

# Patient-Centred Care and Quality of Life

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PULMONARY HYPERTENSION  
ASSOCIATION OF CANADA

L'ASSOCIATION D'HYPERTENSION  
PULMONAIRE DU CANADA



UNIVERSITY OF  
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## **Disclosure of Conflict of Interest**

(over the past 2 years)

**Consultancy/Advisory Board:** Actelion, Janssen

**Speaker Honoraria:** Actelion, Janssen

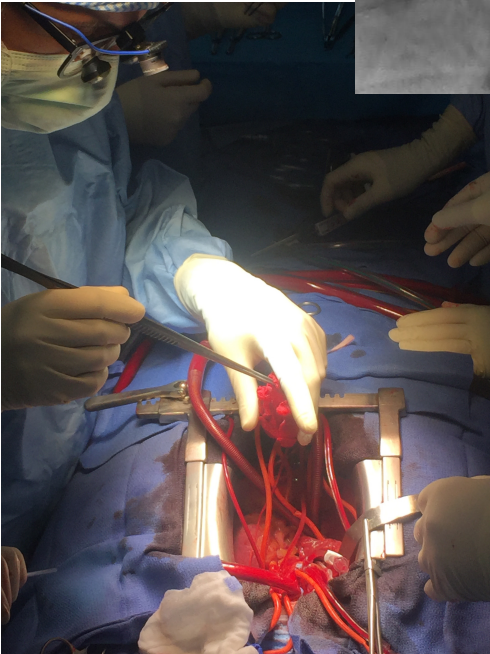
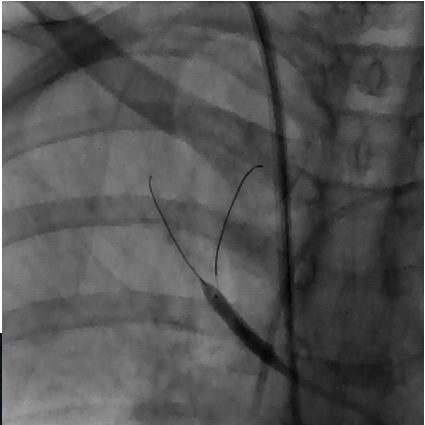
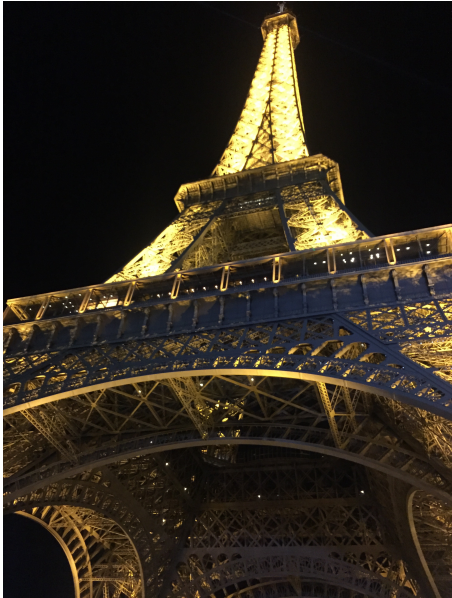
**Speaker's Bureau:** None

**Funded Grants or Clinical Trials:** Janssen, Merck

**Patents on a drug, product or device:** None

**Employee/Role/Other:** None

# About Me





# About Me





## Learning Objectives

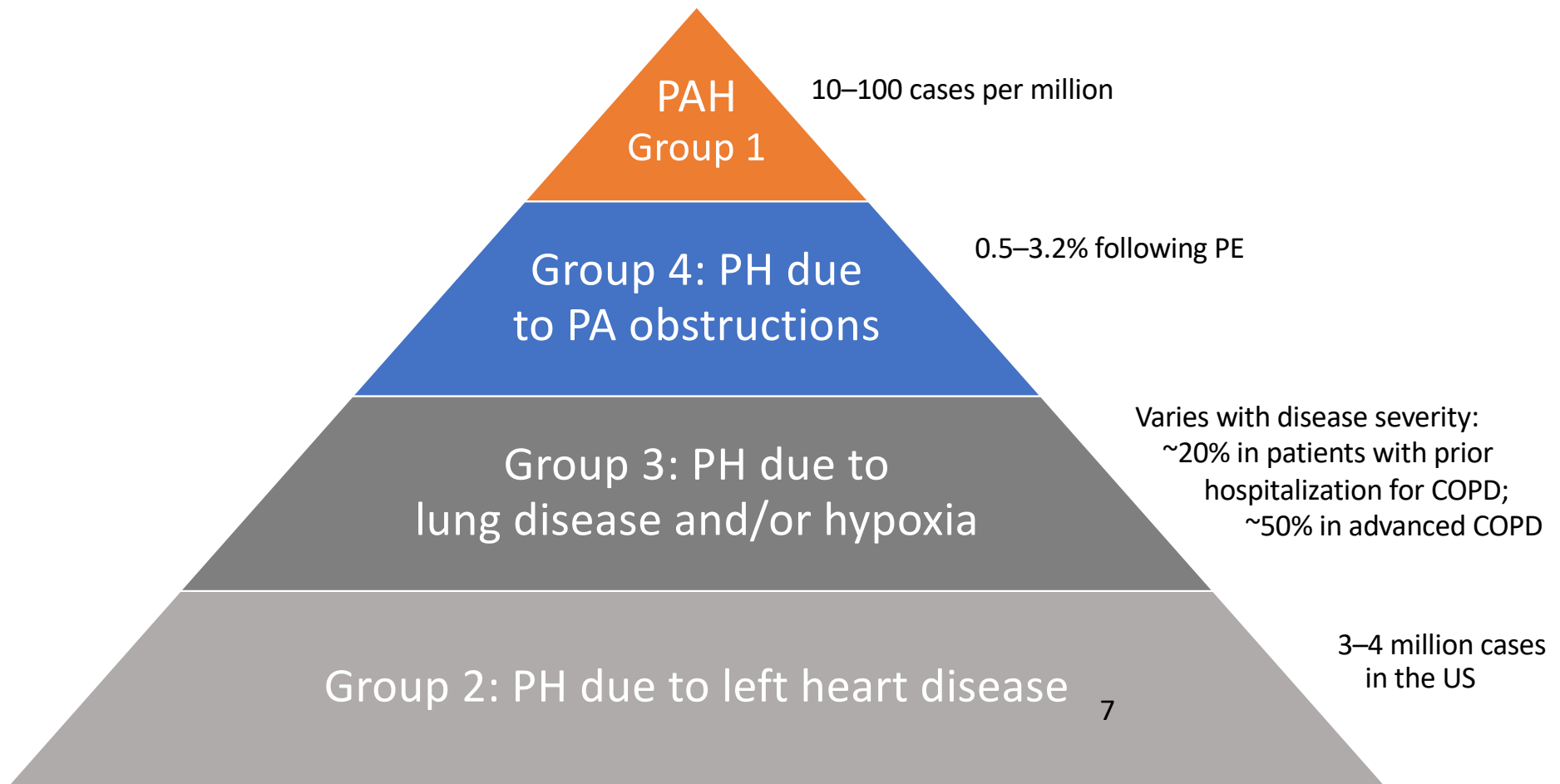
At the end of this session, participants will be able to:

1. Understand the concept of Patient-Centred Care
2. Understand how Quality of Life can be measured in PH
3. Understand why it's important to measure Quality of Life in PH.

