Patient perspectives on engagement and shared decision-making in pulmonary arterial hypertension: A modified Delphi study

Denise Sese[1], Lori Reed[2], Michelle Cho[3], Ankita Adhia[3], Christina Benninger[3], Roland Massaad[3], Medi Stone[4], Daisy Bridge[4], Ashley Enstone[4], Holly Smith[4], Lana Melendres-Groves[5]

[1]The Medical University of South Carolina, Charleston, SC, USA; [2]Piedmont Healthcare, Atlanta, GA, USA; [3]Johnson & Johnson, Titusville, NJ, USA; [4]Adelphi Values PROVE, Bollington, Cheshire, UK; [5]University of New Mexico, Albuquerque, NM, USA

Background

- Pulmonary arterial hypertension (PAH) is a progressive disease that affects patients' physical, psychological, social, and emotional wellbeing[1]
- Shared decision-making is a collaborative process where patients are included to make treatment decisions with their healthcare providers (HCPs)[2]
- Shared decision-making can empower patients to actively participate in the management of their disease, potentially improving treatment adherence, attainment of low-risk status, and survival[3–7]

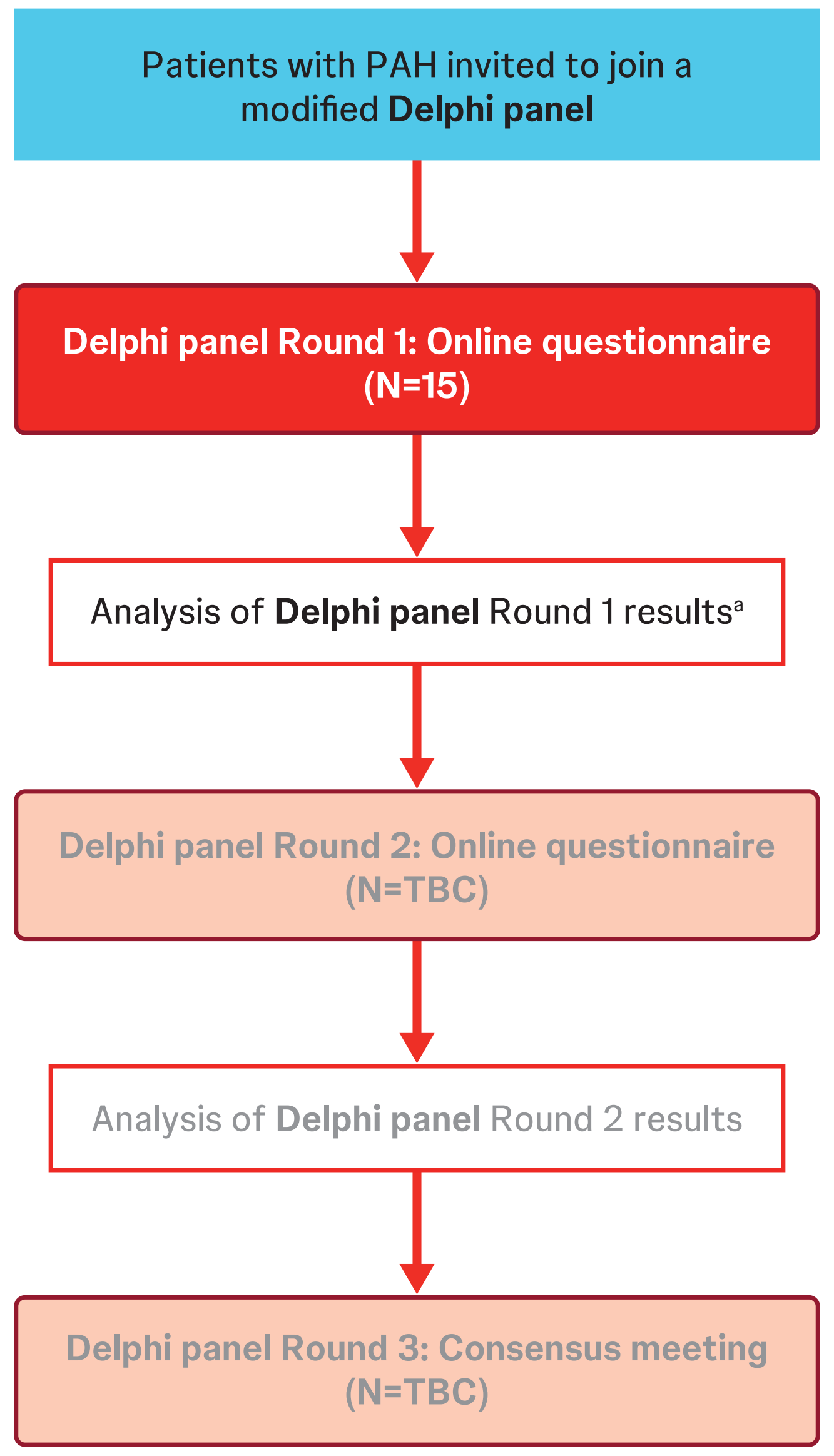
Objective

- Explore patient perspectives on engagement, defined as the active involvement of patients in their care, to inform and optimize shared decision-making practices

Methods

- Patients with PAH in the United States were recruited to a modified Delphi panel,[8] which includes two rounds of online questionnaires and a consensus meeting
- Consensus was defined as ≥80% agreement on points 7–9 of a 9-point Likert scale
- Here, we report results from Round 1 (**Figure 1**)

FIGURE 1: Modified Delphi panel process



Patients with PAH invited to join a modified **Delphi panel**

Delphi panel Round 1: Online questionnaire (N=15)

Analysis of **Delphi panel** Round 1 results[a]

Delphi panel Round 2: Online questionnaire (N=TBC)

Analysis of **Delphi panel** Round 2 results

Delphi panel Round 3: Consensus meeting (N=TBC)

[a]Current stage.

PAH, pulmonary arterial hypertension; **TBC**, to be confirmed.

Results

Participant characteristics

- In total, 15 patients with PAH participated in Round 1 of the Delphi panel
- Two-thirds of participants (n=10) had idiopathic PAH, and over half (n=8) had been diagnosed more than 6 years previously
- All participants had at least a high school education, the most common salary range was US$25,000–$49,999 per annum (n=4), and most participants were not working (n=4 retired, n=3 on disability, and n=2 not looking for work) (**Table 1**)

