

PHenomenal Hope 2024

Knowledge, Research & Advocacy in PH

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Knowledge, Research & Advocacy in PH

Expert consensus on patient engagement strategies and shared decision-making to improve patient outcomes in pulmonary arterial hypertension

John J. Ryan

MD, MB, BCh, BAO

University of Utah, Salt Lake City, Utah, USA



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Authors

John J. Ryan¹, Sandra Lombardi², Rajan Saggar³, Melisa Wilson⁴, Christina Benninger⁵, Jenny Lam⁵, Gurinderpal Doad⁵, Michelle Cho⁵, Medi Stone⁶, Daisy Bridge⁶, Richard Perry⁶, Ashley Enstone⁶, Holly Smith⁶, Lisa Perrett⁶, Michelle Han⁵

¹University of Utah, Salt Lake City, Utah, USA.

²University of California San Diego Medical Center, San Diego, California, USA.

³University of California, Los Angeles, California, USA.

⁴Advent Health Orlando, Orlando, Florida, USA.

⁵Actelion Pharmaceuticals US, Inc., a Johnson & Johnson Company, Titusville, New Jersey, USA.

⁶Adelphi Values PROVE, Bollington, Cheshire, UK.

Speaker Disclosures

- JR has served as research, advisor, and speaker for Johnson & Johnson, Kiniksa Pharmaceuticals, Liquidia, Merck, and United Therapeutics.

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Background

- Pulmonary arterial hypertension (PAH) remains a disease with a significant impact on the clinical, psychological, social, and emotional functioning of patients requiring a multidisciplinary approach.¹⁻³
- Educational initiatives, shared decision-making, and timely access to care empowers patients to be more engaged in managing their disease.¹ Such strategies may help patients improve adherence to therapy, especially when starting or escalating treatment, achieve and maintain a low-risk status, and improve overall survival.⁴⁻⁸
- However, there still exists a gap for best practices and strategies to improve patient engagement and promote shared-decision making in PAH.

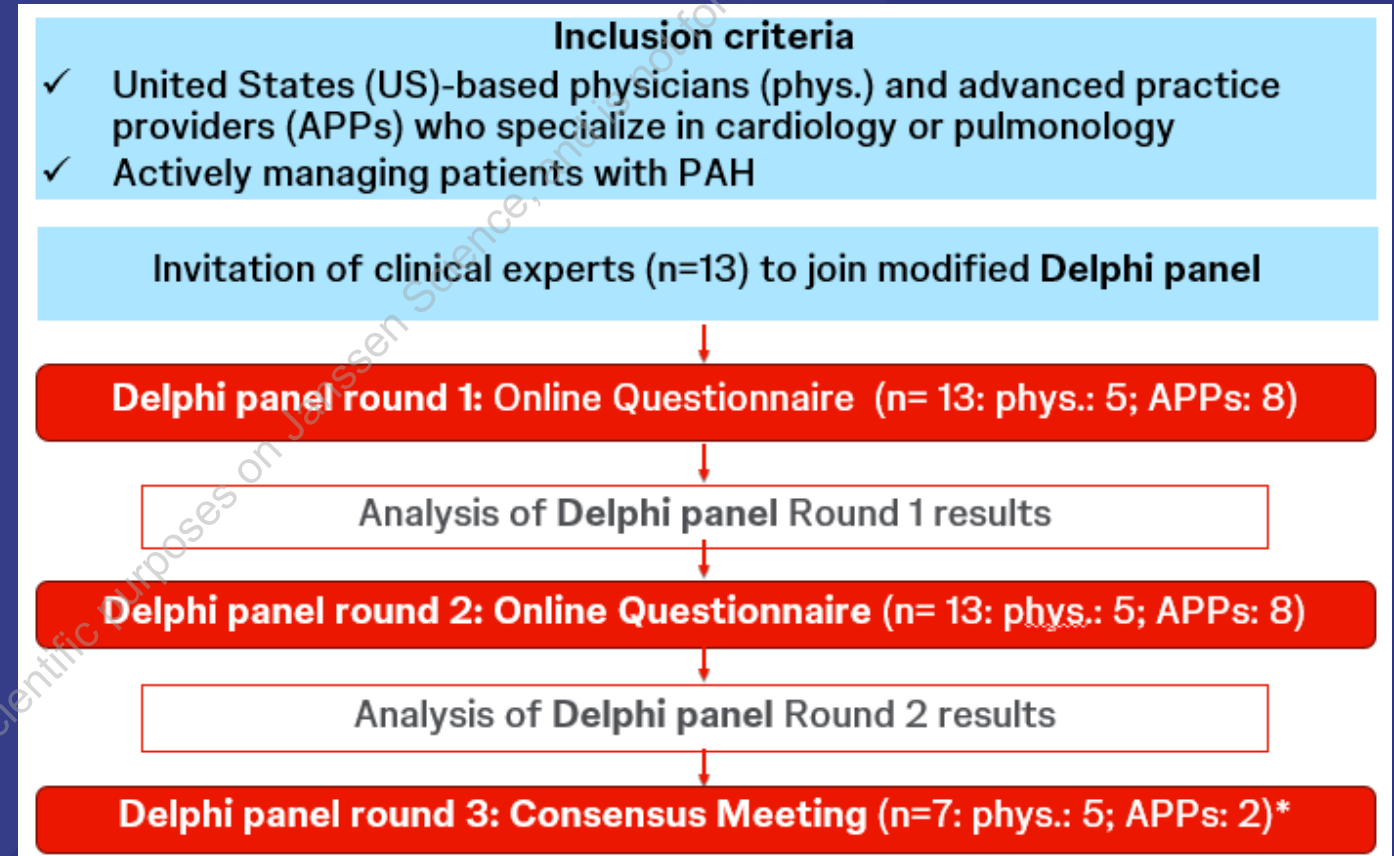
Objective: To collate, clarify, and develop a consensus of expert clinical opinion on strategies for patient engagement and shared decision-making in treating patients with PAH.

