAH diagnosis?**

Single answer per item

	My role/ status has not changed at all									My role/ status has changed significantly
<b>1. My autonomy/independence</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>
<b>2. My role in my personal relationship with my partner/spouse</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>
<b>3. My role in my family</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>
<b>4. My role as a parent/my role with my children or grandchildren (FOR PARENTS/GRANDPARENT)</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>
<b>5. My role in my relationship with friends</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>
<b>6. My role in society</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>

**Q6a. Have you had to stop working since being diagnosed with PAH?** Single answer

Yes, totally	1. <input type="checkbox"/>	}	PLEASE ANSWER Q6b AND Q6c
Yes, partially	2. <input type="checkbox"/>		
No, but I changed my occupation	3. <input type="checkbox"/>		
No, but my working conditions have changed (e.g. work from home, changed responsibilities, adaptations at my work place)	4. <input type="checkbox"/>		
No	5. <input type="checkbox"/>	}	PLEASE GO TO Q7
Not relevant as I was not working prior to being diagnosed with PAH	6. <input type="checkbox"/>		

**Q6b. How would you describe the impact of having to change job/change working conditions/stop working partially or totally had on your emotional well-being?** Single answer

Very negative	1. <input type="checkbox"/>
Negative	2. <input type="checkbox"/>
Neutral (neither negative nor positive)	3. <input type="checkbox"/>
Positive	4. <input type="checkbox"/>
Very positive	5. <input type="checkbox"/>

**Q6c. Did this change in your working activity have an impact on the overall income of your household?** Single answer

Yes	1. <input type="checkbox"/> → PLEASE ANSWER QUESTION Q6d
No	2. <input type="checkbox"/> → GO TO Q7

**Q6d. Could you please estimate the impact it had on the overall income of your household?** Single answer

The overall income of my household...	
Decreased by 76% or more	1. <input type="checkbox"/>
Decreased by 51-75%	2. <input type="checkbox"/>
Decreased by 26-50%	3. <input type="checkbox"/>
Decreased by 25% or less	4. <input type="checkbox"/>
Increased by 25% or less	5. <input type="checkbox"/>
Increased by 26-50%	6. <input type="checkbox"/>
Increased by 51-75%	7. <input type="checkbox"/>
Increased by 76% or more	8. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q7. In the last month how often did you experience the following?**

Single answer per item

	Never	Rarely	Sometimes	Often	Very often (almost every day)
1. Feeling low in the morning	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Feeling worthless	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. Little pleasure in doing activities I used to enjoy	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. Fearful/frightened during the day	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. Fearful/frightened at night	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. Feeling angry	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. Feeling frustrated	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. Low self-esteem/confidence	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. Afraid to leave home (including travel)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
10. No desire to socialise	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
11. Feelings of guilt	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
12. Feeling embarrassed	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
13. Hopeless	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
14. Feeling misunderstood	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
15. Feeling isolated	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**IF YOU INDICATED THAT YOU EXPERIENCED “FEELING ISOLATED” IN THE LAST MONTH, PLEASE ANSWER QUESTION Q8a, OTHERWISE GO TO QUESTION Q9**

**Q8a. If you experienced a feeling of isolation at times after your diagnosis, what caused this?**

Several answers possible. Please select all that apply.

Lack of understanding of your disease by my friends/colleagues	1. <input type="checkbox"/> → <b>PLEASE ANSWER QUESTION Q8b</b>
Lack of understanding of your disease by my partner/spouse	2. <input type="checkbox"/>
Lack of understanding of your disease by my family	3. <input type="checkbox"/>
Lack of understanding of my disease by my children or grandchildren <b>(FOR PARENTS/GRANDPARENTS ONLY)</b>	4. <input type="checkbox"/>
Lack of understanding of my disease by the wider society/my community	5. <input type="checkbox"/>
Lack of empathy/compassion towards my PAH condition	6. <input type="checkbox"/>
I find it difficult to share my experience with other patients	7. <input type="checkbox"/>
I find it difficult to share my experience with PAH specialists/nurses	8. <input type="checkbox"/>
I find it difficult to express myself effectively	9. <input type="checkbox"/>
The fact that this disease is not “visible”	10. <input type="checkbox"/>
There is a frequent confusion with simple hypertension	11. <input type="checkbox"/>

**IF YOU INDICATED THAT YOU EXPERIENCED “LACK OF UNDERSTANDING BY YOUR FRIENDS/COLLEAGUES” PLEASE ANSWER QUESTION Q8b, OTHERWISE GO DIRECTLY TO QUESTION Q9**

**Q8b. On a scale from 1 to 10, how has the lack of understanding by your friends/colleagues impacted on your friendship?**

Please use the following scale where 1 means “no impact at all” and 10 means “very significant impact”. Single answer.

No impact at all										Very significant impact
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>	

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q9a. On a scale from 1 to 10, please indicate how you felt when you were first told by your specialist or doctor that you had PAH?**

Single answer

I was not shocked										I was extremely shocked
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>		10. <input type="checkbox"/>

**Q9b. On a scale from 1 to 10, please indicate how you felt when you were first told by your specialist or doctor that you had PAH?**

Single answer

I was not afraid										I was extremely afraid
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>		10. <input type="checkbox"/>

**Q10. How easy is it to discuss your feelings with the following people?**

Single answer per item.

	Very easy	Somewhat easy	Neither easy nor difficult	Somewhat difficult	Very difficult
1. Spouse/partner	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Parents	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. Children	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. Family doctor or General Practitioner	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. Specialists involved in the management of PAH	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. Nurses	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. Other PAH patients	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. Members of patient association/support group	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. Other, please specify	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**Q11a. In which place or space are you generally most comfortable discussing your feelings related to living with PAH?**

Single answer

1. At home	1. <input type="checkbox"/>	
2. Hospital or doctor's or General Practitioner's office	2. <input type="checkbox"/>	
3. Patient organization meetings	3. <input type="checkbox"/>	
4. Internet (blog, chat)	4. <input type="checkbox"/>	
5. Other, please specify	5. <input type="checkbox"/>	
6. No particular place	6. <input type="checkbox"/>	→ PLEASE GO TO QUESTION Q12a

**Q11b. Based on your response to Q11a, why you are most comfortable discussing your feelings in that place or space?**

Select the most relevant one. Single answer

1. I feel more safe	1. <input type="checkbox"/>
2. Find it easier to discuss my feelings	2. <input type="checkbox"/>
3. I get upset and don't want to let it show elsewhere	3. <input type="checkbox"/>
4. I need immediate answers	4. <input type="checkbox"/>
5. I like personal contact	5. <input type="checkbox"/>
6. I want anonymity	6. <input type="checkbox"/>
7. Other, please specify	7. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q12a. Who is providing you with emotional support around living with PAH?**

Several answers possible. Please select all that apply.

