

PH Global Patient Survey (PHGPS): The invisible burden of PH

Resources pack

This resource pack has been created to help patient organisations, clinicians, and partners share PVRi's latest PHGPS papers with their communities. It includes ready-to-use resources for three new peer-reviewed papers:

The Pulmonary Hypertension Global Patient Survey: Physical and Psychosocial Impacts on Health-Related Quality of Life

- [Patient email template](#)
- [Social media template](#)
- [One-pager leaflet](#)

The Pulmonary Hypertension Global Patient Survey: Groups 2 and 3

- [Patient email template](#)
- [Social media template](#)
- [One-pager leaflet](#)

The Pulmonary Hypertension Global Patient Survey: Understanding the Invisible Burden of Paediatric Pulmonary Hypertension

- [Patient email template](#)
- [Social media template](#)
- [One-pager leaflet](#)

About the PHGPS

Launched in October 2023, the PHGPS was created to understand what it is truly like to live with PH worldwide. Phase 1 received responses from nearly 4,000 patients and carers across 90 countries, in 22 languages — making it one of the most comprehensive global surveys of PH patient experience to date.

New insights from the survey have now been published in [Pulmonary Circulation](#), including:

- Katherine Bunclark, Joseph Newman, Hakim Ghani, Shiv Munagala, Eva Otter, et al. (2026) '[The Pulmonary Hypertension Global Patient Survey: Groups 2 and 3](#)'. Pulmonary Circulation, 16(1), e70256
- Katherine Bunclark, Joseph Newman, Hakim Ghani, Shiv Munagala, Eva Otter, et al. (2026) '[The Pulmonary Hypertension Global Patient Survey: Physical and Psychosocial Impacts on Health-Related Quality of Life](#)'. Pulmonary Circulation, 16(1), e70269
- Sadia Quyam, Sarah Drumm, Shiv Mungala, Katherine Bunclark, Gerald Fischer, et al. (2026) '[The Pulmonary Hypertension Global Patient Survey: Understanding the Invisible Burden of Paediatric Pulmonary Hypertension](#)'. Pulmonary Circulation, 16(1), e70264

Available resources

To help you share these new papers with your community, we have created editable flyers in Canva, alongside the email and social media templates below.

- [The PHGPS: Physical & Psychosocial Impacts on Health-Related QoL Flyer](#)
- [The PHGPS: Groups 2 & 3 Flyer](#)
- [The PHGPS: Understanding the Invisible Burden of Paediatric PH](#)

All flyers are fully editable in Canva, allowing you to easily add your logo and tailor them to your organisation. If you're new to Canva, you can watch the video walkthrough to the right for guidance.



Email template to patients – The PHGPS: Physical & Psychosocial Impacts on Health-Related QoL

Subject line: The invisible impact of PH

Hi [Firstname],

PH isn't always visible. But its impact on daily life is real.

New insights from [PVRI's PH Global Patient Survey \(PHGPS\)](#) highlight the lived experience of people with PH worldwide, beyond clinical tests and measurements.

One of the newest papers recently published, [The PHGPS: Physical & Psychosocial Impacts on Health-Related QoL](#), shows:

- 79% live with physical limitations, including 42% experiencing poor sleep quality
- Women of childbearing age experience a significant physical and psychological burden, with 54% of female respondents worrying about pregnancy
- 36% feeling misunderstood, often wanting to discuss emotional symptoms but experiencing a lack of empathy

One participant said, "PH is a hidden thing, no one sees the struggle and no one cares."

If you'd like support talking to your care team about your quality of life, explore [PVRI's How to Empower Yourself & Others series](#). It offers practical guidance on preparing for appointments and advocating for yourself.

All the best,
[Your name & organisation]

Social media template – The PHGPS: Physical & Psychosocial Impacts on Health-Related QoL

The invisible impact of PH.

New insights from  PVRI's PH Global Patient Survey (PHGPS) highlight the lived experience of people with PH worldwide.

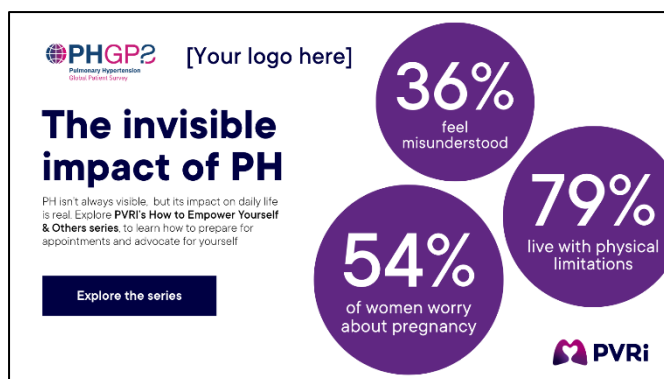
Key insights include:

- 79% live with physical limitations, including 42% experiencing poor sleep quality
- 36% feeling misunderstood, often wanting to discuss emotional symptoms
- 54% of female respondents worrying about pregnancy

"PH is a hidden thing, no one sees the struggle and no one cares." – PHGPS respondent

If you'd like support preparing for conversations with your care team, explore PVRI's How to Empower Yourself & Others series: pvrinstitute.org/phpatients

#PulmonaryHypertension #PHGPS



[Access the editable social media template here.](#)

Email template to patients – The PHGPS: Groups 2 & 3

Subject line: The invisible impact of PH

Hi [Firstname],

The impact of living with PH isn't always visible and this is especially true for Groups 2 and 3 PH.