5 1. McGoon MD, et al. *Eur Respir J*. 2019;53(1). 2. Humbert M, et al. *Eur Heart J*. 2022;43(38):3618-3731. 3. Gin-Sing W. *Nursing Standard*. 2010;24(38). 4. Wilson M, et al. *Pulm Circ*. 2022;12(3):e12106. 5. Wilson M, et al. *Pulm Circ*. 2022;12(1):e12003. 6. Lombardi S, et al. *Respir Med*. 2018;143:139-146. 7. Kingman M, et al. *Pulm Circ*. 2017;7(3):598-608. 8. Brewer J, et al. *Pulm Circ*. 2021;11(2):20458940211015813.

Methods

- A nine-point Likert scale (from 1 [strongly disagree] to 9 [strongly agree]) was used to rate consensus.
- Panelist characteristics:
 - Accredited PH centers – 2
 - Centers of comprehensive care – 4
 - Academic medical centers – 2
 - Community hospital – 4
 - PHA accredited regional clinical programs- 1

Modified Delphi panel process



*The consensus meeting was scheduled based on panelist availabilities.

PAH=pulmonary arterial hypertension; PH=pulmonary hypertension; PHA=Pulmonary Hypertension Association.

Results



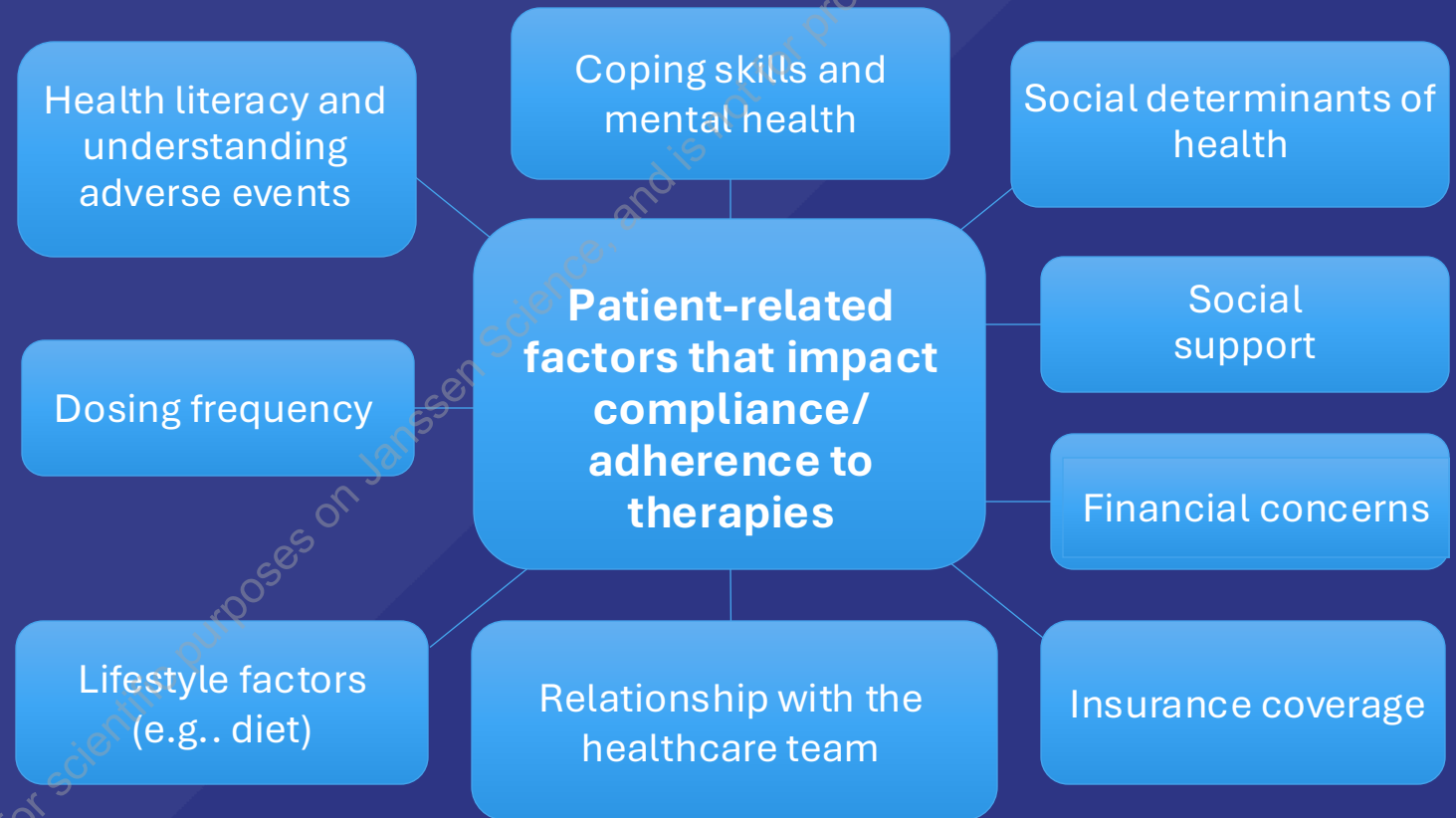
Definition of clinical shared decision-making