	Available support
1. My family	1. <input type="checkbox"/>
2. My carer/main support	2. <input type="checkbox"/>
3. My family doctor/general practitioner	3. <input type="checkbox"/>
4. My PAH Specialists	4. <input type="checkbox"/>
5. A nurse	5. <input type="checkbox"/>
6. Patient organization	6. <input type="checkbox"/>
7. A psychologist	7. <input type="checkbox"/>
8. My friends	8. <input type="checkbox"/>
9. My colleagues/former colleagues	9. <input type="checkbox"/>
10. Spiritual or religious support	10. <input type="checkbox"/>
11. Other	11. <input type="checkbox"/>

**Q12b. From whom is the most useful emotional support coming from?**

Single answer

	Most effective support
1. My family	1. <input type="checkbox"/>
2. My carer/main support	2. <input type="checkbox"/>
3. My family doctor/general practitioner	3. <input type="checkbox"/>
4. My PAH Specialists	4. <input type="checkbox"/>
5. A nurse	5. <input type="checkbox"/>
6. Patient organization	6. <input type="checkbox"/>
7. A psychologist	7. <input type="checkbox"/>
8. My friends	8. <input type="checkbox"/>
9. My colleagues/former colleagues	9. <input type="checkbox"/>
10. Spiritual or religious support	10. <input type="checkbox"/>

**Q12c. On a scale from 1 to 10, how much do you let this person/people know how you are feeling?**

Single answer

I do not talk about/show my feelings at all to this person/people										I talk completely openly about/show my feelings freely to this person/people
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>	

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q13. How often have you found yourself adopting any of the following attitudes / behaviours relative to living with PAH?**

Single answer per item.

	Never	Rarely	Sometimes	Often	Very often
1. Positive attitude	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Seeking information about PAH	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. Denial/rejecting diagnosis of PAH	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. Alcohol use	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. Over-eating or under-eating	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. Illicit drug use	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. Withdrawal socially/emotionally	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. Join a patient association	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. Talk more openly about my disease with others	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
10. Anger	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
11. Seeking spiritual or religious support	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
12. Other, please specify	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**Q14a. How would you describe the overall public awareness of PAH?**

Single answer

1. Non existent	1. <input type="checkbox"/>
2. Very low	2. <input type="checkbox"/>
3. Low	3. <input type="checkbox"/>
4. High	4. <input type="checkbox"/>
5. Very high	5. <input type="checkbox"/>

**Q14b. Does this have an impact on your overall well-being?**

Single answer

Yes	1. <input type="checkbox"/>
No	2. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q15. What type of information on PAH do you feel you need or you wish you received?**

*Several answers possible. Please select all that apply.*

1. Information about the disease (symptoms, prognosis)	1. <input type="checkbox"/>
2. Information about the specialists and doctors involved in PAH care	2. <input type="checkbox"/>
3. Information about treatment options/drugs used for PAH therapy	3. <input type="checkbox"/>
4. Information about the follow ups, including their schedules and purposes of these	4. <input type="checkbox"/>
5. Information about the financial consequences of the disease	5. <input type="checkbox"/>
6. Information about the administrative consequences of the disease (disability claims, insurance coverage, travel grants for hospital appointments...)	6. <input type="checkbox"/>
7. Information about the roles shifting within the family/couple	7. <input type="checkbox"/>
8. Information about depression, anxiety risk and other emotional consequences	8. <input type="checkbox"/>
9. Information about possible consequences on sexual relationships	9. <input type="checkbox"/>
10. Information about travel (tips and tricks how to make travelling possible)	10. <input type="checkbox"/>
11. Testimonials and patients stories	11. <input type="checkbox"/>
12. Patient Associations contacts	12. <input type="checkbox"/>
13. Other please specify	13. <input type="checkbox"/>

**Q16a. Please indicate the most suitable time for you to be given the following information?**

*Single answer per item.*

	At the time of diagnosis	1 month after diagnosis	3 months after diagnosis	6 months after diagnosis	1 year or more after diagnosis
1. Information about the disease (symptoms, prognosis)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Information about the specialists and doctors involved in PAH care	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. Information about treatment options/drugs used for PAH therapy	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. Information about the follow ups, including their schedules and purposes of these	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. Information about the financial consequences of the disease	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. Information about the administrative consequences of the disease (disability claims, insurance coverage, travel grants for hospital appointments...)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. Information about the roles shifting within the family/couple	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. Information about depression, anxiety risk and other emotional consequences	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. Information about possible consequences on sexual relationships	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
10. Information about travel (tips and tricks how to make travelling possible)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
11. Testimonials and patients stories	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
12. Patient Associations contacts	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
13. Other please specify:	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q16b. Please indicate the next most suitable times (if any) for you to be given the following information?**

*Several answers per item.*

*If you consider it exists different suitable times (different from the one you mentioned in the previous question) for you to be given the following information, please indicate them. Otherwise you can select the answer (no other suitable time)*

	<b>At the time of diagnosis</b>	<b>1 month after diagnosis</b>	<b>3 months after diagnosis</b>	<b>6 months after diagnosis</b>	<b>1 year or more after diagnosis</b>	<b>No other suitable time</b>
<b>1. Information about the disease (symptoms, prognosis)</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>2. Information about the specialists and doctors involved in PAH care</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>3. Information about treatment options/drugs used for PAH therapy</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>4. Information about the follow ups, including their schedules and purposes of these</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>5. Information about the financial consequences of the disease</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>6. Information about the administrative consequences of the disease (disability claims, insurance coverage, travel grants for hospital appointments...)</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>7. Information about the roles shifting within the family/couple</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>8. Information about depression, anxiety risk and other emotional consequences</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>9. Information about possible consequences on sexual relationships</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>10. Information about travel (tips and tricks how to make travelling possible)</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>11. Testimonials and patients stories</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>12. Patient Associations contacts</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
<b>13. Other please specify:</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>



**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q17a. Where are you likely to go and look for information about PAH?**

Several answers per column. Please select all that apply.

