



Lifting the lid **ON NUTRITION AND PH**

What people with pulmonary hypertension told us about ***their food habits, choices, and challenges...***



An appetite for sharing thoughts and experiences...

We were unsure of the response to expect when we launched our survey into nutrition and PH.

Would people be interested in telling us about their eating habits, food preferences, and cooking or weight management challenges? Would they be willing to share the areas they feel they need support in?

It turned out that many were, with a total of over **600 responses** to our questionnaire – which was the first of its kind in the UK.

As well as statistics, this report shares some of the comments left by respondents, painting an enlightening picture of PH and nutrition in the UK.

The high response number shows how much people with PH care about this topic, and how much appetite there is for support.

This booklet contains an overview of the key findings from the survey. A full detailed report can be accessed at www.bit.ly/PHandNutritionFindings



“Thank you to everyone who shared their thoughts and experiences in this first-of-its-kind research.

We responded quickly to the findings and we will continue to build upon our work to support people with PH to enjoy the benefits of good nutrition.

We understand the challenges that people face in this area, and we're here to help. Watch this space! ”

Shaun Clayton

**Certified Nutritionist
Director of Finance and Operations
PHA UK**



ABOUT THE RESEARCH

The PHA UK developed the survey in collaboration with Registered Dietician Chermaine Kwant, and Professor David Kiely, Director of the Sheffield Pulmonary Vascular Disease Unit.

It aimed to understand the eating habits, food choices, and challenges facing people living with pulmonary hypertension in the UK, to inform the development of supportive tools and resources.

Responses were collected between March and June 2023. The survey was available to complete online, and paper copies were included in the Spring 2023 issue of our member magazine.

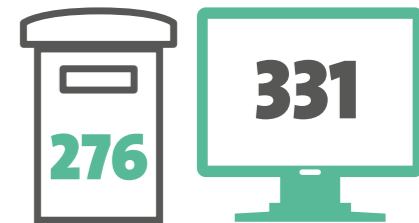
“It was a pleasure to support the development of this pioneering survey, which has produced really interesting results. **As someone who has lived with pulmonary hypertension, I’ve experienced first-hand the difference that good nutrition can make.** I’m looking forward to continuing my partnership with the PHA UK to support people with PH to live well, using these survey results as the foundation.”

Chermaine Kwant, Registered Dietician, researcher, and former PH patient

(Chermaine underwent a double lung transplant in 2016, five years after being diagnosed with pulmonary arterial hypertension).



607 responses were received



331 people completed the survey online, and 276 people posted a paper questionnaire back to us.

About those who completed the survey:

Half of those who completed the survey are aged between 50 and 73

♀ 74% are female

👤👤 54% live with a partner or spouse

👤 21% live alone

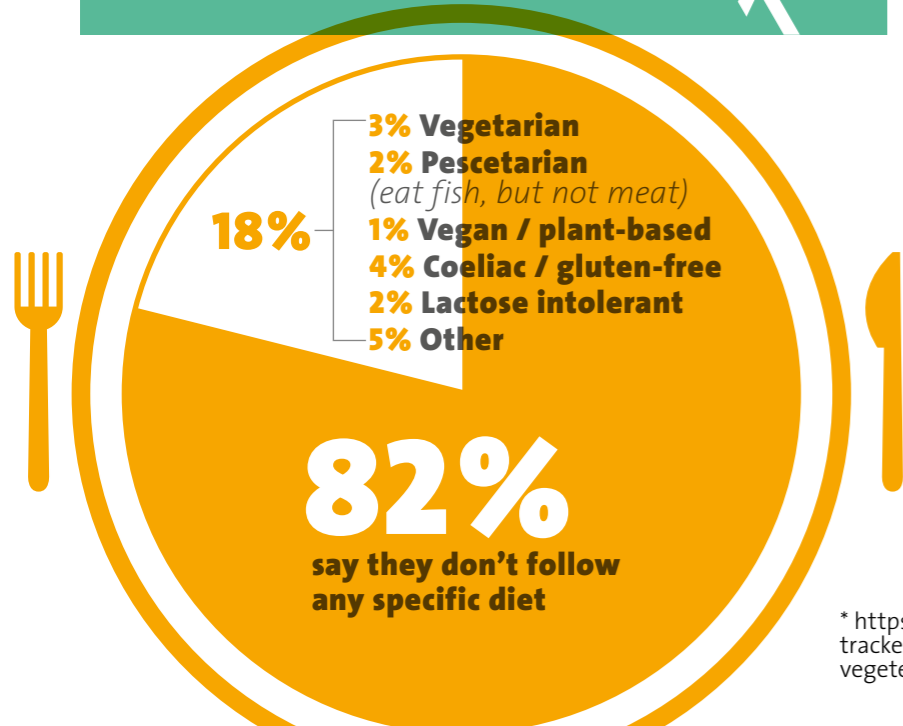
👤👤👶 14% live with a partner or spouse and a child / children

“Food is one of my few pleasures left, if I don’t follow dietary rules it’s because I choose not to.”



