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Understanding patient perspectives on patient engagement in the PAH care journey to improve shared decision-making: a modified Delphi panel

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Background

- Shared decision-making in pulmonary arterial hypertension (PAH) supports disease management choices that reflect both clinical priorities and patient preferences. However, current approaches may overlook broader aspects of patient concerns.
- Gaining a deeper understanding of patient views on engagement is essential to enhance collaborative decision-making and optimize patient-centered care and outcomes for patients.[1]

Objective

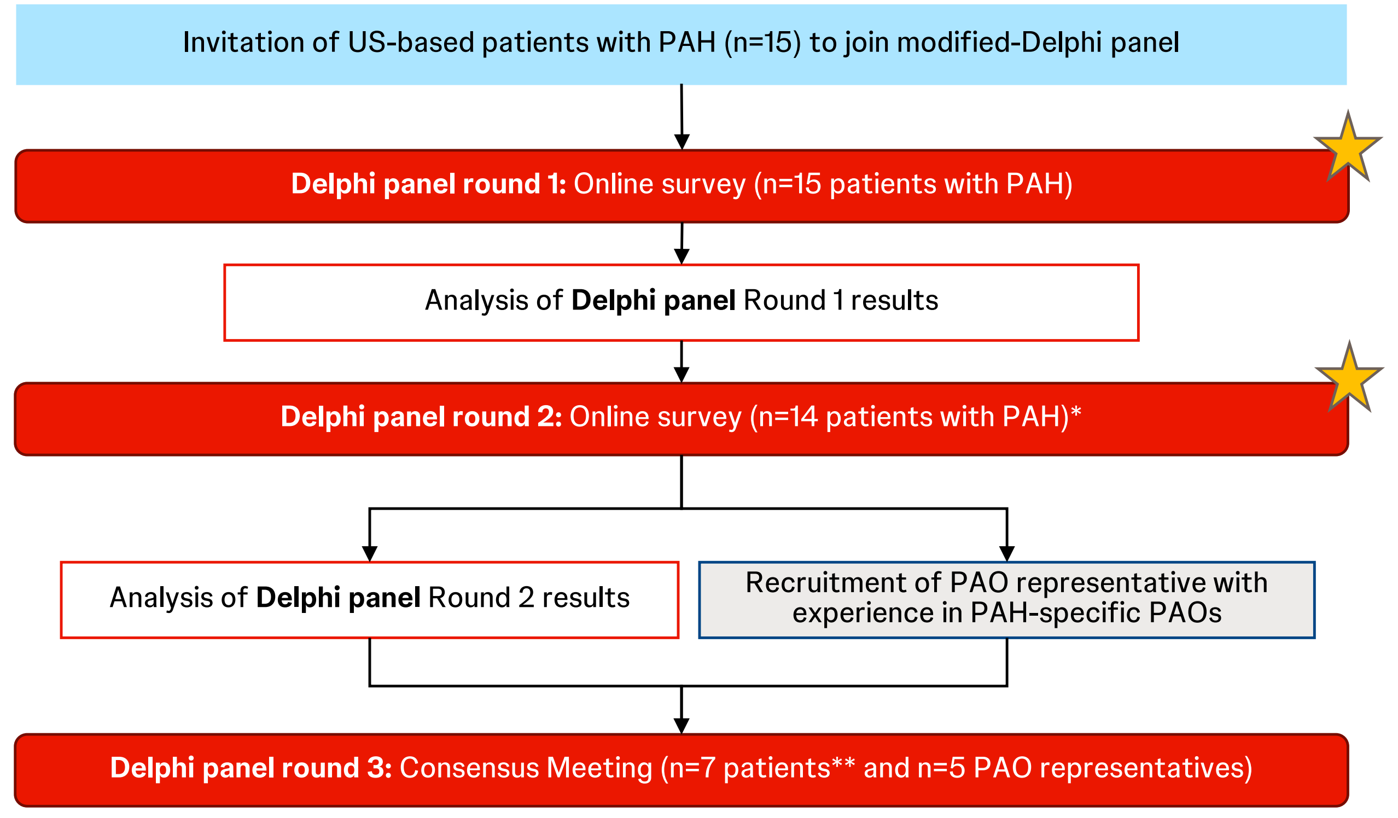
- To understand how the patient perspective on patient engagement differs from that of healthcare providers in PAH and where these views align to optimize shared decision-making.