## Pulmonary Hypertension – Definitions and Classification

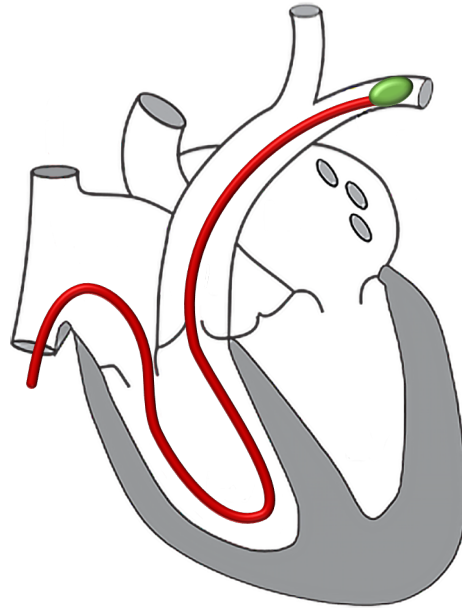
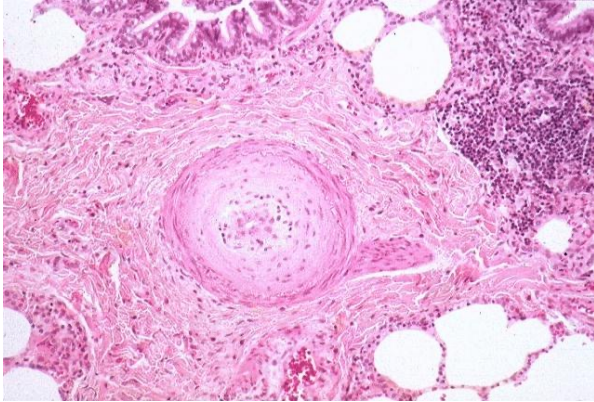
Classification		Causes
Group 1	Pulmonary arterial hypertension (PAH)	Idiopathic, connective tissue diseases, drugs, HIV, congenital heart diseases, etc.
Group 2	Left Heart Disease	Low EF, preserved EF, valve disease
Group 3	Lung Diseases/Chronic Hypoxia	COPD, ILD, Mixed disorders, etc.
Group 4	Pulmonary artery obstructions	CTEPH, PA sarcoma, arteritis, etc.
Group 5	Unclear/Multifactorial Mechanisms	Sarcoidosis, sickle cell, LAM, PLCH, etc.

Simonneau G, et al. Eur Respir J. 2019 Jan 24;53(1):1801913.



COPD: chronic obstructive pulmonary disease; CTEPH: chronic thromboembolic pulmonary hypertension; PA: pulmonary artery; PAH: pulmonary arterial hypertension; PE: pulmonary embolism; PH: pulmonary hypertension; US: United States  
 Adapted from: Choudhary G *et al.* In: Maron BA *et al* (eds). *Pulmonary Hypertension: Basic Science to Clinical Medicine*. Springer International Publishing; Switzerland: 2016.  
 Ende-Verhaar YM *et al.* *Eur Respir J.* 2017; 49(2). pii: 1601792; Hoepfer MM *et al.* *Eur Respir Rev.* 2014; 23(134):450-7.





#### **RECOMMENDATION**

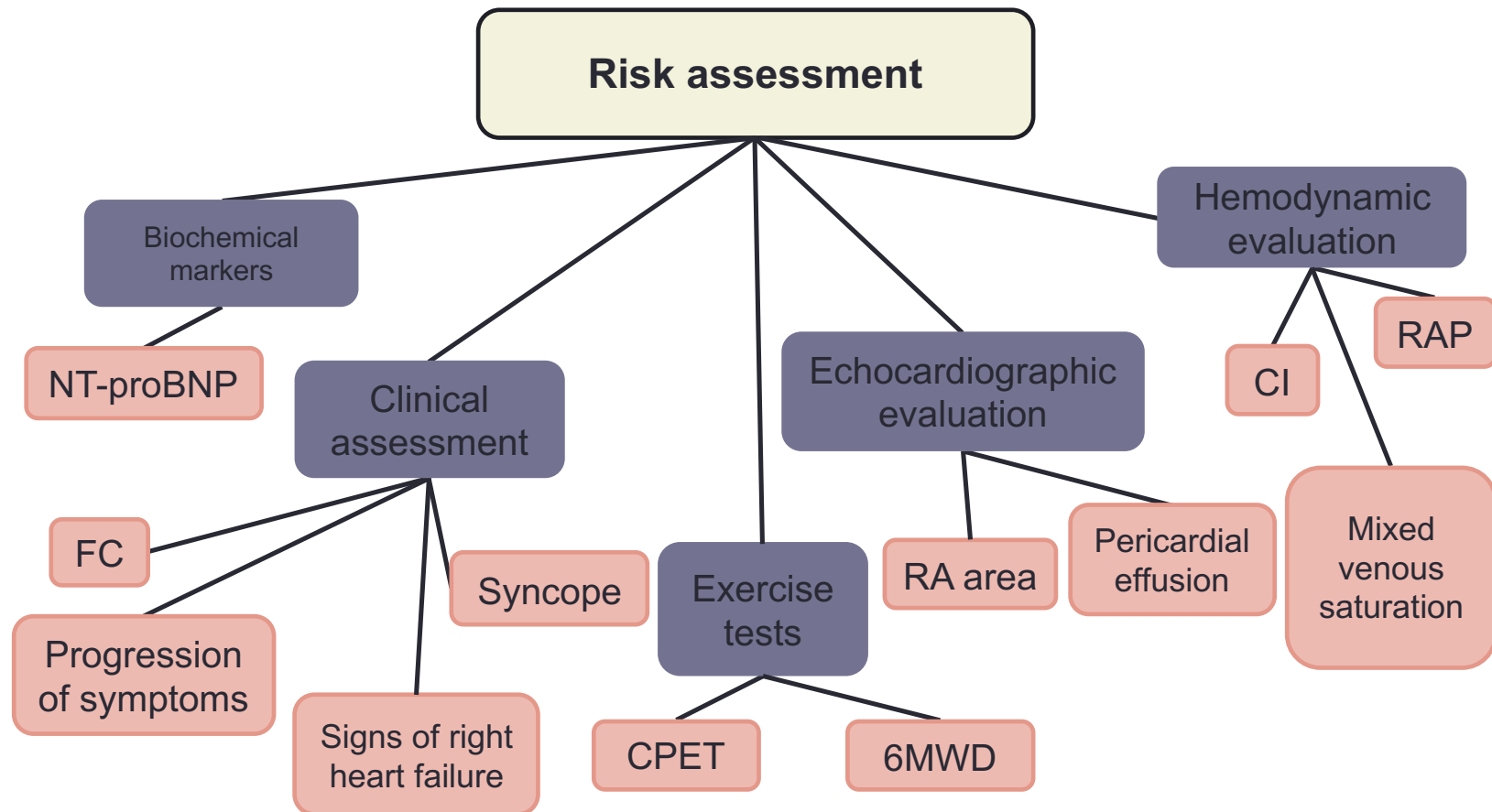
7. We recommend RHC in all patients with suspected PAH or CTEPH to confirm the hemodynamic diagnosis of precapillary PH and to assess the severity of PH (Strong Recommendation, Moderate-Quality Evidence).
8. We recommend RHC in PH patients be performed only in centres with technical expertise and experience to accurately assess cardiopulmonary hemodynamics and to diagnose and appropriately classify the cause of PH (Strong Recommendation, Low-Quality Evidence).