KEY FINDINGS

THE VAST MAJORITY OF PEOPLE WITH PH **DO NOT HAVE DIETARY RESTRICTIONS**



* <https://yougov.co.uk/topics/society/trackers/dietary-choices-of-brits-eg-vegetarian-flexitarian-meat-eater-etc>



How does this compare with the general population?

According to YouGov data*, 5-7% of the UK's population are vegetarian and 2-3% are vegan.

OVER A THIRD OF PEOPLE WITH PH **NEVER DRINK ALCOHOL**

This is how often people with PH consume an alcoholic drink:



* <https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/2021/part-3-drinking-alcohol>

“I could do with reducing alcohol intake **but I don't**”

“Ticking ‘healthy’ doesn't take account of the **daily red wine** in the evening”



How does this compare with the general population?

A 2021 NHS Digital survey* showed that 21% of adults had not drunk alcohol in the last 12 months. 49% reported that they drank alcohol at least once a week.

IAIN ARMSTRONG
Chair, PHA UK



“I don't eat much veg that needs preparing and cooking, I struggle with this. **Depression around PH means no motivation to eat.**”

“I'm on **oxygen** 24/7 so not allowed to cook due to **fire risk**, I use the microwave.””

“I have digestive issues due to systemic sclerosis, **knowing which foods to eat without being near a toilet is difficult.**”

“Sometimes **fatigue** makes standing/ cooking difficult.””

21%

of people with PH eat out at a restaurant or café at least once a week

60%

of people with PH usually do the cooking or meal preparation in their home

68%

of people with PH shop for most of the food in their household

21% of people with PH told us they live alone, which may influence some of these statistics.

THE MAJORITY OF PEOPLE WITH PH THINK **CHANGES NEED TO BE MADE TO THEIR DIET.**

63%

said: “I generally eat well but could make some improvements”

13%

said: “I need to make significant changes to my diet”

24%

said: “I have a healthy diet”

This shows that there is a need for help and support in this area.

MARY FERGUSON

Communications Manager, PHA UK



THERE ARE **MULTIPLE BARRIERS** STOPPING PEOPLE WITH PH EATING AS WELL AS THEY WOULD LIKE TO. ↗

The main causes of them not eating well are:

37%

'The cost of healthy food'

5%

'Cooking skills'

26%

'PH symptoms'

(eg. fatigue or strength limitations) preventing me from cooking

8%

'Lack of interest in cooking and nutrition'

26%

'Motivation or willpower to make changes'

We will use this insight to support people in the areas identified above.

"I'm a believer in food as a cure, but I don't have time or money or motivation."



"I'm capable of cooking but by the end of the day exhaustion can prevent me doing it."



THE **CONNECTION BETWEEN NUTRITION AND PHYSICAL AND MENTAL WELLBEING** IS RECOGNISED BY SOME PEOPLE WITH PH. ↗

39%

of people with PH agree that when they eat well, they have more energy / feel happier

18%

agree that when they eat badly, they notice they feel worse

24%

agree that when they don't eat enough, they lack energy

29%

agree that when they eat too much, they feel bad

Our work will aim to help people feel better by eating well.

"I turn to comfort food on a sad day."

"When my CTEPH is bad I am too fatigued to cook."



ALMOST HALF OF THOSE WITH PH WANT TO **REDUCE THEIR WEIGHT.**

41%
would like to **lose** weight



7%
would like to **gain** weight

Our resources and support will address both goals.



This is what people with PH told us they **need the most help with when it comes to nutrition:**

- 1** Understanding how nutrition can influence PH symptoms
- 2** Weight management (gaining, losing, or maintaining weight)
- 3** How to prepare nutritious food without using too much energy

These responses will help us to prioritise the subject matter of our support materials.

“I would like more information on diet and **how it affects my breathing.**”

“**I need more ideas for different meals.**”

“Anything available to stop me eating when full **would transform my life.**”

We asked whether **PH medications, or their side effects**, influence people's food choices or meal timings. Here are a few of the answers we received:



“ **Digestive issues**, need to take meds with or after food.”





“ **Diuretics** interrupt mealtimes.”




“ **Meds dictate** when I eat and drink.”

“ **Frusemide effects** have to be considered when **scheduling meals** away from home.”



“ **More dairy intolerance** due to mycophenolate. **Reflux** is an issue.”

“ **Meds causing nausea and bloating.** Foods taste bland, even curry.”



