

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

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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.

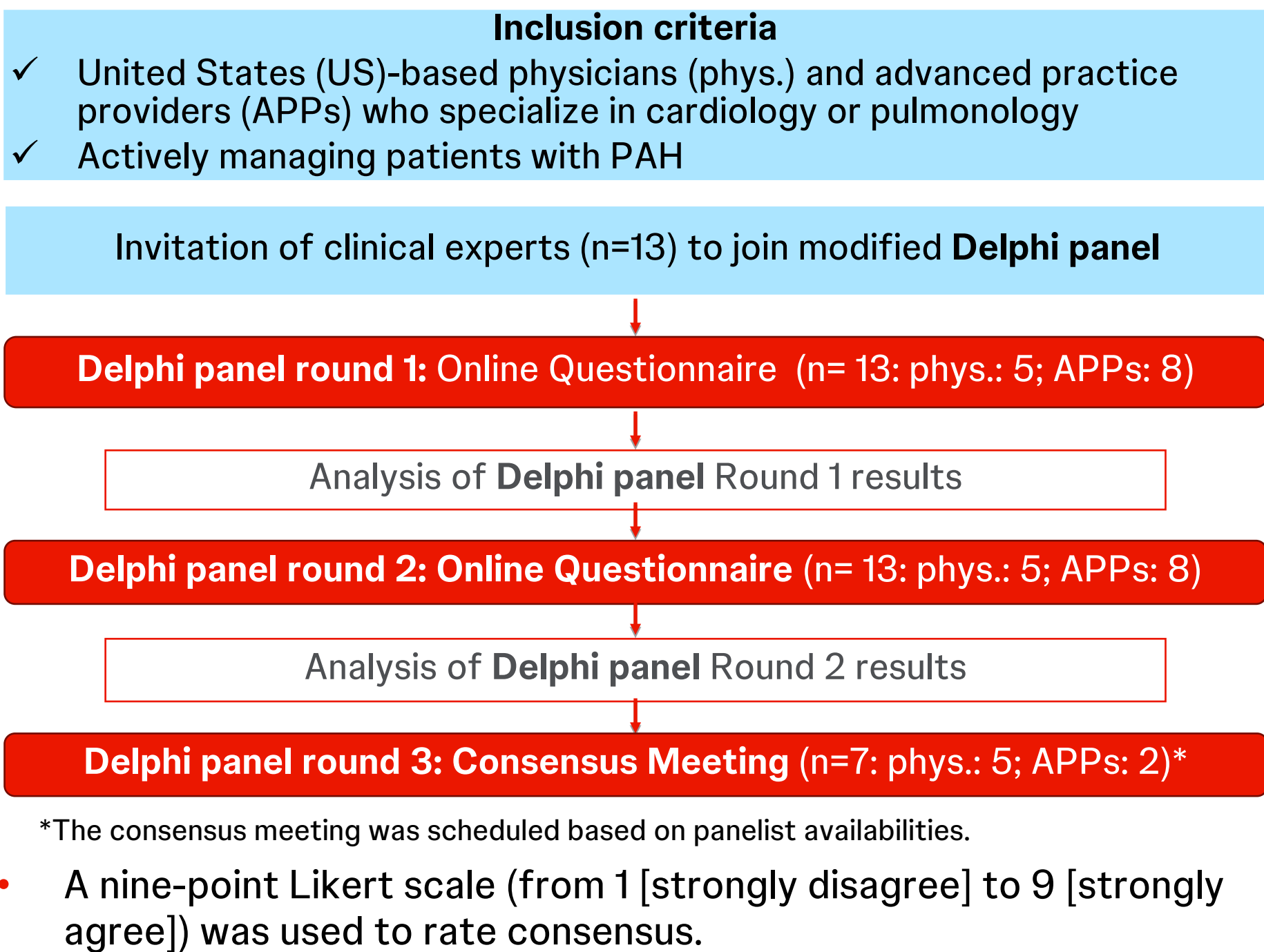
Objective

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

Methods

- A modified Delphi panel involving two survey rounds followed by a final consensus meeting was conducted with clinical experts.