1. Family doctor/general practitioner	1. <input type="checkbox"/>
2. Physicians involved in the management of your PAH	2. <input type="checkbox"/>
3. A nurse	3. <input type="checkbox"/>
4. My pharmacist	4. <input type="checkbox"/>
5. My partner/spouse	5. <input type="checkbox"/>
6. People close to me/family/friends	6. <input type="checkbox"/>
7. Patient associations/support groups	7. <input type="checkbox"/>
8. Other patients	8. <input type="checkbox"/>
9. Social network sites	9. <input type="checkbox"/>
10. Other web sites	10. <input type="checkbox"/>
11. Blogs/forums	11. <input type="checkbox"/>
12. Press that covers medical topics	12. <input type="checkbox"/>

**Q17b. Please indicate which of the following sources do you consider reputable/credible?**

Several answers per column. Please select all that apply.

1. Family doctor/general practitioner	1. <input type="checkbox"/>
2. Physicians involved in the management of your PAH	2. <input type="checkbox"/>
3. A nurse	3. <input type="checkbox"/>
4. My pharmacist	4. <input type="checkbox"/>
5. My partner/spouse	5. <input type="checkbox"/>
6. People close to me/family/friends	6. <input type="checkbox"/>
7. Patient associations/support groups	7. <input type="checkbox"/>
8. Other patients	8. <input type="checkbox"/>
9. Social network sites	9. <input type="checkbox"/>
10. Other web sites	10. <input type="checkbox"/>
11. Blogs/forums	11. <input type="checkbox"/>
12. Press that covers medical topics	12. <input type="checkbox"/>

**Q17c. Would you please indicate your level of satisfaction with each of the following sources of information about PAH?**

Single answer per item.

	Very dissatisfied	Somewhat dissatisfied	Neither dissatisfied nor satisfied	Somewhat satisfied	Very satisfied
1. Family doctor/general practitioner	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Physicians involved in the management of your PAH	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. A nurse	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. My pharmacist	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. My partner/spouse	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. People close to me/family/friends	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. Patient associations/support groups	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. Other patients	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. Social network sites	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
10. Other web sites	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
11. Blogs/forums	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
12. Press that covers medical topics	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**IF YOU GO AND LOOK FOR INFORMATION ABOUT PAH ON THE INTERNET (SOCIAL NETWORK, BLOG, OTHER WEBSITES)  
PLEASE ANSWER Q17d**

**Q17d. Please indicate the websites you are likely to visit.**

*Mention the domain name of the site*

Social network site(s):

Other web site(s):

Blog(s)/ forum(s):

**THANKS YOU FOR YOUR PARTICIPATION.**

**PLEASE USE THE ENCLOSED PRE PAID ENVELOPE TO SEND US YOUR COMPLETED QUESTIONNAIRE BY Saturday  
31<sup>st</sup> DECEMBER AT THE LATEST**

**Thank you for requesting a copy of this questionnaire.** In total we hope to receive feedback from approximately 300 patients and carers, across France, Germany, Spain, Italy and the UK, whose lives are affected by pulmonary arterial hypertension (PAH). We would like to explore how PAH has affected your life. In particular we would like to know the impact PAH has had on your emotional wellbeing, since you have been caring for someone with PAH, as this is an area that has not been researched widely in the past. Your responses will be collected with those from the other patients and carers and used to improve our understanding of the impact of PAH. We would like to use these insights to develop new information resources to support patients, carers and healthcare professionals. The findings from the questionnaire will also help us to raise public awareness about the emotional impact PAH has on the lives of both patients and carers. We will be developing the information resources during 2012. If you would like to know more about their status please contact your local PAH patient organisation, which will be able to update you on progress.

**About the questionnaire**

This questionnaire has been commissioned by Actelion Pharmaceuticals Ltd, Switzerland, and the content has been developed and approved by a team of doctors and nurses who manage patients with PAH. Patient organisations and healthcare professionals at PAH centre in the participating countries are aware that this research is taking place.

**Thank you**

We would like to thank you for agreeing to take part in this survey. Your input to this piece of work as a carer is highly appreciated. If possible, please return your questionnaire by Saturday 31<sup>st</sup> December.

**When completing the questionnaire, please consider the following:**

- a “carer” or “care giver” is someone who provides ongoing assistance and support to a loved one (e.g. partner, child, relative or friend) who due to illness needs additional day to day help
- We recommended that you find a quiet and comfortable place to sit by yourself and complete this. If you need to stop and take a break while completing the questionnaire, we suggest that you do this and continue with the remainder of the questionnaire when you are ready. If you are completing this questionnaire on the Internet, you may get an automated reminder to complete the questionnaire. In addition, online administration of questionnaire allows you to complete it either all in one sitting or to complete it a little at a time, logging on and off the questionnaire according to your preference. Our secure platform will automatically keep track of your progress, so when you log back into the questionnaire you will pick up where you left off. This will be the same in case your browser remains inactive for a while. Once you have started the online completion, there is not any time limit to complete the entire questionnaire.
- You will be asked about physical, practical, social and emotional impact of the PAH from the “carer” perspective. **We understand that it must be difficult for you to talk about these life aspects and you have the possibility to not answer to a specific question should you not want to disclose such information.** The content has been developed and approved by a team of doctors and nurses who manage PAH patients

**Before completing the questionnaire, we would like to reassure you that:**

- As an independent market research company, we (Harris Interactive) comply with the codes of conduct of market research associations (ESOMAR and EphMRA) and all British laws in protecting your personal data
- Your responses will be collated with other respondents and presented to the sponsor in aggregated or anonymous form; your identity will not be revealed at any time. Your responses will be confidential and will not be used for any other purposes than the above mentioned or disclosed to any third party without your approval.
- Any personal information you give us is only used for the purposes for which you provide it; e.g. your mail/email address will only be used to send you information you specifically requested. We will never send you unsolicited mails/emails, we will not pass any data you supply to any other party and all employees who process your data are required to respect the confidentiality of your personal data.