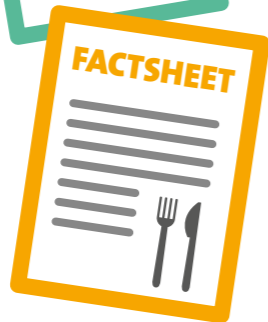
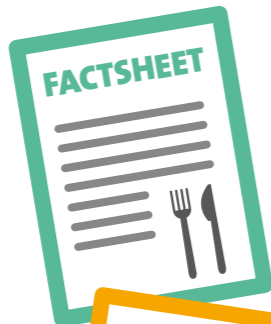
Our support and advice will take all of these things into account, to help people overcome challenges posed by medications in order to enjoy good nutrition.



ACCESSING HELP

52%

of people with PH said they **would like to receive** nutrition guidance or advice as part of their PH care from their hospital / specialist centre, but **only 10% have received it.**



Here at the PHA UK, our aim is to fulfil this unmet need by providing resources and advice in the areas you told us you need most.

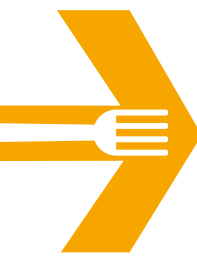


“ I cook in stages due to fatigue. Prepare, rest, then cook.”

“ Eating well, staying healthy and alive **saves NHS money.** ”

“ **Breathlessness** sometimes discourages me from eating.”





WHAT HAVE WE DONE WITH THE RESULTS OF THIS SURVEY?

Sharing your thoughts and experiences has already made a big difference!

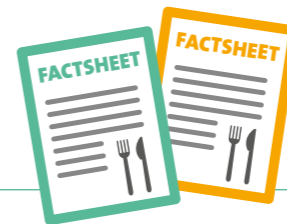
We acted quickly on the findings of this research by producing advice materials that address the things you told us you need the most support with.

We now have a **dedicated nutrition area on our website**, housing videos and articles on topics including cooking with fatigue, eating to manage the common side effects of medication, and understanding the basics of energy balance and good nutrition. This valuable online hub will continue to expand. Access it at www.phocusonlifestyle.org or scan this code with your mobile phone.



We have introduced a **regular 4-page nutrition feature in every issue of Emphasis**, our member magazine, and our monthly e-newsletters now include recommended recipes that take into account the specific needs of people with PH.

Work has begun on the production of a series of **printed publications** addressing the areas you told us you need the most help with, and we will continue to build a library of printed and online resources to support you.



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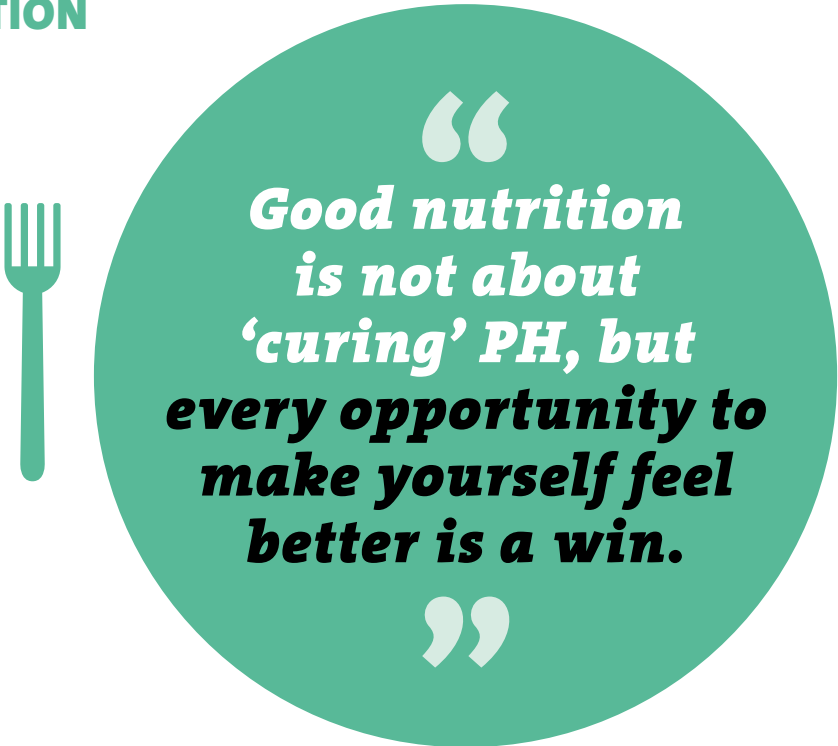
The findings of this survey were presented at the **Pulmonary Vascular Research Institute Global Congress**, reaching PH researchers and scientists from all over the world.



Do you have a question about nutrition?

We now have a dedicated email support service for any queries relating to food or nutrition. Email nutrition@phauk.org and a **Certified Nutritionist** or **Registered Dietician**, experienced in the field of PH, will respond.





“
***Good nutrition
is not about
'curing' PH, but
every opportunity to
make yourself feel
better is a win.***
”

Chermaine Kwant

Registered Dietician with lived experience of PH