TABLE 1: Participant characteristics

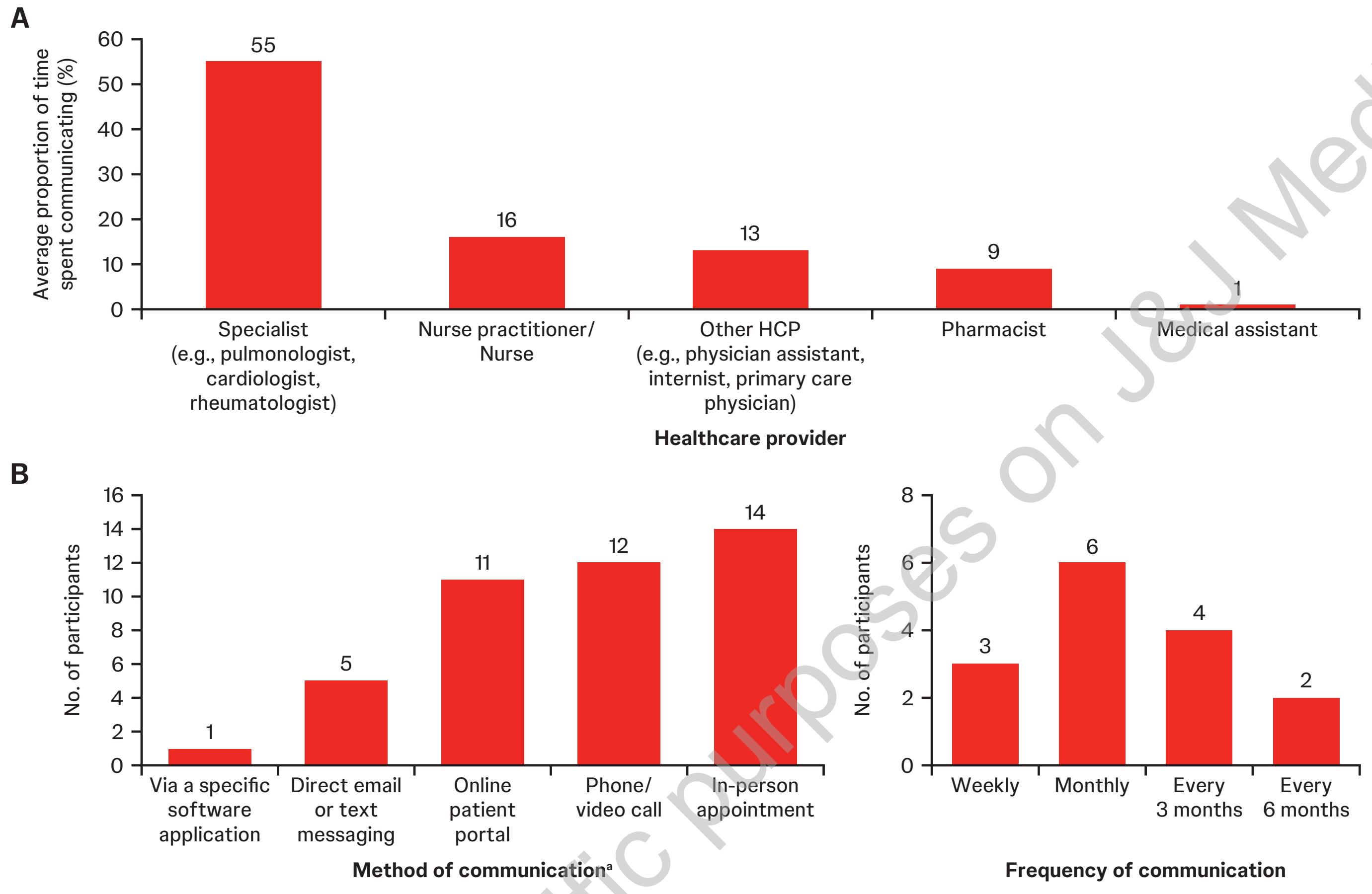
Characteristic	Participants (N=15)
US region, n (%)	
Northeast	2 (13)
Midwest	3 (20)
South	7 (47)
West	3 (20)
Level of education, n (%)	
High school or GED	1 (7)
Some college, associate's degree, or technical training	3 (20)
College graduate (bachelor's degree)	7 (47)
Graduate school (master's or doctoral degree)	4 (27)
Work status, n (%)	
Working full time	5 (33)
Retired	4 (27)
On disability and not looking for work	3 (20)
Not working and not looking for work	2 (13)
Working part time	1 (7)
Salary range per annum (USD), n (%)	
$1–$9999	1 (7)
$25,000–$49,999	4 (27)
$50,000–$74,999	2 (13)
$75,000–$99,999	3 (20)
$100,000–$149,999	2 (13)
$150,000 or more	1 (7)
Prefer not to answer	2 (13)
Ethnic background, n (%)	
Not Hispanic or Latino	11 (73)
Hispanic or Latino	2 (13)
Other	2 (13)
Racial background, n (%)	
White	10 (67)
Asian/Asian American	2 (13)
American Indian/Alaskan Native	1 (7)
Black/African American	1 (7)
Prefer not to answer	1 (7)
Time since diagnosis, n (%)	
<6 months ago	1 (7)
2–4 years ago	3 (20)
4–6 years ago	3 (20)
>6 years ago	8 (53)
Type of PAH, n (%)	
Idiopathic	10 (67)
Associated with connective tissue disease	4 (27)
Do not know	1 (7)

GED, general equivalency diploma; **PAH**, pulmonary arterial hypertension; **USD**, US dollars.