Hirani N, et al. Can J Cardiol. 2020 Jul;36(7):977-992.

# Diagnosis of PAH

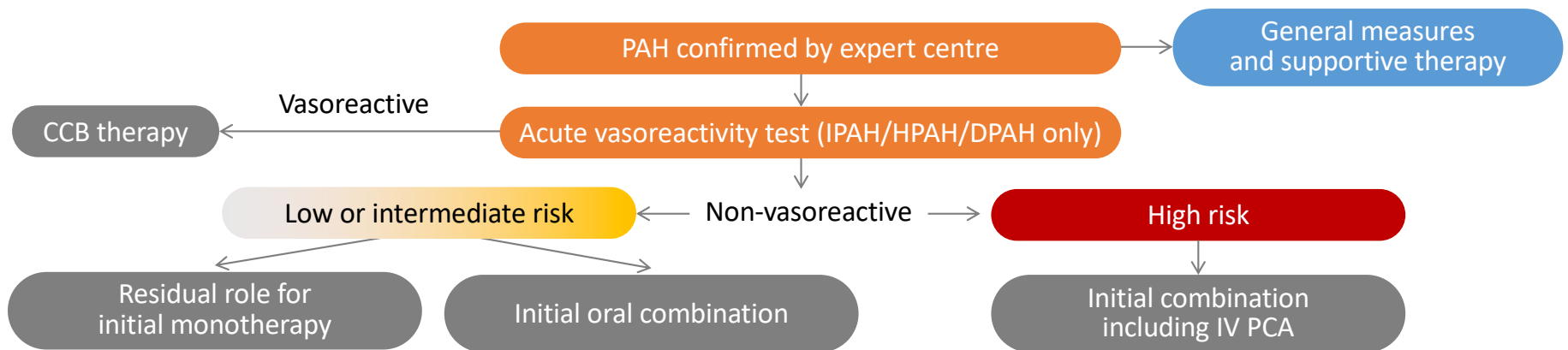
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## How Do PH Doctors Approach Treatment Decisions?



Adapted from Galiè N, et al. *Eur Heart J* 2016; 37:67-119 & *Eur Respir J* 2015; 46:903-75.

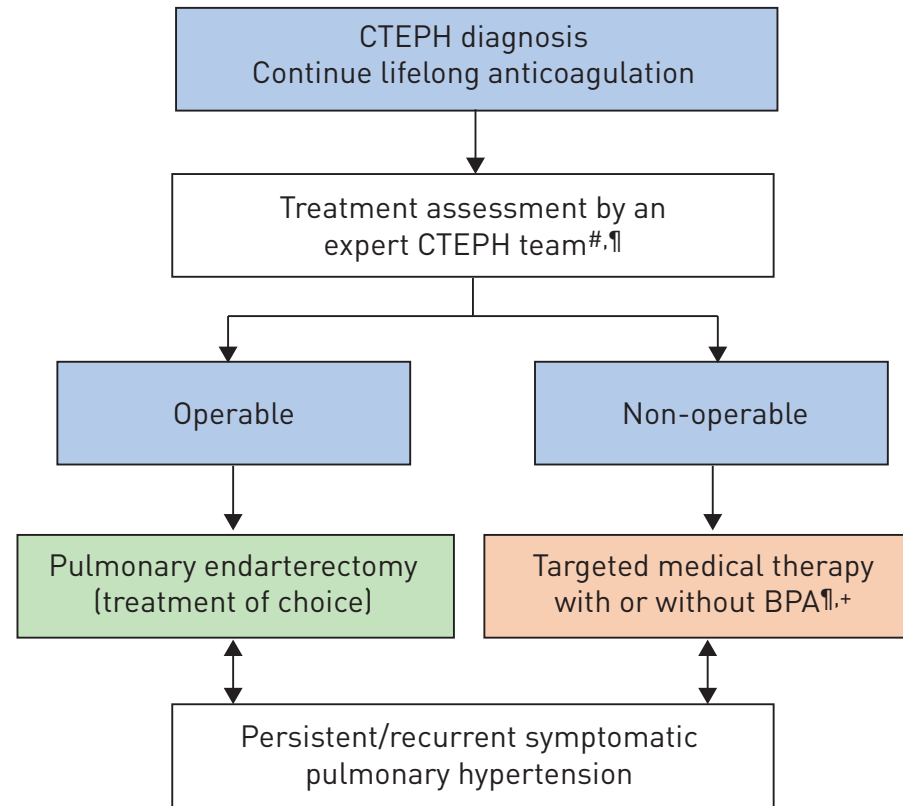
## How Do PH Doctors Approach Treatment Decisions?



DPAH: drug-induced PAH; HPAH: heritable PAH; IPAH: idiopathic PAH; IV: intravenous; PAH: pulmonary arterial hypertension PCA: prostacyclin analogue  
Adapted from Galiè *N et al. Eur Resp J.* 2019; 53(1):1801889.



## How Do PH Doctors Approach Treatment Decisions?



# Patient Perspectives: A Key Component in Patient-Centered Care

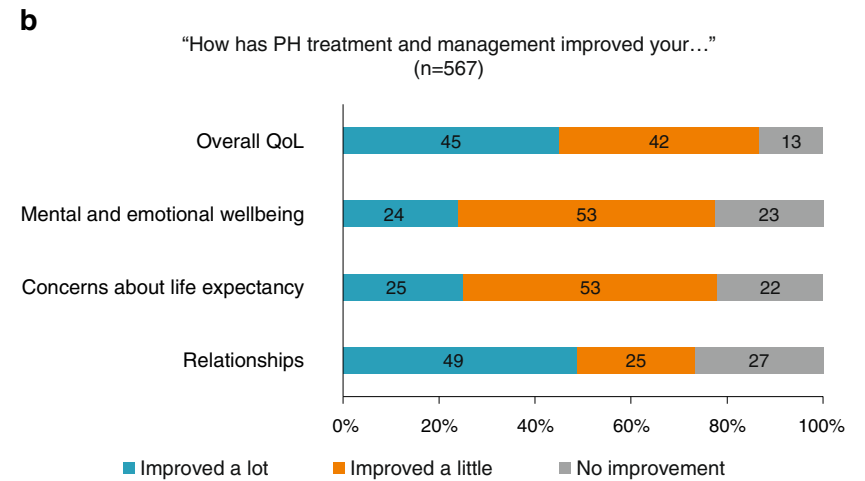
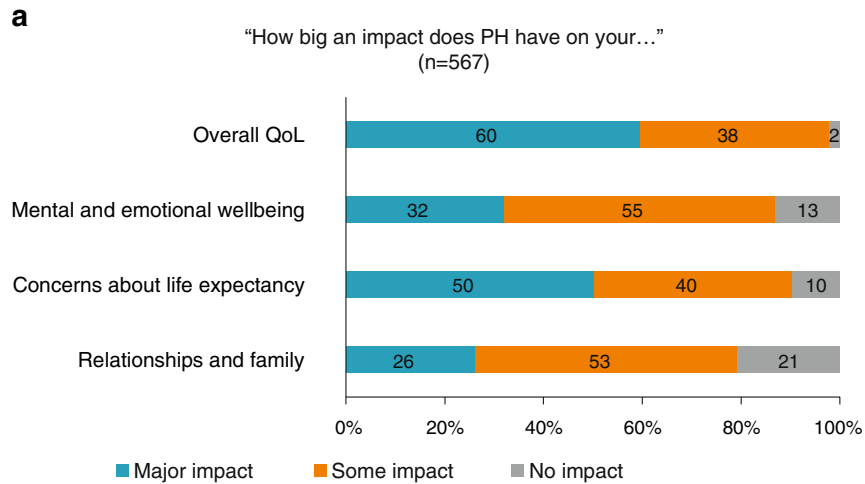