**PLEASE NOTE:**

***If you experience any distress while taking part in this survey please stop the survey immediately and seek assistance from either your PAH patient organization or your healthcare professional.***

**Do you agree to participate in this survey under the above conditions and that you will be asked to provide information on your experiences of caring for someone with PAH and details about their health?**

Yes	1. <input type="checkbox"/>
No	2. <input type="checkbox"/>

**GENERAL INFORMATION**

**S1. Please specify YOUR gender**

Male	1. <input type="checkbox"/>	Female	2. <input type="checkbox"/>
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**S2. Please specify YOUR age: | \_\_\_\_\_ | years old**

**S3. What is YOUR marital status?**

*Single answer*

Married	1. <input type="checkbox"/>
Living with a partner	2. <input type="checkbox"/>
Widowed	3. <input type="checkbox"/>
Divorced	4. <input type="checkbox"/>
Separated	5. <input type="checkbox"/>
Single, never married	6. <input type="checkbox"/>
Other, please specify:	7. <input type="checkbox"/>

**S4. Please specify the relationship you have with the person you care for who has PAH. I am their...**

*Single answer*

Spouse/partner	1. <input type="checkbox"/>
Parent	2. <input type="checkbox"/>
Child	3. <input type="checkbox"/>
Another member of the family	4. <input type="checkbox"/>
Friend	5. <input type="checkbox"/>
Colleague	6. <input type="checkbox"/>
Neighbour	7. <input type="checkbox"/>
Other, please specify	8. <input type="checkbox"/>

**For the remainder of the questionnaire when referring to “the person you care for who has PAH” we will refer to this person as “YOUR RELATIVE”.**

**S5. Currently, how many children are there in YOUR household?**

*Single answer*

0	1. <input type="checkbox"/>	<p>→ GO TO QUESTION S7</p>      <p>→ PLEASE FILL IN THE QUESTION S6</p>
1	2. <input type="checkbox"/>	
2	3. <input type="checkbox"/>	
3	4. <input type="checkbox"/>	
4	5. <input type="checkbox"/>	
5 or more	6. <input type="checkbox"/>	

**S6. Please specify the age for each of these children?**

Child N# 1	Child N# 2	Child N# 3	Child N# 4	Child N# 5
_____   years	_____   years	_____   years	_____   years	_____   years

**S7. What is YOUR level of education?**

*Single answer*

Up to high school	1. <input type="checkbox"/>
Up to university	2. <input type="checkbox"/>
Technical/non-university	3. <input type="checkbox"/>
Post-graduate education	4. <input type="checkbox"/>
Other	98. <input type="checkbox"/>

**S8. What is the annual income of YOUR household?**

*Single answer*

Under £10,000	1. <input type="checkbox"/>
£10,000 – £14,999	2. <input type="checkbox"/>
£15,000 – £19,999	3. <input type="checkbox"/>
£20,000 – £24,999	4. <input type="checkbox"/>
£25,000 – £29,999	5. <input type="checkbox"/>
£30,000 or more	6. <input type="checkbox"/>

**BACKGROUND INFORMATION ON PAH**

**S9a. Please indicate the year of the first symptoms and the year of PAH diagnosis of YOUR RELATIVE**

Please indicate the year in the following boxes using this date format: yyyy.

First symptoms	First diagnosis
1	2
_ _ _	_ _ _

**S9b. What were these first symptoms?**

Several answers possible. Please select all that apply.

Breathlessness/dyspnoea	1. <input type="checkbox"/>
Tiredness/fatigue	2. <input type="checkbox"/>
Chest pain	3. <input type="checkbox"/>
Fainting/loss of consciousness	4. <input type="checkbox"/>
Irregularities in heart beat	5. <input type="checkbox"/>
Anxiety	6. <input type="checkbox"/>
Other	7. <input type="checkbox"/>

**S10. PAH can have no known cause, run in the family or be associated with one or more related conditions. Do you know what type of PAH YOUR RELATIVE has?**

Single answer

No known cause	1. <input type="checkbox"/>
Family history of PAH	2. <input type="checkbox"/>
Associated with connective tissue disease (such as scleroderma or lupus)	3. <input type="checkbox"/>
Associated with congenital heart disease	4. <input type="checkbox"/>
Associated with HIV	5. <input type="checkbox"/>
Associated with other condition	6. <input type="checkbox"/>
Not sure	7. <input type="checkbox"/>

**S11. Which of the following statements best describes the impact of PAH on YOUR RELATIVE'S current level of activity?**

Single answer

He/she has no symptoms and no limitations in ordinary physical activity (e.g. when walking, climbing stairs, running errands etc)	1. <input type="checkbox"/>
He/she experiences mild symptoms and slight limitations during ordinary activity (e.g. gets breathless when walking, climbing stairs, running errands etc)	2. <input type="checkbox"/>
He/she experiences significant limitation in ordinary physical activity due to his/her symptoms. He/she is comfortable only when resting/not active	3. <input type="checkbox"/>
He/she is not able to carry out any physical activity without symptoms and symptoms may even be present at rest. His/her discomfort is increased by any physical activity (e.g. feels breathless all the time and/or finds it difficult to sleep)	4. <input type="checkbox"/>

**BACKGROUND INFORMATION ON PAH**

**S12a. Have YOU heard of the term “World Health Organization (WHO) or (New York Heart Association) NYHA Functional Class” in the PAH area?**

Single answer

Yes	1. <input type="checkbox"/> → PLEASE ANSWER QUESTION S12b
No	2. <input type="checkbox"/> → GO TO QUESTION S13