Methods

Study Design and Data Source

- A double-blinded modified-Delphi panel involving two survey rounds followed by a final consensus meeting was conducted (**Figure 1**). The Delphi methodology allows iterative consensus building on key topics, with consensus predefined as ≥80% agreement on a 9-point Likert scale (7–9 = agreement). Statements that did not reach consensus in the survey rounds were discussed at the consensus meeting.
- Patients with PAH were recruited to participate in the survey rounds and the consensus meeting. The Johnson & Johnson Patient Engagement Research Council (PERC; a collaborative body bringing together patients to ensure medical research is patient-centered) reviewed the questionnaires in focus groups to ensure appropriateness for a patient audience, particularly in terms of language used.
- Patient advocacy organization (PAO) representatives (N=5) were recruited for participation in the consensus meeting to provide a broader PAH patient perspective.

Figure 1. Modified-Delphi panel process



Invitation of US-based patients with PAH (n=15) to join modified-Delphi panel

Delphi panel round 1: Online survey (n=15 patients with PAH) ★

Analysis of **Delphi panel** Round 1 results

Delphi panel round 2: Online survey (n=14 patients with PAH)* ★

Analysis of **Delphi panel** Round 2 results

Recruitment of PAO representative with experience in PAH-specific PAOs

Delphi panel round 3: Consensus Meeting (n=7 patients** and n=5 PAO representatives)

★ = PERC involvement.
*One panelist dropped out due to lack of engagement/response (panelist attrition).
**A reduced number of patients participated in the consensus meeting due to availability in scheduling rather than a selection process, which aligns with current literature on Delphi panel methodology.[2]

Limitations

- Different personalities in the consensus meeting raise the possibility of biasing effects, in which more extroverted personalities may dominate the discussion. However, a moderator was present to guide the discussion and to encourage all members of the panel to contribute, and the chat box function was used throughout to allow panelists another option to participate.
- This study was limited to only United States (US)-based patients and PAO representatives. Thus, results can only be inferred to be applicable to the US, and there may be regional differences even within the US due to varying clinical practices in different states.

Results

Panelist Characteristics

- A total of 15 patients with PAH were recruited to this modified-Delphi panel, their characteristics as recorded via the study screener are summarized in **Table 1**.

Table 1. Patient characteristics

Criteria	Patients (N=15)
Age	
18–24 years	0
25–39 years	2
40–59 years	7
≥60 years	6
Time since PAH diagnosis	
≤1 year	1
>1–2 years	1
>2–4 years	2
>4 years	11
Center at which patients received most of their PAH care (n=14)*	
Comprehensive Care Center	9
Regional Care Center	2
Unsure	3

*Question included in second-round survey; therefore, n=14 as one panelist dropped out after the first round due to lack of engagement/response (panelist attrition).

- Five US-based PAO representatives were recruited based on pre-specified screening criteria to participate in the consensus meeting. PAO representatives held senior roles within their organization and had experience ranging from 1 to 20 years. Two patients who participated in the survey rounds were also PAO representatives and were invited to participate in the consensus meeting as PAO representatives. During the survey rounds, they contributed from the perspective of their individual lived experience.

PAH Care Setting and PAH Healthcare Providers

- Patients discussed that the care received from medical specialists (e.g., Pulmonologist, Cardiologist, Rheumatologist) often exceeds their expectations, due to medical specialists' knowledge and continued dedication to maintaining their medical education.

Patient Relationship with their PAH Healthcare Providers

- Consensus was reached that PAH healthcare providers are supportive and collaborative, with further consensus that PAH healthcare providers are proactive and involve patients in the decision-making process.

> *"I feel like it's my provider and myself against PAH, and I think we have a great relationship."* ***– patient quote from consensus meeting***

- The patients reached consensus that understanding the long-term outcomes of PAH is important to patients, and consensus was also reached that PAH healthcare providers discuss opportunities to amend their treatment plan in the future. However, panelists noted that further considerations around their future would be appreciated in conversations with their providers.