Why Should  
Clinicians  
Care About  
Quality of  
Life?

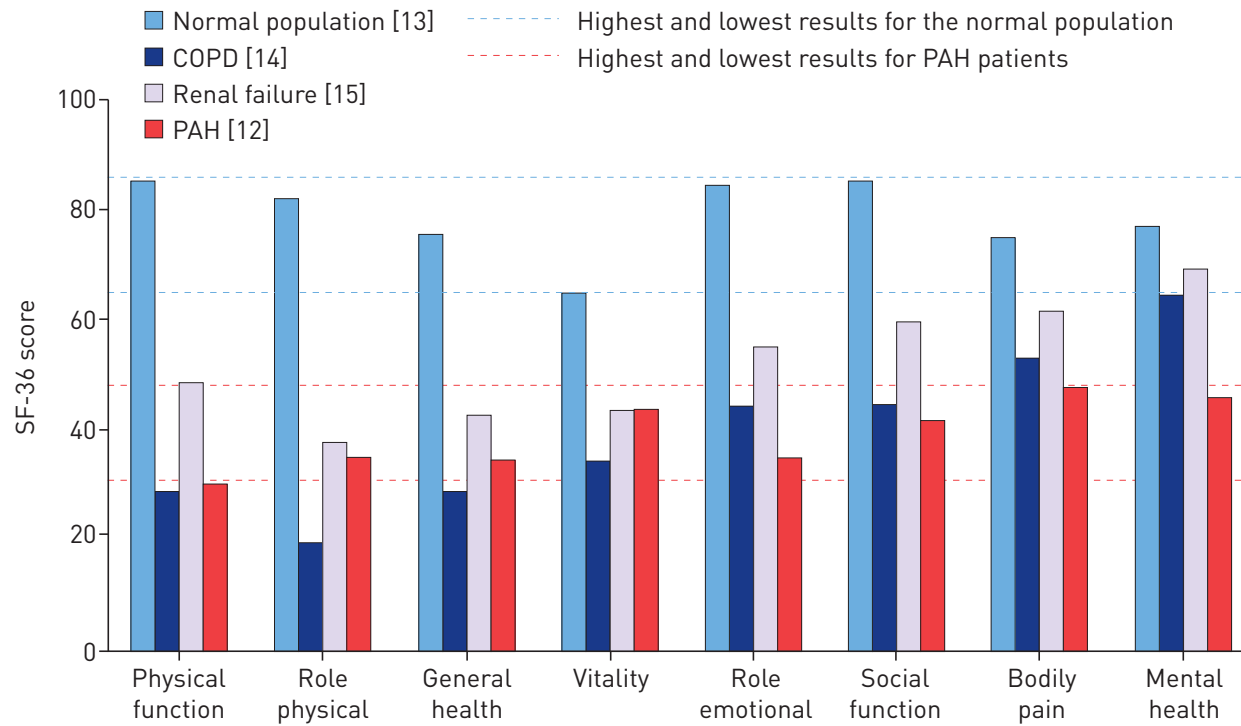




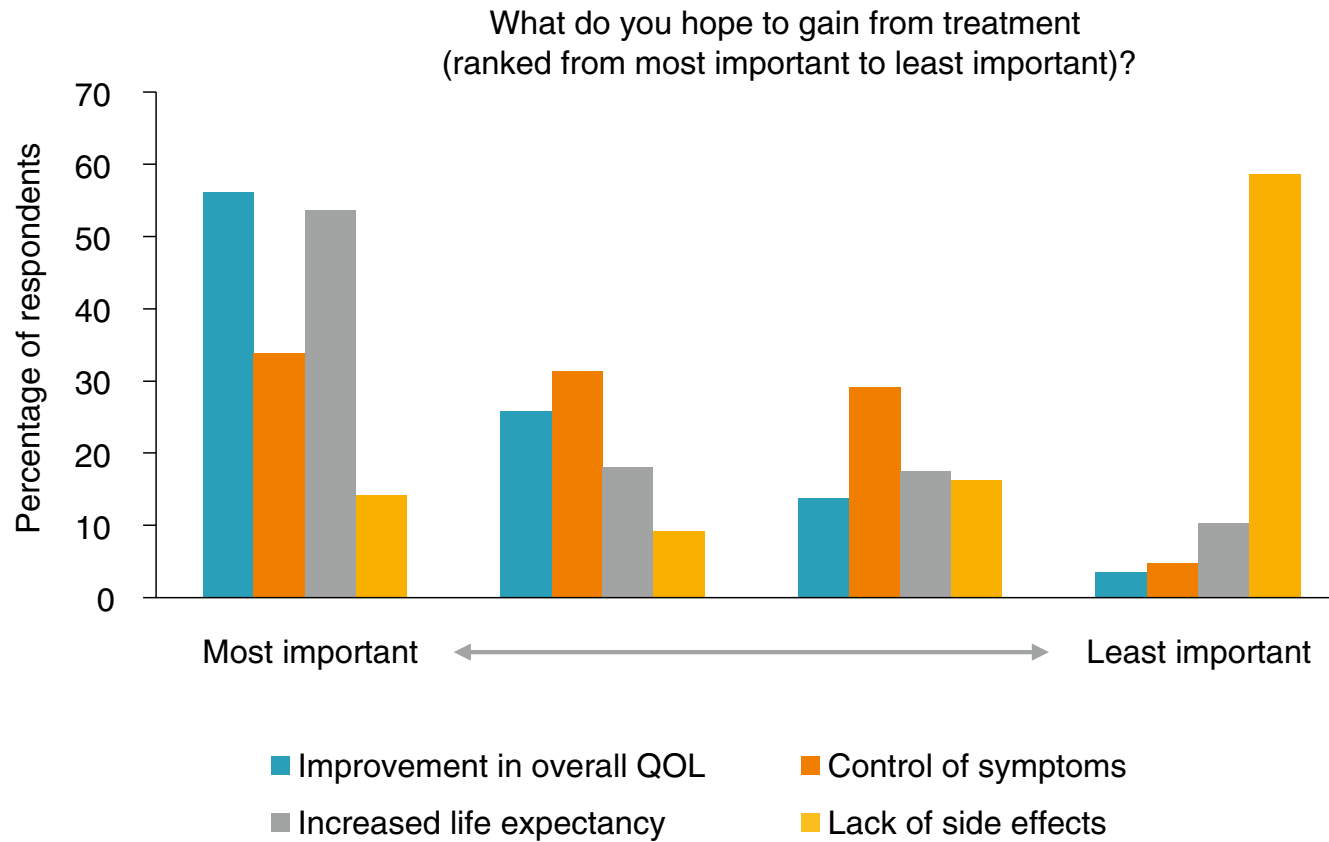
# Quality of Life is Impacted by PH and PH Treatment