Relationships with PAH HCPs

- When interacting with PAH HCPs in the past 12 months, participants spent an average of 55% of their time with a pulmonologist, cardiologist, or rheumatologist (**Figure 2A**)
- The most common method of communication was in-person appointments (n=14), followed by phone/video calls (n=12) and online patient portals (n=11) (**Figure 2B**)
- Two-thirds of participants (n=10) reported that medical information was clearly explained to them by their PAH HCP and that they always understood fully
- The following statements reached consensus agreement:
  - *"My HCP is proactive and involves me in the decision-making process"*
  - *"My HCP is supportive and collaborative"*

FIGURE 2: Average proportion of communication time with HCPs in the past 12 months. (A) Average proportion of time spent with each type of PAH HCP; (B) methods and frequency of communication (N=15)



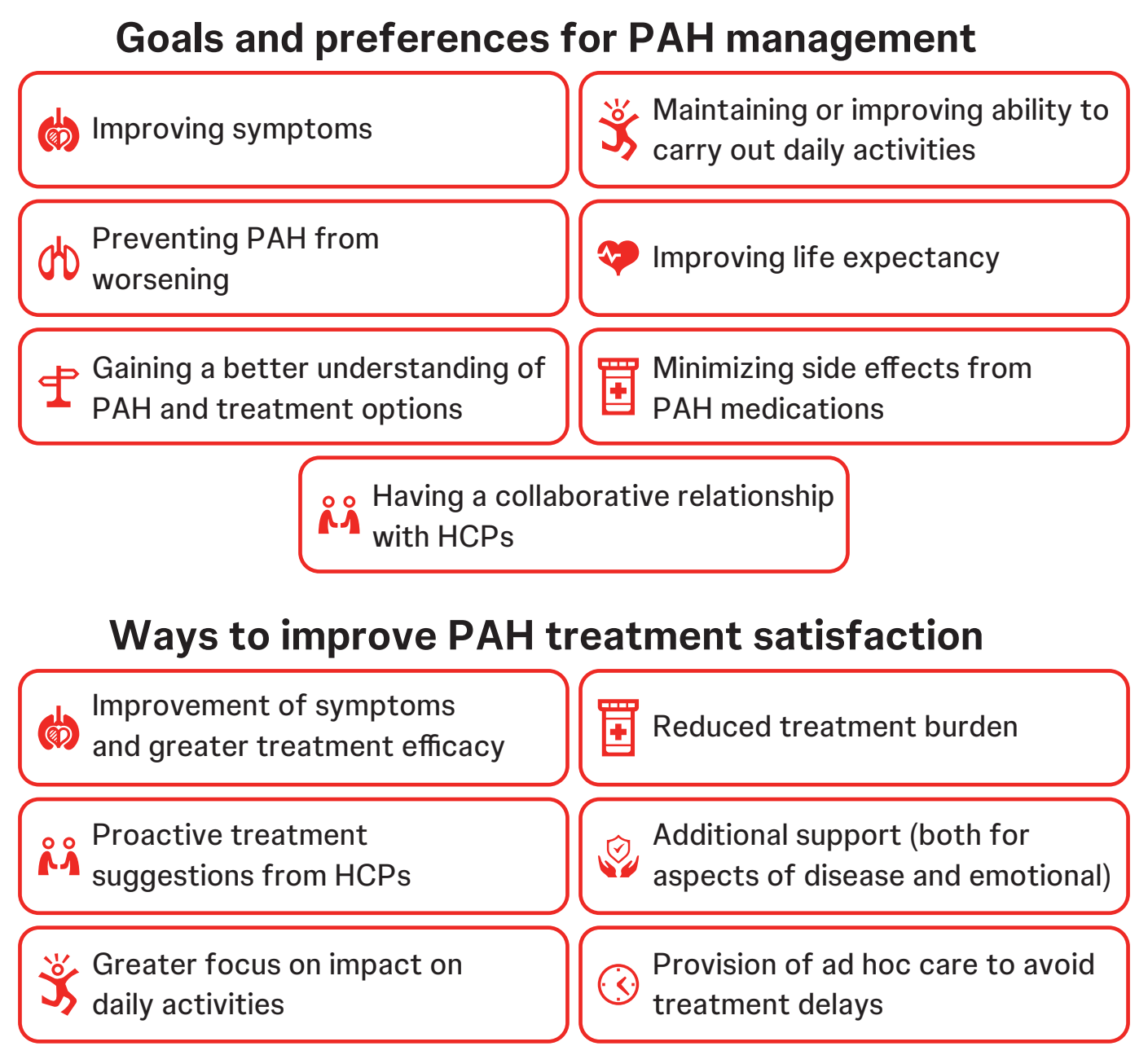
[a]Multiple options possible for method of communication, therefore total >15.