> *"It seems sometimes that the future is missed when we're having those conversations. We talk about how we felt yesterday and how we felt today, but, you know, knowing where a concrete plan would be, would be extremely helpful."* ***– patient quote from consensus meeting***

Shared Decision-Making

- Patients reported being satisfied with their PAH management (i.e., the care that they receive from healthcare providers) received within the last 12 months.
- Patients also expressed trust in their PAH healthcare providers to share comprehensive information for informed decision-making.
- However, patients expressed a need for more proactive guidance on managing treatment-related side effects.

- The panel reached consensus that the following factors are important in the management of PAH as presented in **Figure 2**.

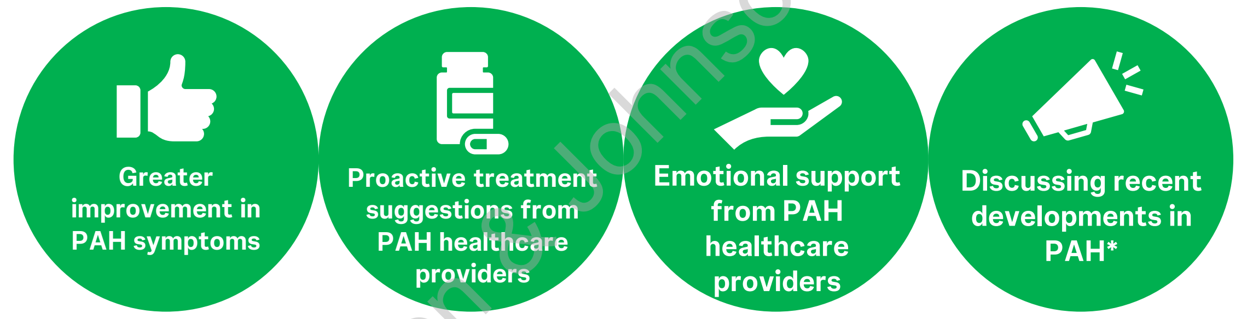
Figure 2. Consensus reached by the panel on important factors in the management of PAH

Important factors in the management of PAH

- ✓ Improving symptoms
- ✓ Maintaining or improving my ability to carry out everyday activities
- ✓ Preventing my PAH from worsening
- ✓ Improving life expectancy
- ✓ Minimizing side effects from PAH medications
- ✓ Gaining a better understanding of my PAH and treatment options
- ✓ Having a collaborative relationship with my healthcare provider

- The positive impact of multidisciplinary approaches to care was highlighted, with patients noting that their PAH healthcare providers often collaborate to ensure the best approach to care. However, patients reached consensus that there are strategies that would improve patient satisfaction with their PAH care and management (**Figure 3**).

Figure 3. Strategies to improve patient satisfaction with PAH care and management that reached consensus



*e.g., clinical trials and other research, new therapies **e.g., rehabilitation programs and support groups.

- Consensus was not reached that caregivers, family members, partners, and friends influence patients' PAH treatment decisions and opinions on their PAH care. While patients appreciate the support of caregivers, family, and friends during visits with their provider or while recovering from procedures, they noted that they prefer discussing PAH with peers who can relate to their experiences.

PAH-Related Information Resources

- Patients reached consensus that they feel confident making decisions about their PAH care based on the PAH-related information sources they use. However, since much of the advice and information received from healthcare providers is largely medication- and disease-focused, patients often extensively search for additional PAH-related information resources (**Figure 4**).

Figure 4. Suggestions to improve PAH-related information resources for patients

Suggestions to improve advice provided in clinical practice:

- ✓ Provide holistic advice as systemic management approach
- ✓ Integrate lifestyle and dietary advice in clinical routine care
- ✓ Provide clear, practical day-to-day management strategies
- ✓ Align online content with clinician guidance
- ✓ Bridge the gap between clinical advice and patient-led information seeking

Suggestions to improve the resources available online:

- ✓ Assurance that information is reviewed for misinformation
- ✓ Include patient-friendly language
- ✓ Avoid or minimise medical jargon and explain necessary technical terms clearly

Financial Burden

- Patients highlighted the significant burden associated with managing the financial aspects of PAH.
- Consensus was reached that manufacturer patient assistance programs and Specialty Pharmacy assistance programs are useful financial support resources for patients with PAH.
- However, insurance coverage has hindered patient ability to access certain PAH therapies or change their PAH therapy, contributing to additional financial burden and emotional distress (**Figure 5**).