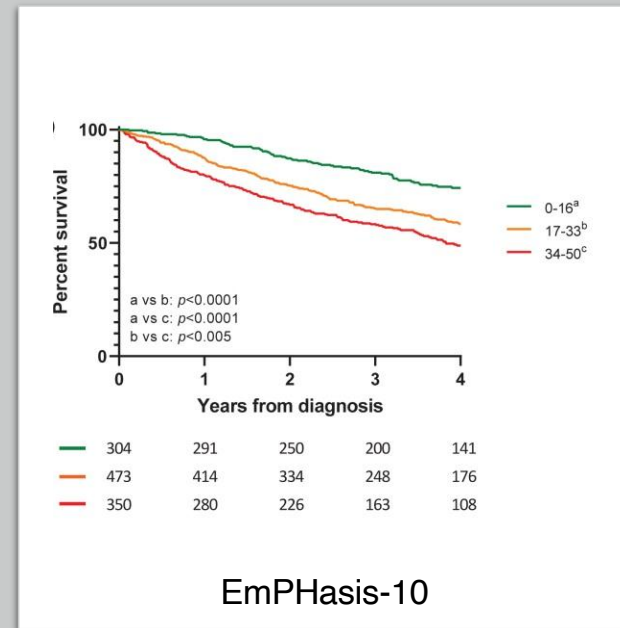
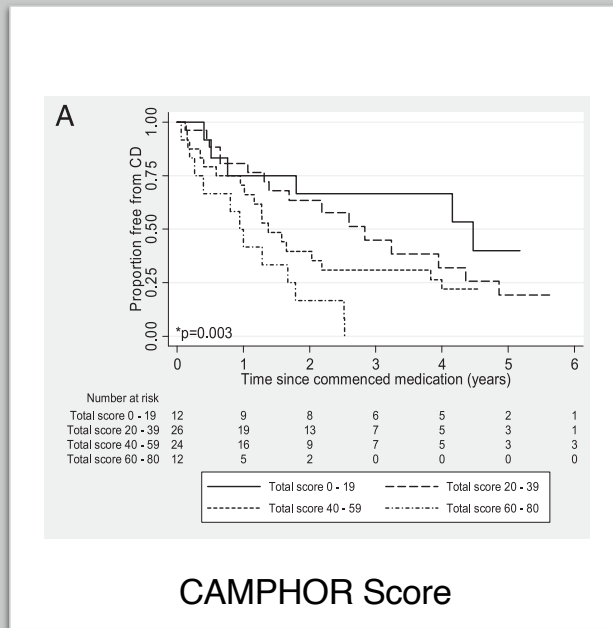
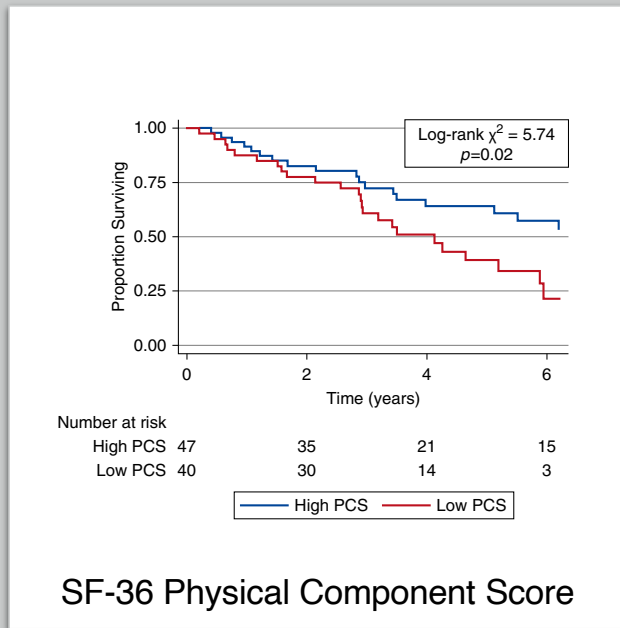
# Quality of Life is Reduced in PH



## QoL is the Most Important Outcome For PH Patients







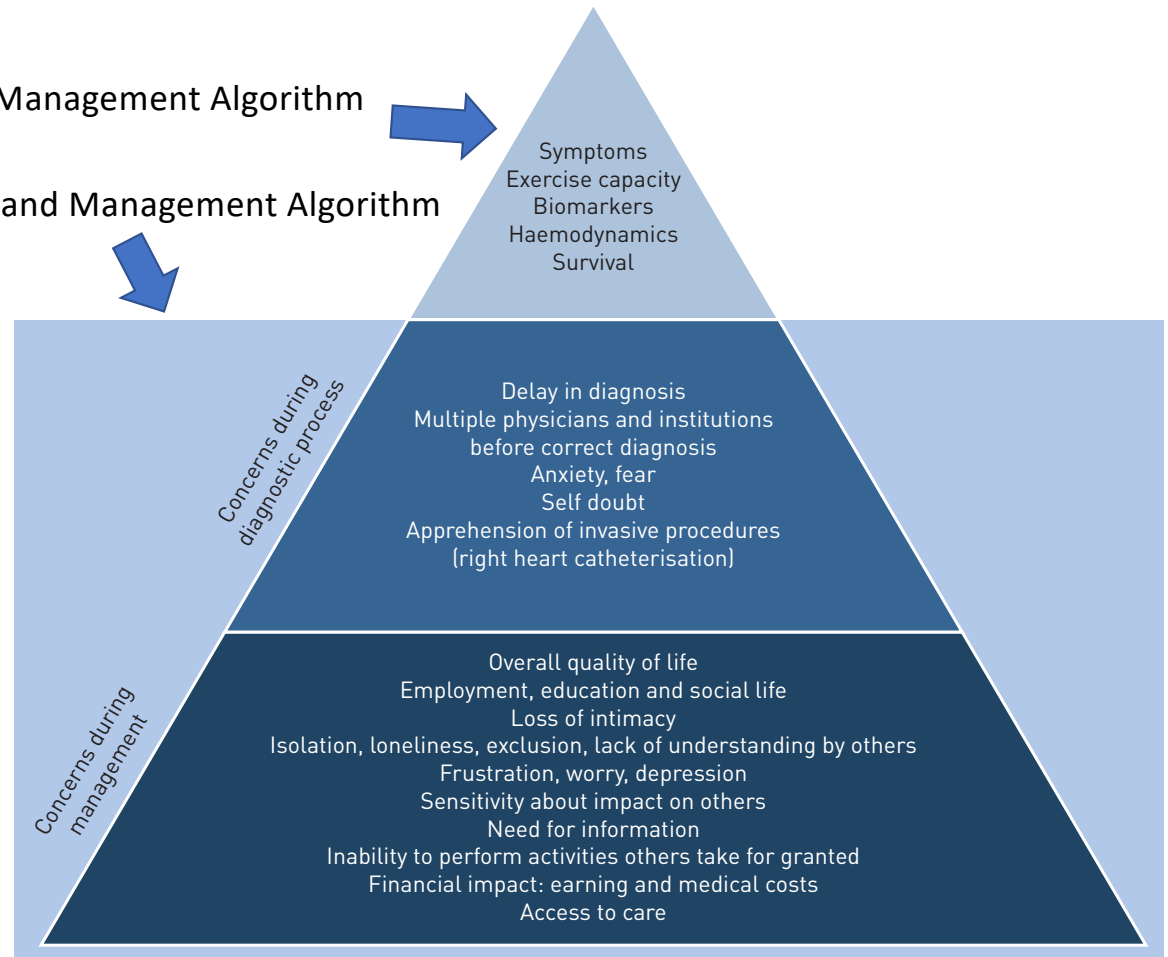
Mathai S, et al. *Annals ATS* 2016;13:31-39; McCabe C, et al. *CHEST* 2013;144:522-530; Lewis R et al *Eur Respir J* 2021;57:2000124.