HCP, healthcare provider; **PAH**, pulmonary arterial hypertension.

Shared decision-making

- Most participants (n=13) were aware of shared decision-making as a concept and viewed it as an equal collaboration between HCPs and patients
  - *"To me this means that **the doctor and I collaborate** on the steps to take **to manage my disease. Not one person is unilaterally making the decision alone**"*
- Overall, participants did not reach consensus on whether they would like to be more involved in the decision-making process
- The following statement reached Delphi consensus agreement:
  - *"I am satisfied with the PAH management that I have received within the last 12 months"*
- Seven goals and preferences for PAH management reached consensus agreement (**Figure 3**)

FIGURE 3: Shared decision-making in PAH management



Goals and preferences for PAH management

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

Ways to improve PAH treatment satisfaction

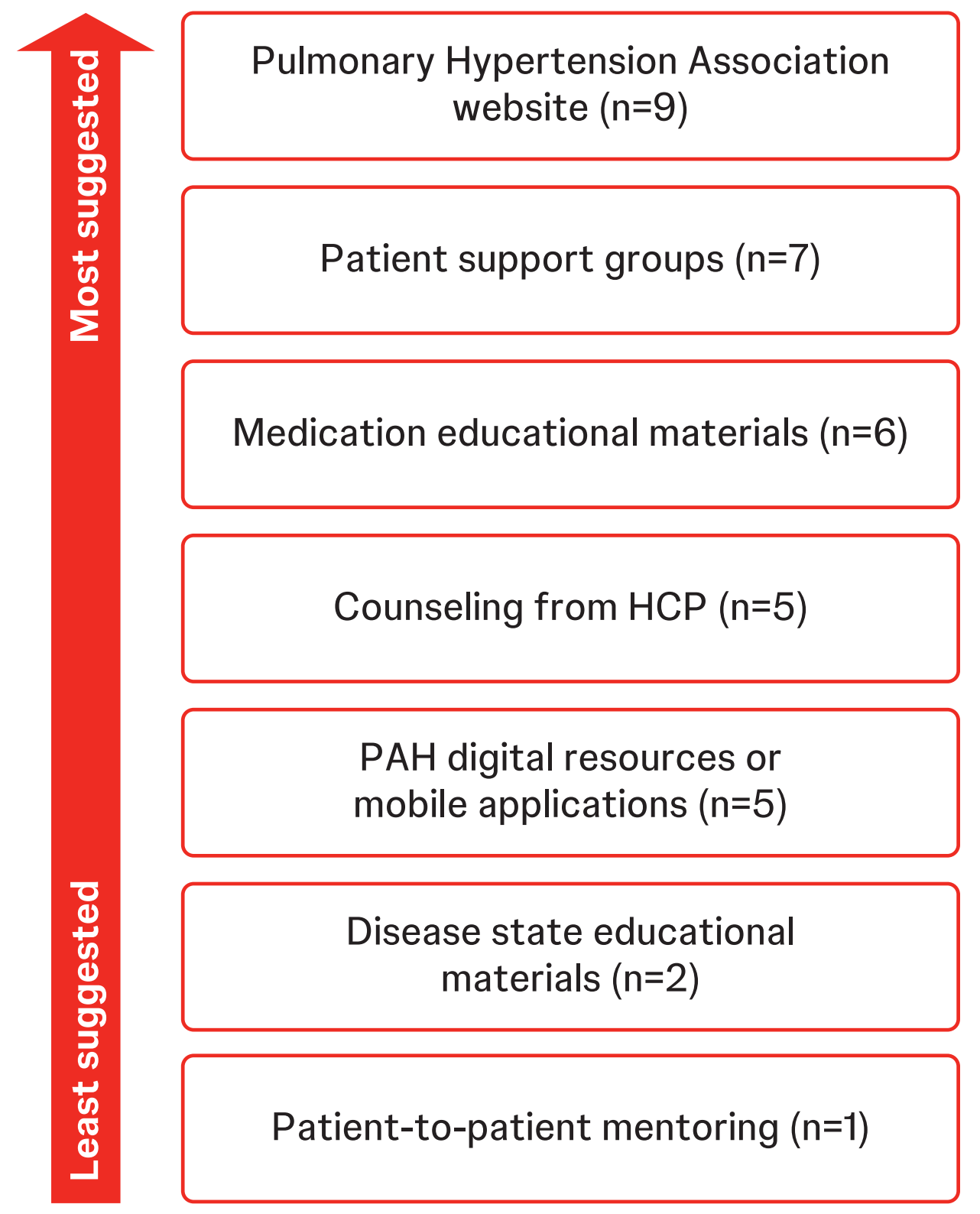
- Improvement of symptoms and greater treatment efficacy
- Reduced treatment burden
- Proactive treatment suggestions from HCPs
- Additional support (both for aspects of disease and emotional)
- Greater focus on impact on daily activities
- Provision of ad hoc care to avoid treatment delays