A new paper from PVRi's PH Global Patient Survey (PHGPS), [The PHGPS: Groups 2 & 3](#), shines a light on the experiences of people living with these forms of PH.

Group 2

- 83% of those in work say PH has affected their work
- 63% struggle with walking short distances or climbing stairs
- 37% experience feelings of restlessness

Group 3

- 88% of those in work say PH has affected their work
- 66% struggle with household chores
- 37% experience feelings of frustration

If you have Group 2 or 3 PH and want to discuss your quality of life with your care team, PVRi's *How to Empower Yourself & Others* series offers guidance on preparing for appointments and advocating for yourself: pvrinstitute.org/phpatients

Kind regards,

[Your name & organisation]

Social media template – The PHGPS: Groups 2 & 3

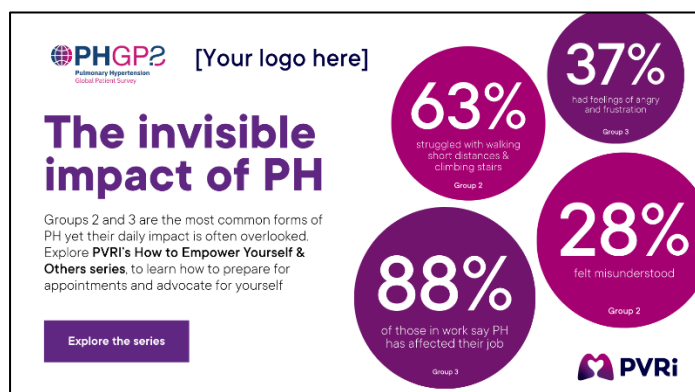
The invisible impact of PH is often overlooked, especially for Groups 2 and 3 PH.

New insights from PVRi's PH Global Patient Survey (PHGPS) shines a light on the daily challenges reported by patients.

- 88% of those in work say PH has affected their job (Group 3)
- 37% experience feelings of restlessness (Group 2)
- 66% struggle with household chores (Group 3)
- 63% struggle with walking short distances or climbing stairs (Group 2)

If you have Group 2 or 3 PH and want to discuss your quality of life with your care team, explore PVRI's How to Empower Yourself & Others series for practical guidance: pvrinstitute.org/phpatients

#PulmonaryHypertension #PHGPS



[Access the editable social media template here.](#)

Email template to patients – The PHGPS: Understanding the Invisible Burden of Paediatric PH

Subject line: The invisible impact of PH

Hi [Firstname],

When a child lives with PH, the impact extends beyond medical appointments.

A new paper from [PVRI's PH Global Patient Survey \(PHGPS\)](#), [The PHGPS: Understanding the Invisible Burden of Paediatric PH](#), highlights the experiences of children living with PH and their families.

- 41% waited more than six months for diagnosis, with only 8% of caregivers having heard of PH
- 40% of caregivers provide constant care, facing significant employment consequences, including leaving work altogether, reduced hours, or career changes
- 35% travel more than two hours for appointments, with 28% receiving no cost reimbursement

"Since I found out, I stopped working to take care of her" – PHGPS Respondent

Having a child with PH brings challenges that aren't always visible. Explore PVRI's How to Empower Yourself & Others series for guidance on financial support and empowering carers and families:

pvrinstitute.org/phpatients

Kind regards,

[Your name & organisation]

Social media template – The PHGPS: Understanding the Invisible Burden of Paediatric PH

The invisible impact of PH.

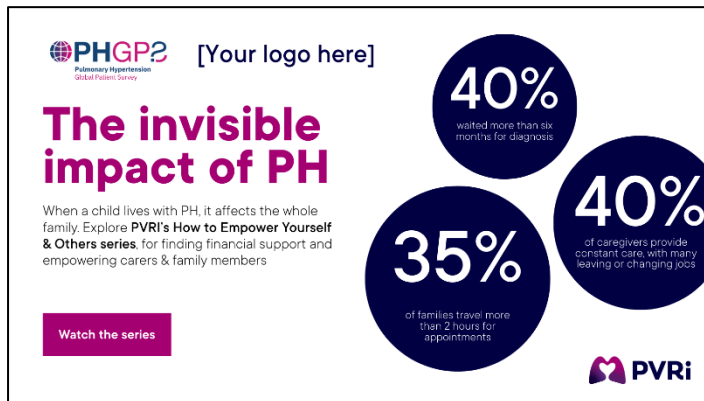
New insights from [PVRI](#)'s PH Global Patient Survey (PHGPS) highlight the lived experiences of children with PH and their families.

- 40% waited more than six months for diagnosis
- 40% of caregivers provide constant care, with many leaving or changing jobs
- 35% of families travel more than two hours for appointments

Having a child with PH brings challenges that aren't always visible.

Explore PVRi's How to Empower Yourself & Others series for guidance on financial support and empowering carers and families: pvrinstitute.org/phpatients

#PulmonaryHypertension #PHGPS



[Access the editable social media template here.](https://pvrinstitute.org/phpatients)