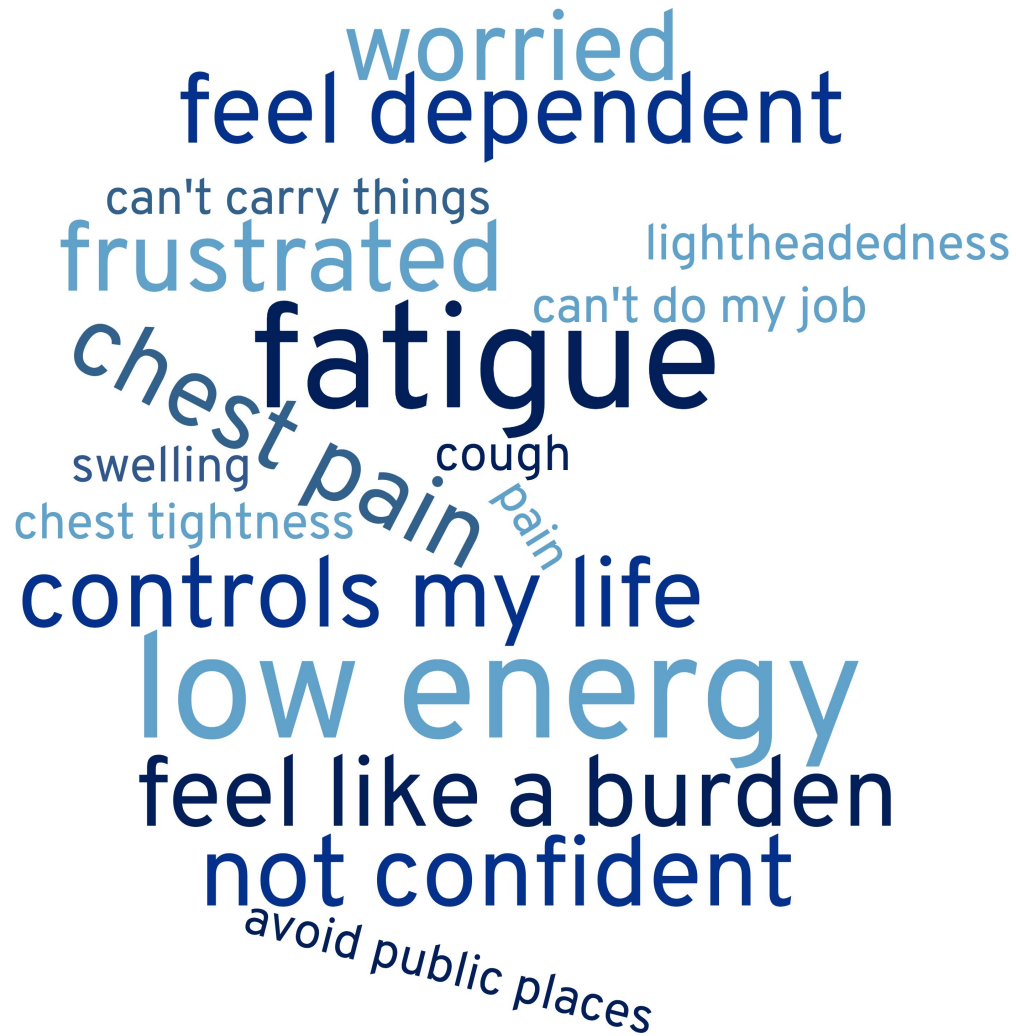
# Is Quality of Life Related to Risk?

# Why Should Clinicians Care About Quality of Life?

Captured in Risk Assessment and Management Algorithm

NOT Captured in Risk Assessment and Management Algorithm





A word cloud of symptoms and feelings. The words are arranged in a roughly circular shape, with 'fatigue' being the largest and most central word. Other prominent words include 'feel dependent', 'low energy', 'controls my life', 'frustrated', and 'worried'. Smaller words include 'chest pain', 'swelling', 'cough', 'can't carry things', 'lightheadedness', 'can't do my job', 'chest tightness', 'feel like a burden', 'not confident', and 'avoid public places'. The colors range from light blue to dark blue.

worried  
feel dependent  
can't carry things  
frustrated  
lightheadedness  
can't do my job  
chest fatigue  
swelling  
cough  
chest tightness  
chest pain  
controls my life  
low energy  
feel like a burden  
not confident  
avoid public places

## What Tools Are Available to Measure QoL in PH?

Instrument	Domains	Number of Items
<b>Generic</b>		
SF-36	8	36
SF-12	8	12
EQ-5D	5	5 + VAS
Nottingham Health Profile	6	38
<b>PH-Specific</b>		
CAMPHOR	3	65
Living with Pulmonary Hypertension	2	21
EmPHasis-10	1	10
PAH-SYMPACT	2	11

# Generic versus Disease Specific Tools

## Disease-Specific Tools

(e.g. EmPHasis-10, PAH-SYMPACT)

- Derived from and validated within patient population
- Better capture elements of patient experience
- Better reflect other disease parameters (e.g. Functional class, 6MWD)

emPHasis10

This questionnaire is designed to determine how pulmonary hypertension (PH) affects your life. Please answer every question by placing a tick over the ONE NUMBER that best describes your recent experience of living with PH.

For each item below, place a tick (✓) in the box that best describes your experience.