**S12b. Which of the following sentences best describes YOUR level of understanding of this term?**

Single answer

I understand what it means	1. <input type="checkbox"/> → PLEASE ANSWER QUESTIONS S12c AND S12d
I partially understand what it means	2. <input type="checkbox"/> → PLEASE ANSWER QUESTIONS S12c AND S12d
I don't understand what it means, I only know it by name	3. <input type="checkbox"/> → GO TO QUESTION S13

**S12c. What relevance does the WHO/NYHA Functional Class have for YOU as the carer?**

Select the most relevant one. Single answer

It helps me to understand my relative's condition	1. <input type="checkbox"/>
It allows me to better know what he/she can do/cannot do	2. <input type="checkbox"/>
It can show how effective his/her treatment is	3. <input type="checkbox"/>
It reassures me	4. <input type="checkbox"/>
It does not help me in my care of my relative	5. <input type="checkbox"/>
It frightens me	6. <input type="checkbox"/>
It helps me plan for the future	7. <input type="checkbox"/>

**S12d. Are YOU aware of your relative's WHO or NYHA Functional class?**

Single answer

Yes	1. <input type="checkbox"/> → PLEASE ANSWER QUESTIONS S12e AND S12f
No	2. <input type="checkbox"/> → GO TO QUESTION S13

**S12e. Who has informed YOU about your relative's WHO or NYHA Functional class?**

Several answers possible. Please select all that apply

PAH doctor	1. <input type="checkbox"/>
Nurse	2. <input type="checkbox"/>
Patient himself/herself	3. <input type="checkbox"/>
Someone else	4. <input type="checkbox"/>

**S12f. What is YOUR RELATIVE'S WHO or NYHA Functional class?**

Single answer

WHO/NYHA Functional Class I	1. <input type="checkbox"/>
WHO/NYHA Functional Class II	2. <input type="checkbox"/>
WHO/NYHA Functional Class III	3. <input type="checkbox"/>
WHO/NYHA Functional Class IV	4. <input type="checkbox"/>
I am not sure / I do not remember	5. <input type="checkbox"/>

**BACKGROUND INFORMATION ON PAH**

**S13. Does YOUR RELATIVE suffer from any other disease(s) or condition(s) requiring regular visits to a doctor or regular drug treatment?**

Several answers possible. Please select all that apply.

High blood pressure	1. <input type="checkbox"/>
Other heart & blood vessel disease	2. <input type="checkbox"/>
Asthma	3. <input type="checkbox"/>
Other lung disease	4. <input type="checkbox"/>
Psoriasis or other skin conditions	5. <input type="checkbox"/>
Kidney disease	6. <input type="checkbox"/>
Diabetes	7. <input type="checkbox"/>
Obesity	8. <input type="checkbox"/>
Depression	9. <input type="checkbox"/>
Anxiety	10. <input type="checkbox"/>
Panic attacks	11. <input type="checkbox"/>
Sleep disorders	12. <input type="checkbox"/>
Cancer	13. <input type="checkbox"/>
Systemic sclerosis / scleroderma	14. <input type="checkbox"/>
Another chronic disease or problem	15. <input type="checkbox"/>
Other conditions, please specify :	16. <input type="checkbox"/>
None	17. <input type="checkbox"/>
Don't know	18. <input type="checkbox"/>

**S14a. Do you currently belong to any patient association/support group in relation to PAH?**

Single answer

Yes, I belong to a patient association <u>and I am an active member</u>	1. <input type="checkbox"/> → PLEASE ANSWER QUESTIONS S14b, S14c AND S14d
Yes, I belong to a patient association <u>but I am not an active member</u>	2. <input type="checkbox"/> → PLEASE ANSWER QUESTIONS S14b, S14c AND S14d
No, I do not belong to / I am not in contact with a patient association	3. <input type="checkbox"/> → GO TO QUESTION S14e

**S14b. Which of the following patient associations/support groups do YOU belong to?**

Several answers possible. Please select all that apply.

Pulmonary Hypertension Association UK	1. <input type="checkbox"/>
Other association(s) please specify	2. <input type="checkbox"/>

**BACKGROUND INFORMATION ON PAH**

**S14c. How did you learn about the above organisation(s)?**

Several answers possible. Please select all that apply.

From family doctor or General Practitioner (GP)	1. <input type="checkbox"/>
From specialists involved in the management of PAH	2. <input type="checkbox"/>
From nurses	3. <input type="checkbox"/>
From other PAH patients	4. <input type="checkbox"/>
Internet search	5. <input type="checkbox"/>
The association approached me	6. <input type="checkbox"/>
Media (press, TV, etc)	7. <input type="checkbox"/>
Other, please specify: _____	8. <input type="checkbox"/>

**S14d. Why did you decide to join the above patient organisation(s)?**

Several answers possible. Please select all that apply.

I have not been satisfied with the information I have received so far	1. <input type="checkbox"/>
I wanted to hear about/meet other patients and carers and how they were coping	2. <input type="checkbox"/>
I needed practical help (with disability, insurance, pensions etc.)	3. <input type="checkbox"/>
I heard about the association from other patients or carers and was curious	4. <input type="checkbox"/>
My family suggested I contact a patient association	5. <input type="checkbox"/>
A doctor told me about the association	6. <input type="checkbox"/>
I wanted to know all about the condition	7. <input type="checkbox"/>
Other, please specify	8. <input type="checkbox"/>

***If you do not currently belong to any patient association / support group***

**S14e. We are trying to understand why patients or carers do not join patient/support groups. Which of the following best describes your reasons for not joining patient/support groups?**

Select the most relevant one. Single answer

I didn't know a PAH related patient organisation/support group existed	1. <input type="checkbox"/>
I don't see what benefit belonging to a patient organisation/support group would have	2. <input type="checkbox"/>
I don't want to be associated with/around other people with PAH	3. <input type="checkbox"/>
I used to be involved with a patient association/support group but did not see the benefit	4. <input type="checkbox"/>
I used to be involved with a patient association/support group but it became emotionally too difficult	5. <input type="checkbox"/>
Other, please specify	6. <input type="checkbox"/>



**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q1a. On a scale from 1 to 10, how would you assess the impact of your relative's PAH on YOUR daily life?**

Please use the following scale where 1 means "no impact at all" and 10 means "very significant impact". Single answer.