HCP, healthcare provider; **PAH**, pulmonary arterial hypertension.

PAH-related information sources

- Nearly two-thirds of participants (n=9) reported that their HCPs recommended PAH-related information sources. The most suggested information source was the Pulmonary Hypertension Association website (**Figure 4**). Almost all participants (n=14) said that their HCPs had not discouraged the use of any such sources
- Around half of participants (n=7) utilized or attended patient support groups
- Participants noted that PAH-related information sources lack content on new and emerging therapies, lifestyle changes (e.g., nutrition and exercise), and the day-to-day emotional impact of living with the disease
  - *"These materials are **very clinical … NOT tailored to me or others like me**. I realize this is a **variable disease**, but there are **things we all share** that affect our day-to-day living"*
- No statements in the PAH-related information sources category reached consensus agreement
- Emotional support from HCPs was highlighted as a theme for further exploration in subsequent Delphi panel rounds
  - *"There needs to be a **balance** between clinical and emotional"*

FIGURE 4: Least and most suggested PAH-related information sources recommended by HCPs reported by participants



Pulmonary Hypertension Association website (n=9)

Patient support groups (n=7)

Medication educational materials (n=6)

Counseling from HCP (n=5)

PAH digital resources or mobile applications (n=5)

Disease state educational materials (n=2)

Patient-to-patient mentoring (n=1)

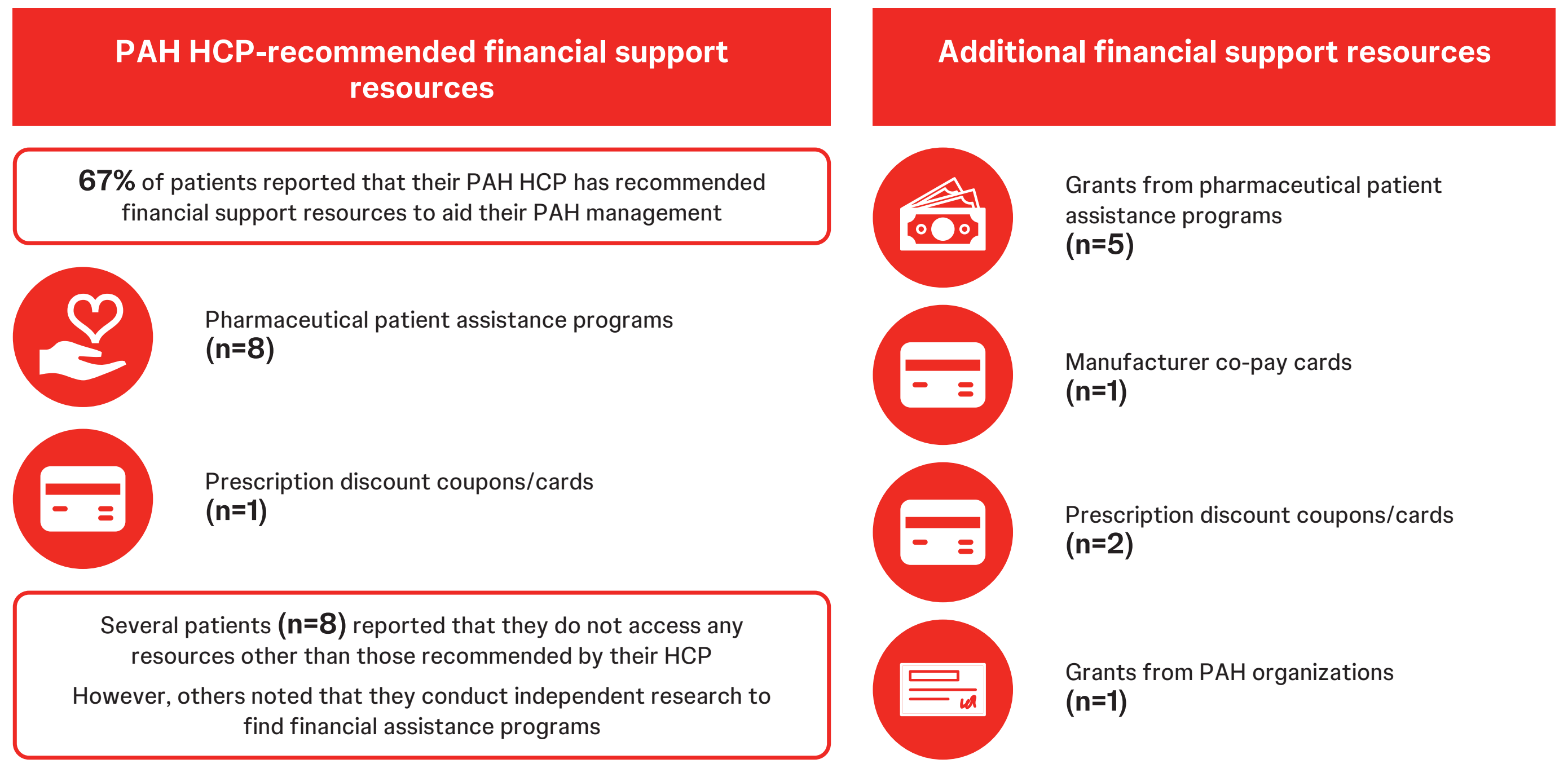
Based on n=9 participants who were recommended any information source by their HCP.