I am not frustrated by my breathlessness	0 1 2 3 4 5	I am very frustrated by my breathlessness
Being breathless never interrupts my conversations	0 1 2 3 4 5	Being breathless always interrupts my conversations
I do not need to rest during the day	0 1 2 3 4 5	I always need to rest during the day
I do not feel exhausted	0 1 2 3 4 5	I always feel exhausted
I have lots of energy	0 1 2 3 4 5	I have no energy at all
When I walk up one flight of stairs I am not breathless	0 1 2 3 4 5	When I walk up one flight of stairs I am very breathless
I am confident out in public places/crowds despite my PH	0 1 2 3 4 5	I am not confident at all in public places/crowds because of my PH
PH does not control my life	0 1 2 3 4 5	PH completely controls my life
I am independent	0 1 2 3 4 5	I am completely dependent
I never feel like a burden	0 1 2 3 4 5	I always feel like a burden



pulmonary hypertension association

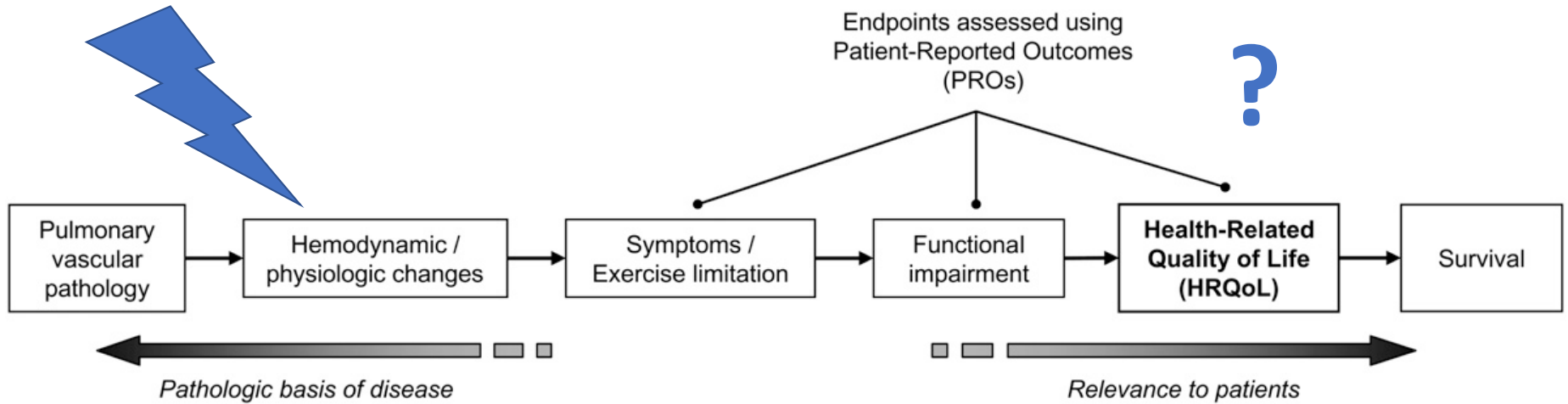


The University of Manchester

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# How Do PAH Treatments Affect QoL?



# Do PAH Medications Improve QoL?

[ Original Research **Pulmonary Vascular Disease** ]



## Effect of Pulmonary Arterial Hypertension-Specific Therapies on Health-Related Quality of Life A Systematic Review

*Gilles Rival, MD; Yves Lacasse, MD; Sylvie Martin, MSc; Sébastien Bonnet, PhD; and Steeve Provencher, MD*

## PAH Treatments: Take Home Message

- Many pivotal PAH clinical trials did not specifically measure QoL
- In trials that measured QoL, most used generic questionnaires rather than disease-specific instruments (doesn't full capture the effects for patients with PAH)
- Most trials show improvement in physical function, but improvements are often smaller than the minimal clinically important difference