No impact at all									Very significant impact
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>

**Q1b. On a scale from 1 to 10, how would you assess the impact of your relative's PAH on HIS/HER daily life?**

Please use the following scale where 1 means "no impact at all" and 10 means "very significant impact". Single answer.

No impact at all									Very significant impact
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>

**Q2. Would you please indicate all the changes your relative's PAH has had on YOUR daily life?**

Several answers possible. Please select all that apply.

I have given up work	1. <input type="checkbox"/>
I have chosen to work part time	2. <input type="checkbox"/>
I have made changes to my work (e.g. work from home, changed responsibilities)	3. <input type="checkbox"/>
I found a different job to fit in taking care of my relative	4. <input type="checkbox"/>
I am more involved in the household chores	5. <input type="checkbox"/>
I am more involved in taking care of our child/children (if any)	6. <input type="checkbox"/>
I am more likely to go on errands	7. <input type="checkbox"/>
I need to be organised all the time (extra planning requirement)	8. <input type="checkbox"/>
I feel exhausted more frequently (due to extra responsibilities)	9. <input type="checkbox"/>
I take on planning of his/her daily life	10. <input type="checkbox"/>
I have to schedule family life around his/her needs	11. <input type="checkbox"/>
I am involved in administration of PAH medication	12. <input type="checkbox"/>
I am more involved in tasks my relative used to manage.	13. <input type="checkbox"/>
I have made no changes as a consequence of my relative's PAH	14. <input type="checkbox"/>
Other, please specify	15. <input type="checkbox"/>

**Q3. To what extent do you agree with the following statements?**

Single answer per statement

	I strongly disagree	I disagree	I neither agree nor disagree	I Agree	I strongly agree
1. Caring/supporting has given new meaning to my life	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Caring/supporting has brought us closer together as a couple/family	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. I find fulfilment in being a carer	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. Caring/supporting has made me realise that I can do things I never thought I was capable of	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. Caring/supporting has brought out a better me	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. By caring/supporting my relative I positively contribute to his/her quality of life	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q4. The following statements reflect how people sometimes feel when they are taking care of another person. Please indicate how often, if ever, you feel that way *Single answer per item***

	Never	Rarely	Sometimes	Often	Very often (Nearly always)
1. I feel stressed between caring for my relative and trying to meet other responsibilities for my family or work	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. I feel that my relative asks for more help than he or she needs	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. I feel that because of the time I spend with my relative, I do not have enough time for myself	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. I feel angry when I am around my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. I feel that my relative negatively affects my relationship with other family members or friends	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. I am afraid about what the future holds for my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. I feel my relative is over-dependent on me	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. I feel strained when I am around my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. I feel my health has suffered because I am caring for my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
10. I feel that I do not have as much privacy as I would like because of my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
11. I feel that I will be unable to take care of my relative much longer	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
12. I feel I have lost control of my life since my relative's illness	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
13. I wish I could just leave the care of my relative to someone else	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
14. I feel uncertain about what to do for my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
15. I think I should be doing more for my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
16. I feel I could do a better job in caring for my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
17. I feel I have no choice but to look after my relative	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
18. I feel caring for my relative gives me less time to spend with my children or grandchildren <b>(FOR PARENTS/GRANDPARENTS ONLY)</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**Q5. On a scale from 1 to 10, how burdened do YOU feel in caring for your relative?**

*Please use the following scale where 1 means "not burdened at all" and 10 means "Extremely burdened".*

*Single answer.*

Not burdened at all									Extremely burdened
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**IF YOU ARE THE SPOUSE OR PARTNER OF THE PATIENT WITH PAH PLEASE ANSWER THE QUESTIONS Q6a OTHERWISE GO TO THE QUESTION Q7**

**Q6a. Has there been an overall decrease in your sexual relations?**

Single answer

Yes	1. <input type="checkbox"/> → PLEASE ANSWER QUESTION Q6b AND Q6c
No	2. <input type="checkbox"/> → GO TO QUESTION Q7
I would rather not answer this question	3. <input type="checkbox"/> → GO TO QUESTION Q7

**Q6b. What do you believe are the reasons for it?**

Several answers possible. Please select all that apply.

Partner has low self-esteem/negative body image	1. <input type="checkbox"/>
I am afraid of making my partner more ill	2. <input type="checkbox"/>
He/she is physically not able due to PAH	3. <input type="checkbox"/>
I have lost interest since the PAH diagnosis	4. <input type="checkbox"/>
My partner has lost interest since having PAH	5. <input type="checkbox"/>
Afraid of pregnancy	6. <input type="checkbox"/>
It was due to the presence of one or more serious diseases or conditions in addition to PAH (or due to the effects of such additional disorders)	7. <input type="checkbox"/>
Other, please specify:	8. <input type="checkbox"/>

**Q6c. How does this make you feel?**

Several answers possible. Please select all that apply.

I feel less close to my partner	1. <input type="checkbox"/>
I struggle to show my affection in other ways	2. <input type="checkbox"/>
I feel like my partner sees me more as a carer than a lover	3. <input type="checkbox"/>
I am not concerned that there has been a decrease in sexual relations	4. <input type="checkbox"/>
I am comfortable with our relationship as we are more affectionate in different ways now (kissing, cuddling etc)	5. <input type="checkbox"/>
I am worried that my partner does not feel desirable to me anymore	6. <input type="checkbox"/>

**Q7. Who, if anyone, do you tell about/have you made aware of YOUR role as a carer?**

Several answers possible except code 7 "Nobody" which is exclusive. Please select all that apply.