Figure 5. Consensus statements on the financial burden of PAH care and management

- ✓ The financial burden of my PAH management impacts my emotional/mental well-being
- ✓ I worry that I will lose access to my PAH medication because of not being able to cover medication costs
- ✓ I worry that I will lose access to my PAH healthcare providers due to the cost associated with my PAH management
- ✓ I feel stressed or anxious about the financial burden of my PAH
- ✓ Insurance delays have made me feel uncertain or powerless in the management of my PAH

- Consensus was reached that PAH healthcare providers advocate for a PAH medication deemed appropriate for their patient's care, despite insurance coverage challenges and do not initiate an alternative medication that was not agreed upon as part of their initial conversation in the event of an insurance delay.

> *"For insurance companies to think that a delay of three days is not a big problem, or however long the delay is, that you can just initiate another medication to hold you over until you can get the actual medication. I don't think that's how it works."* ***– patient quote from consensus meeting***

- Findings indicate that patients would benefit from more proactive financial support from PAH healthcare providers (e.g., earlier provision of copayment support resources) as opposed to advice when they voice a financial concern.

> *"For a few years, I had no idea that those co-payment assistance foundations existed. During one visit to my doctor, I said that I couldn't afford my treatment and that's when I found out. That's information I definitely could have used sooner, but very grateful to have it now."* ***– patient quote from consensus meeting***

Emotional Support

- The panelists reached consensus that their emotional needs have changed during their PAH journeys.

> *"My emotional needs have definitely changed during my journey. It's a lot to handle, both physically and mentally."* ***– patient quote from consensus meeting***

- Patients frequently discussed the lack of emotional support within their PAH care and management, and the impact that PAH has on their mental wellbeing.

> *"I have had to seek mental health resources on my own and that can be very tricky on top of the management of [PAH]."* ***– patient quote from consensus meeting***

> *"I am asked to fill out a brief survey about my mental health, and I feel like that information goes nowhere. I am not then offered any kind of services or any kind of support…and then it's not spoken about [during] the appointment."* ***– patient quote from consensus meeting***

Opportunities to support patient engagement

- ✓ Enhanced education for caregivers, family, and friends to facilitate a greater level of emotional support within personal networks
- ✓ Proactive sharing of information regarding holistic management of PAH (e.g., nutrition), symptom management, and long-term care considerations, with actionable advice for making these changes in day-to-day life
- ✓ Proactive provision of financial support and advice from PAH healthcare providers
- ✓ Improved education for insurance providers on PAH and the associated care pathway
- ✓ Greater provision of emotional support from PAH healthcare providers

Conclusions

- ✓ The findings of this modified-Delphi panel provide insight into patient perspectives on engagement in the PAH care journey, highlighting opportunities to enhance care and support patient-centered approaches.
- ✓ Overall, patients reported positive experiences with their care, emphasizing the importance of shared decision-making; however, they also identified opportunities to further improve care, in particular related to financial and emotional support.

Disclosures

DS reports consultancy fees from Johnson & Johnson. LR has received honoraria for speaking and consultant services from United Therapeutics, Johnson & Johnson, and Merck, and advisory board compensation from United Therapeutics, Johnson & Johnson, and Liquidia. DL, GGR, FOY are employees of Johnson & Johnson. CO, DB, and HS are employees of Adelphi Values PROVE, which was contracted by Johnson & Johnson to conduct this study. PW is an employee of Evidera. LM-G reports receiving fees for research and consulting roles from Johnson & Johnson, Gossamer Bio, Merck, and Bayer; and fees for research, consulting, and advisory board roles from United Therapeutics.

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All consensus statements included in this poster represent consensus in agreement unless stated otherwise.
PAH: pulmonary arterial hypertension; PAO: patient advocacy organization; PERC: Patient Engagement Research Council; US: United States.

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