FIGURE 1: Modified Delphi panel process



Results

Panelist characteristics

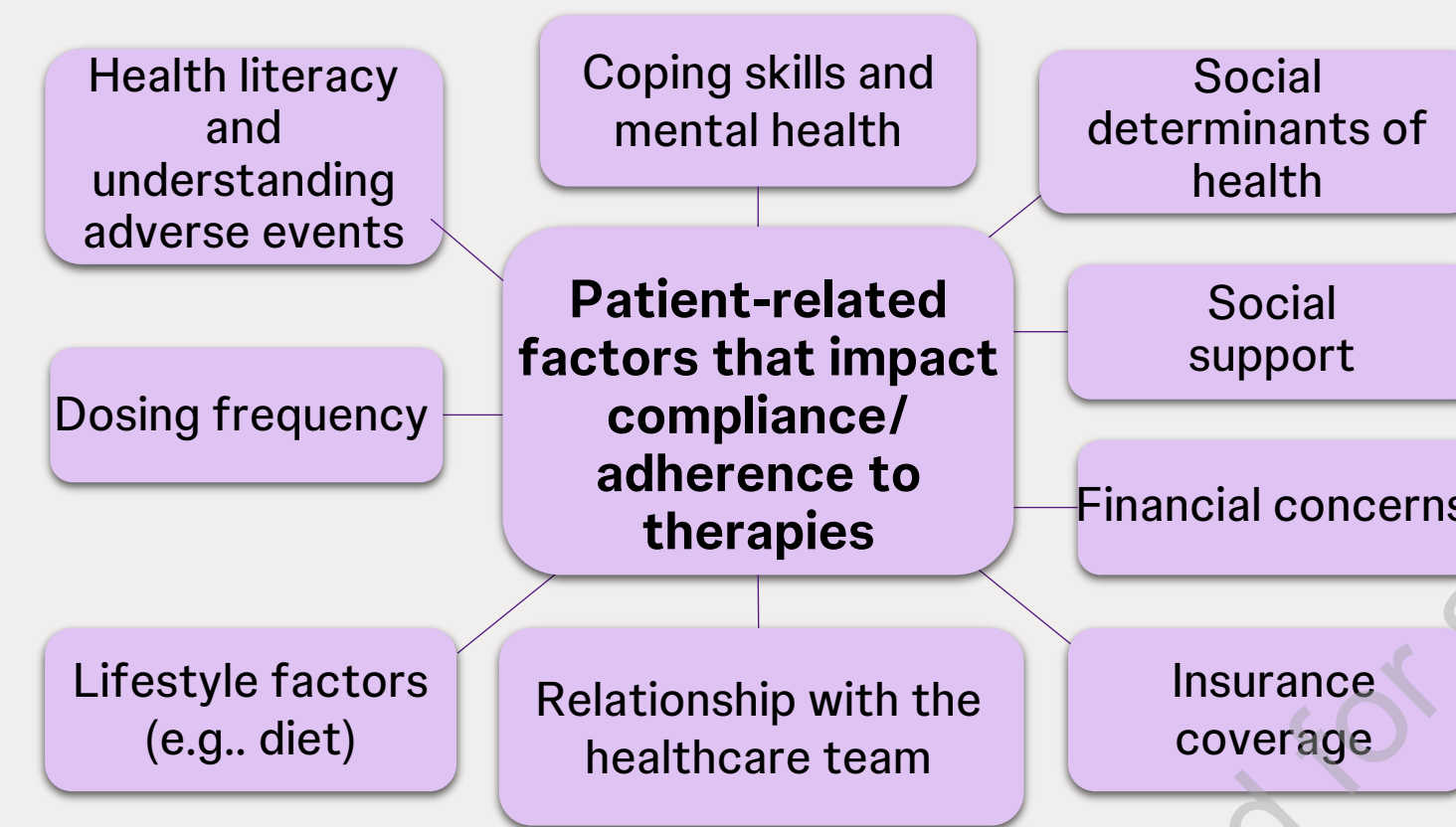
- Panelists practiced in accredited pulmonary hypertension centers (n=2), centers of comprehensive care (n=4), academic medical centers (n=2), community hospital (n=4) and PHA accredited regional clinical programs (n=1).

Defining shared decision-making

- Clinical shared decision-making (SDM) was defined as **the 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.

Challenges of managing patients with PAH

- Consensus was reached that compliance with medication therapy is a useful indicator of patient engagement. However, challenges, such as disease complexity, financial aid access, therapy burden, time limitations, and patient social support, may affect the patient's ability to adhere to therapy.



Factors which frustrate patients in their PAH 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 Medication adverse reactions/ side effects
Overwhelming diagnosis	Quality of life Life expectancy
Throughout the PAH journey	
Financial burden and medical access challenges	
Symptom severity	

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Conclusions and Key Takeaways

Key takeaway

PAH is a difficult disease to manage for both patients and HCPs. There are many different strategies that can be practiced to empower patients to be more engaged in their care.

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.

Disclosures

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

Pulmonary Arterial Hypertension



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