Family members	1. <input type="checkbox"/>	→ GO TO QUESTION Q8
Friends	2. <input type="checkbox"/>	
Colleagues	3. <input type="checkbox"/>	
Neighbours	4. <input type="checkbox"/>	
PAH specialists or nurses	5. <input type="checkbox"/>	
Family doctor/general practitioner (GP)	6. <input type="checkbox"/>	
Nobody <b>[EXCLUSIVE]</b>	7. <input type="checkbox"/>	→ GO TO QUESTION Q9a

**Q8. To what extent do you agree with the following statements?**

"When I tell people I am a carer they.... "

Single answer per statement

	I strongly disagree	I disagree	I neither agree nor disagree	I Agree	I strongly agree
<b>1. better understand my situation</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
<b>2. are more empathic/compassionate with me</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
<b>3. change their perceptions of my situation</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
<b>4. change their perception of the person I support</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
<b>5. No change in their understanding of my situation</b>	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q9a. Do YOU feel isolated/excluded at times as a result of caring for someone with PAH?**

Single answer

Yes	1. <input type="checkbox"/> → PLEASE ANSWER QUESTION Q9b and Q10
No	2. <input type="checkbox"/> → GO TO QUESTION Q11

**Q9b. If at times YOU experience feelings of isolation/exclusion, what causes this?**

Several answers possible. Please select all that apply

Lack of understanding of the disease by the person I care for who has PAH	1. <input type="checkbox"/>
Lack of understanding of the disease by my/our friends/colleagues	2. <input type="checkbox"/>
Lack of understanding of the disease by my partner/spouse	3. <input type="checkbox"/>
Lack of understanding of the disease by my/our family	4. <input type="checkbox"/>
Lack of understanding of the disease by our children/grandchildren <b>(FOR PARENTS/GRANDPARENTS ONLY)</b>	5. <input type="checkbox"/>
Lack of understanding of the disease by the wider society/my community	6. <input type="checkbox"/>
My Lack of empathy/compassion towards my relative's PAH condition	7. <input type="checkbox"/>
I find it difficult to share my/our experience with others	8. <input type="checkbox"/>
I find it difficult to share my/our experience with PAH Specialists/nurses	9. <input type="checkbox"/>
I find it difficult to express myself effectively	10. <input type="checkbox"/>
The fact that this disease is not "visible"	11. <input type="checkbox"/>
There is a frequent confusion with simple hypertension	12. <input type="checkbox"/>
Lack of overall communication between me and the person I care for	13. <input type="checkbox"/>
My relative feeling guilty that I have now less time for my self	14. <input type="checkbox"/>

**Q10. On a scale from 1 to 10, what impact does feeling isolated/excluded have on YOUR daily life?**

Please use the following scale where 1 means "no impact at all" and 10 means "very significant impact". Single answer.

No impact at all										Very significant impact
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>	

**Q11. How often do YOU have contact with healthcare professionals involved in PAH management of your relative?**

Single answer

Never	Less than once a year	Once a year	once every six month	Once every three months	Once a month	More than once a month
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>

**Q12. What do you expect from these healthcare professionals?**

Several answers possible. Please select all that apply.

Detailed and theoretical information about the disease	1. <input type="checkbox"/>
Detailed information of drugs used in PAH therapy	2. <input type="checkbox"/>
Information which is not too technical and is easy for me to understand	3. <input type="checkbox"/>
Regular update of the health status of my relative and potential progression of PAH	4. <input type="checkbox"/>
Active support in my role of carer (listening to what I need to say/how I feel)	5. <input type="checkbox"/>
Tips and advice to improve my daily life	6. <input type="checkbox"/>
Practical information about PAH management e.g. where to buy oxygen if needed, changes to house to improve accessibility	7. <input type="checkbox"/>
Contacts details for patient associations/support groups	8. <input type="checkbox"/>
Support to manage financial and administrative issues related to PAH	9. <input type="checkbox"/>
Other, please specify	10. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q13a. In a normal month, how much time do YOU spend on average doing the following?**

Please indicate your answer in %".

1. Activities for my relative	_____   %
2. Activities for myself (e.g. work, socialising)	_____   %
	<b>TOTAL = 100%</b>

**Q13b. In a normal month, how much time did YOU spend doing the following prior to your relative being diagnosed with PAH?**

Please indicate your answer in %".

1. Activities for my relative	_____   %
2. Activities for myself (work, socialising...)	_____   %
	<b>TOTAL = 100%</b>

**Q14. On scale from 1 to 10, how would you rate how much YOU have positively contributed to the quality of life of your relative?**

Please use the following scale where 1 means "no contribution at all" and 10 means "very significant contribution". Single answer.

No contribution at all										Very significant contribution
1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>	7. <input type="checkbox"/>	8. <input type="checkbox"/>	9. <input type="checkbox"/>	10. <input type="checkbox"/>	

**Q15. What type of information on PAH do you feel YOU need or you wish you received?**

Several answers possible. Please select all that apply.

Information about the disease (symptoms, prognosis)	1. <input type="checkbox"/>
Information about the specialists and doctors involved in PAH care	2. <input type="checkbox"/>
Information about treatment options/drugs used for PAH therapy	3. <input type="checkbox"/>
Information about the follow ups, including their schedules and purposes of these	4. <input type="checkbox"/>
Information about the financial consequences of the disease	5. <input type="checkbox"/>
Information about the administrative consequences of the disease (disability claims, insurance coverage, travel grants for hospital appointments...)	6. <input type="checkbox"/>
Information about the roles shifting within the family/couple	7. <input type="checkbox"/>
Information about depression, anxiety risk and other emotional consequences	8. <input type="checkbox"/>
Information about possible consequences on sexual relationships	9. <input type="checkbox"/>
Information about travel (tips and advice how to make travelling possible)	10. <input type="checkbox"/>
Testimonials and carer stories	11. <input type="checkbox"/>
Information about my new role of carer (practical consequences)	12. <input type="checkbox"/>
Information about support for children / education <b>(FOR PARENTS/GRANDPARENTS ONLY)</b>	13. <input type="checkbox"/>
Patient association contacts	14. <input type="checkbox"/>
Other please specify:	15. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q16a. Please indicate the most suitable time for YOU to be given the following information**