## PAH Treatments and Quality of Life

Improve some symptoms

Improve ability to walk

Improve survival



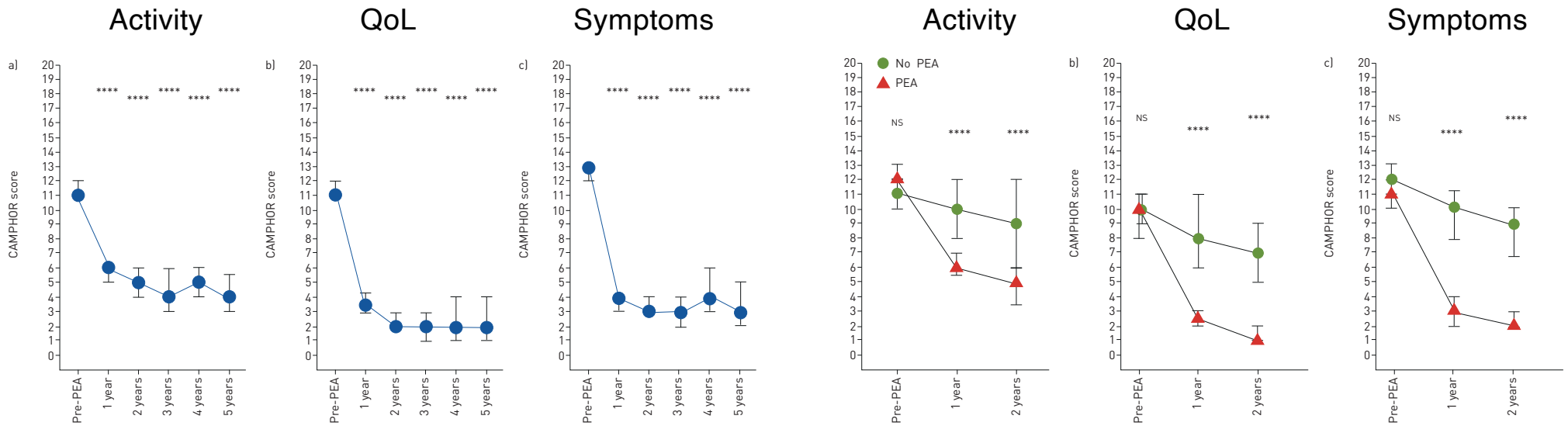
Side effects

Time needed to manage

Don't help psychological,  
social, financial aspects

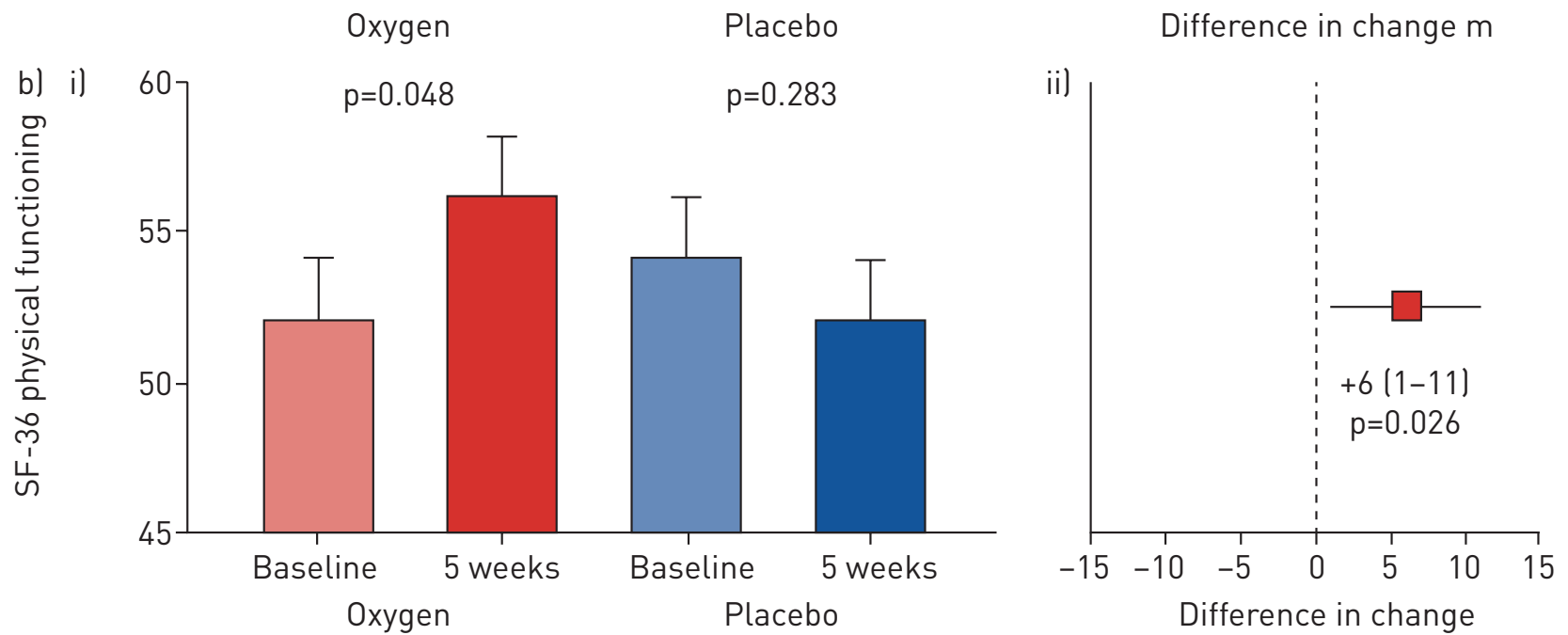
# What Other Interventions Can Improve QoL in PH?

## Pulmonary Endarterectomy for CTEPH



# What Other Interventions Can Improve QoL in PH?

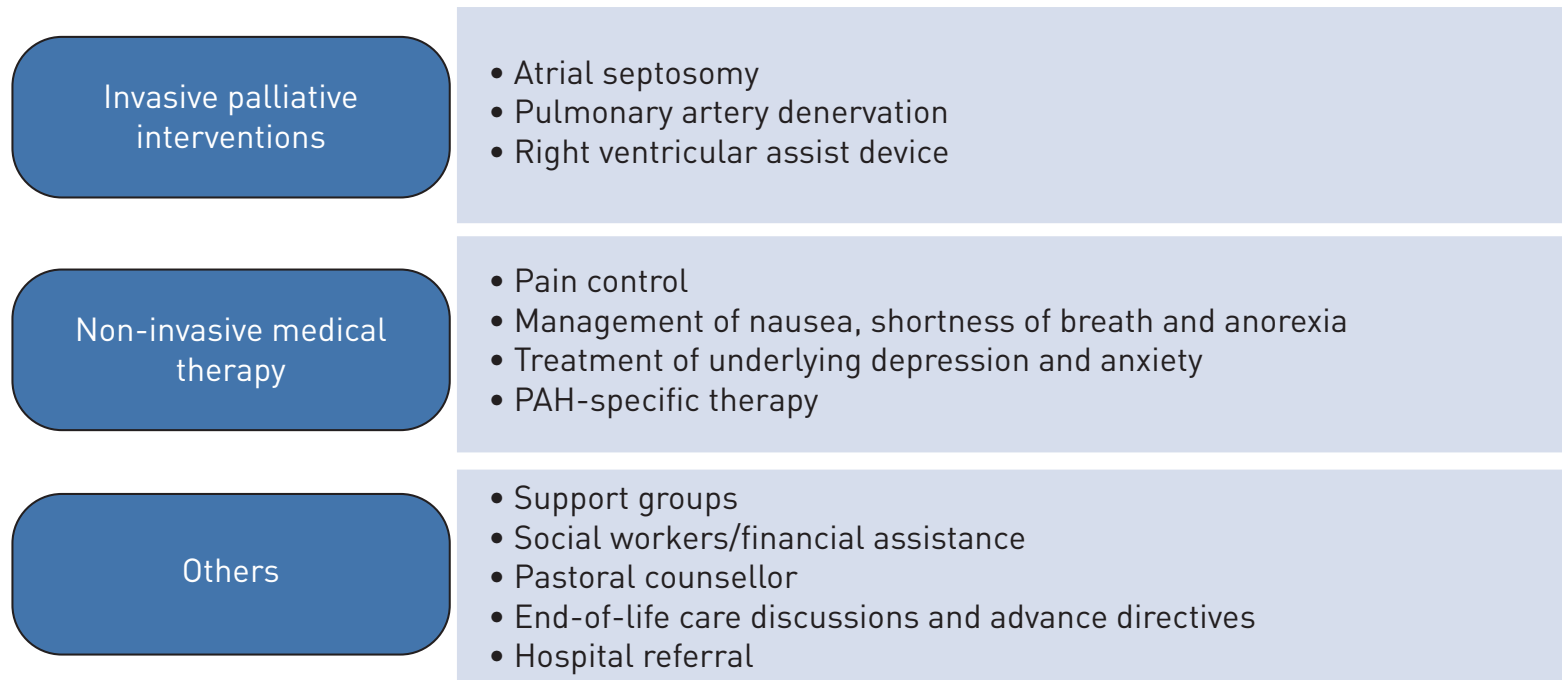
## Oxygen





# What Other Interventions Can Improve QoL in PH?

## Palliative Care?



# How Should We Integrate QoL In PH Care?

## **Clinical management**

- Promote access to optimal care
- Expand MDT approach
- Accreditation of PH centres
- Twinning of expert and developing centres
- Empower patient participation in management
- Multimedia patient information/materials
- Create and endorse methods to enhance HCP and patient/caregiver communication:
  - Shared decision making
  - Narrative-based medicine ←
  - Palliative care techniques ←

## **Provider development**

- Integrate concepts of narrative-based medicine, shared decision making and HRQoL into clinical training ←

## **Clinical research**

- Support, expand and harmonise HRQoL databases ←
- Prioritise HRQoL as a distinct end-point in clinical trials
- Foster patients' input into clinical study design and outcome measurements

## **Patient associations**

- Promote the mission and role of PH patient organisations worldwide

## Summary

1. Assessment of Quality of Life is a key component of Patient-Centred Care
2. Current management strategies for PH focus on multidimensional risk assessment but largely omit patient perceptions, experience, and quality of life.
3. Generic and disease-specific tools can be used to assess QoL in patients with PH.
4. Pharmacologic and non-pharmacologic interventions can improve QoL in PH.
5. QoL should be measured routinely and when implementing new interventions or therapies.

**Thank you**



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