HCP, healthcare provider; **PAH**, pulmonary arterial hypertension.

Financial burden

- Approximately half of participants (n=8) reported that their insurance facilitates access to or changes in PAH therapy, while others (n=6) indicated that coverage can hinder or delay this access
  - *"My initial treatment was delayed by **3 months**, and my current treatment course was delayed **almost 6 months** by insurance red tape"*
- Many participants (n=11) felt that financial considerations impact their PAH management, causing distress and worry
- The following statement reached consensus agreement:
  - *"Manufacturer patient assistance programs and specialty pharmacy assistance programs are very useful financial support resources"*
- HCP-recommended and additional financial support resources used by the participants are shown in **Figure 5**

FIGURE 5: Financial support resources used by participants



PAH HCP-recommended financial support resources

67% of patients reported that their PAH HCP has recommended financial support resources to aid their PAH management

Pharmaceutical patient assistance programs **(n=8)**

Prescription discount coupons/cards **(n=1)**

Several patients **(n=8)** reported that they do not access any resources other than those recommended by their HCP

However, others noted that they conduct independent research to find financial assistance programs

Additional financial support resources

Grants from pharmaceutical patient assistance programs **(n=5)**

Manufacturer co-pay cards **(n=1)**

Prescription discount coupons/cards **(n=2)**

Grants from PAH organizations **(n=1)**

N≠15 because this question was displayed based on responses to previous questions and patients responded in multiple categories.

HCP, healthcare provider; **PAH**, pulmonary arterial hypertension.

Conclusions

- ✓ Individuals with PAH perceive high levels of engagement and support from their HCPs, as reported in this Delphi panel analysis of a relatively experienced patient population
- ✓ Notable barriers for patients with PAH include financial concerns and the limited availability of PAH-related resources that address day-to-day needs
- ✓ The subsequent rounds of the Delphi panel will further clarify consensus priorities and help inform strategies to enhance patient-centered care in PAH
- ✓ Study limitations that may limit generalizability include the small sample size and risk of inherent self-selection bias due to potentially recruiting patients who are more engaged and willing to participate in this type of project than the average patient with PAH, as well as methodological limitations of the Delphi panel process[9]

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Pulmonary Hypertension

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