*Single answer per item*

	At the time of diagnosis	1 month after diagnosis	3 months after diagnosis	6 months after diagnosis	1 year or more after diagnosis
1. Information about the disease (symptoms, prognosis)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Information about the specialists and doctors involved in PAH care	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. Information about treatment options/drugs used for PAH therapy	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. Information about the follow ups, including their schedules and purposes of these	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. Information about the financial consequences of the disease	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. Information about the administrative consequences of the disease (disability claims, insurance coverage, travel grants for hospital appointments...)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. Information about the roles shifting within the family/couple	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. Information about depression, anxiety risk and other emotional consequences	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. Information about possible consequences on sexual relationships	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
10. Information about travel (tips and advice how to make travelling possible)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
11. Testimonials and carer stories	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
12. Information about my new role of carer (practical consequences)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
13. Information about support for children / education ( <b>FOR PARENTS/GRANDPARENTS ONLY</b> )	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
14. Patient association contacts	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
15. Other please specify:	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q16b. Please indicate the next most suitable times (if any) for you to be given the following information?**

*Several answers per item.*

*If you consider it exists different suitable times (different from the one you mentioned in the previous question) for you to be given the following information, please indicate them. Otherwise you can select the answer (no other suitable time)*

	At the time of diagnosis	1 month after diagnosis	3 months after diagnosis	6 months after diagnosis	1 year or more after diagnosis	No other suitable time
1. Information about the disease (symptoms, prognosis)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
2. Information about the specialists and doctors involved in PAH care	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
3. Information about treatment options/drugs used for PAH therapy	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
4. Information about the follow ups, including their schedules and purposes of these	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
5. Information about the financial consequences of the disease	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
6. Information about the administrative consequences of the disease (disability claims, insurance coverage, travel grants for hospital appointments...)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
7. Information about the roles shifting within the family/couple	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
8. Information about depression, anxiety risk and other emotional consequences	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
9. Information about possible consequences on sexual relationships	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
10. Information about travel (tips and advice how to make travelling possible)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
11. Testimonials and carer stories	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
12. Information about my new role of carer (practical consequences)	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
13. Information about support for children / education ( <b>FOR PARENTS/GRANDPARENTS ONLY</b> )	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
14. Patient association contacts	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>
15. Other please specify:	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>	6. <input type="checkbox"/>

**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**Q17a. Where are YOU likely to go and look for information about PAH?**

Several answers per column. Please select all that apply.

1. Family doctor or General Practitioner/my relative's General Practitioner	1. <input type="checkbox"/>
2. Physicians involved in the management of your relative's PAH	2. <input type="checkbox"/>
3. A nurse	3. <input type="checkbox"/>
4. My pharmacist	4. <input type="checkbox"/>
5. People close to me/family/friends	5. <input type="checkbox"/>
6. Patient associations/support groups	6. <input type="checkbox"/>
7. Other patients	7. <input type="checkbox"/>
8. Social network sites	8. <input type="checkbox"/>
9. Other websites	9. <input type="checkbox"/>
10. Blogs/forums	10. <input type="checkbox"/>
11. Press that covers medical topics	11. <input type="checkbox"/>

**Q17b. Please indicate which of the following sources YOU consider reputable/credible**

Several answers per column. Please select all that apply.

1. Family doctor or General Practitioner/my relative's General Practitioner	1. <input type="checkbox"/>
2. Physicians involved in the management of your relative's PAH	2. <input type="checkbox"/>
3. A nurse	3. <input type="checkbox"/>
4. My pharmacist	4. <input type="checkbox"/>
5. People close to me/family/friends	5. <input type="checkbox"/>
6. Patient associations/support groups	6. <input type="checkbox"/>
7. Other patients	7. <input type="checkbox"/>
8. Social network sites	8. <input type="checkbox"/>
9. Other websites	9. <input type="checkbox"/>
10. Blogs/forums	10. <input type="checkbox"/>
11. Press that covers medical topics	11. <input type="checkbox"/>

**Q17c. Please indicate YOUR level of satisfaction with each of the following sources of information about PAH**

Single answer per item.

	Very dissatisfied	Somewhat dissatisfied	Neither dissatisfied nor satisfied	Somewhat satisfied	Very satisfied
1. Family doctor or General Practitioner/my relative's General Practitioner	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
2. Physicians involved in the management of your relative's PAH	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
3. A nurse	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
4. My pharmacist	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
5. People close to me/family/friends	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
6. Patient associations/support groups	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
7. Other patients	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
8. Social network sites	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
9. Other websites	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
10. Blogs/forums	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>
11. Press that covers medical topics	1. <input type="checkbox"/>	2. <input type="checkbox"/>	3. <input type="checkbox"/>	4. <input type="checkbox"/>	5. <input type="checkbox"/>



**IMPACT OF PAH ON YOUR DAY TO DAY LIFE**

**IF YOU GO AND LOOK FOR INFORMATION ABOUT PAH ON THE INTERNET (SOCIAL NETWORK, BLOG, OTHER WEBSITES) PLEASE ANSWER Q17d**

**Q17d. Please indicate the websites you are likely to visit.**

*Mention the domain name of the site*

Social network site(s):

Other web site(s):

Blog(s)/ forum(s):

**Q18. Have you ever avoided sharing information you have found/received about PAH with your relative?**

*Several answers possible per column. Please select all that apply.*

	<b>a. At diagnosis</b>	<b>b. Currently</b>
Yes, to protect him/her from information about the seriousness of PAH	1. <input type="checkbox"/>	1. <input type="checkbox"/>
Yes, because I felt uncomfortable understanding the information	2. <input type="checkbox"/>	2. <input type="checkbox"/>
Yes, because I felt uncomfortable expressing it	3. <input type="checkbox"/>	3. <input type="checkbox"/>
Yes, because he/she was in a denial (rejecting diagnosis of PAH) phase	4. <input type="checkbox"/>	4. <input type="checkbox"/>
Yes, because I did not want to add his/her feelings of guilt	5. <input type="checkbox"/>	5. <input type="checkbox"/>
Yes, for other reasons	6. <input type="checkbox"/>	6. <input type="checkbox"/>
No, I have never filtered any information	7. <input type="checkbox"/>	7. <input type="checkbox"/>

**THANK YOU FOR YOUR PARTICIPATION.**

**PLEASE USE THE ENCLOSED PRE PAID ENVELOPE TO SEND US YOUR COMPLETED QUESTIONNAIRE BY SATURDAY 31<sup>st</sup> DECEMBER AT THE LATEST**