Collaboration of the patient and healthcare providers (HCPs) during the discussion of their treatment plan so that the care plan aligns with the patient's goals, values, and preferences

Expert panelists agreed that SDM is very necessary in the management of PAH

Results

- Consensus was reached - compliance is a useful indicator of patient engagement; however, there are acknowledged challenges



Results

Factors which frustrate patients in their patient journey

Early in the PAH journey	Later in the PAH journey
Side effects of medication	Oxygen therapy
	Continued clinical decline/ lack of response to therapy
Overwhelming diagnosis	Medication adverse reactions/ side effects
	Quality of life
	Life expectancy
Throughout the PAH journey	
Financial burden and medical access challenges	
Symptom severity	

Results

What defines an engaged patient and provider?

Engaged Patient

Actively participates in clinical SDM by asking questions, giving feedback, and following up routinely to better understand the disease processes and management of PAH.

Engaged HCP

Acts as a patient advocate, tailoring resources to individuals based on circumstance/background, and involving both the patient and multidisciplinary team in SDM.

Results

Practices to improve patient engagement in PAH management



Patient access to additional specialists e.g., mental health services



Explain important information and their implications in a simple, patient friendly manner



More frequent touchpoints or longer appointment duration with patients



Encourage accountability for patients in their own care



Easily accessible tracker



Involving caregivers and meetings with family



PHA website resources



Allow patient portal messaging with patients via electronic medical records for easier access to nurses



Availability of non-English language versions of patient information



Enable patient access to their information (lab test results; tools)

Results

Important considerations for discussing therapy escalation

Understanding the patient's needs and goals:



Patient lifestyle

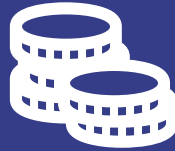


Treatment goals of the patient



Social support

Understanding the patient's financial situation:



Therapy affordability



Insurance coverage

Providing guidance to patients:



Ensuring comfort in using devices for therapy



Ensuring understanding of therapy options

Results

Factors impacting successful shared decision making and/or disease management in PAH

Factor

- | | |
|---|---|
| ✓ Patient values and goals are incorporated into the treatment plan | ✓ Encouraging participation in research |
| ✓ Trust between HCP and patient | ✓ Discussing current therapy, recommendations, goals and values |
| ✓ Patient education | ✓ An experienced care team |
| ✓ Patients feel like they have some control over the treatment plan | ✓ Providing a clear action plan |

Panelists also felt the following were important but depend on the patient:

- | | |
|---|-------------------------------------|
| - Use of appropriate educational material | - Patient-to-patient (peer-to-peer) |
| - Regular multi-disciplinary meetings | - Patient support groups |

Conclusions

- ✓ The panel agreed on the importance of SDM and patient engagement in treating patients with PAH.
- ✓ An engaged patient actively participates in clinical SDM by asking questions and giving feedback.
- ✓ An engaged HCP acts as a patient advocate, tailors resources to individuals and their circumstances, and involves both the patient and the multidisciplinary team.
- ✓ Practices to improve patient engagement include involving caregivers and providing health information in simple, patient-friendly language, preferably in the patient's native language.
- ✓ Factors that may impact patient engagement include health literacy, social and mental health support.
- ✓ The identified areas of improvement can be used to ensure more patients, and caregivers, are involved in the management of PAH to advocate for their goals and preferences.

HCP=healthcare provider; PAH=pulmonary arterial hypertension; SDM=shared decision making.

Additional Disclosures

- SL has served as a consultant, speaker's bureau participant, and advisory board participant for Johnson & Johnson and Bayer Corporation.
- RS has served as an advisor or consultant for United Therapeutics, Gossamer Bio, and J&J Innovative Medicine.
- MW has served as a speaker for United Therapeutics, Bayer, Janssen and consultant for Merck, Janssen, Bayer, United Therapeutics, Gossamer Bio, and Liquidia.
- MH, MC, GD, JL, and CB are employees of Actelion Pharmaceuticals US, Inc.
- DB, MS, AE, RP, HS and LP are employees of Adelphi Values PROVE, who were contracted by J&J Innovative Medicines to conduct this research.

Thank you!

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