

Original research

# Core outcome set for pulmonary rehabilitation of patients with COPD: results of a modified Delphi survey

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15<sup>e</sup> Journées Francophones Alvéole – mars 2024

# Liens d'intérêts

Honoraires, prises en charges...

- AstraZeneca
- Boehringer Ingelheim
- Chiesi
- CSL Behring
- GlaxoSmithKline
- Mayoli
- MSD
- Mylan
- Novartis
- Pfizer
- Vertex
- Vitalaire
- Zambon

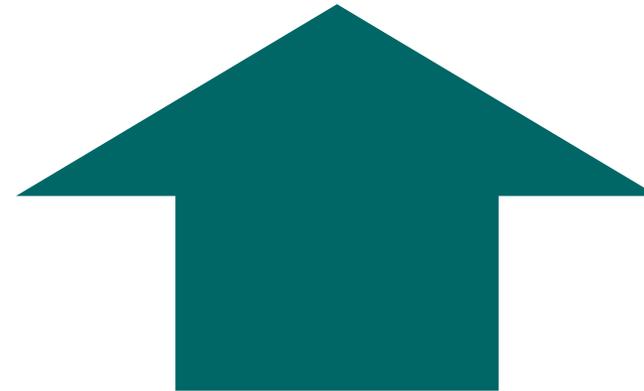
# Contexte scientifique



Les bénéfices de la réadaptation respiratoire dans la BPCO ne sont plus à démontrer.



Critères d'évaluation de son efficacité ne sont pas consensuels.



# Objectif de l'article

Définir un ensemble de résultats essentiels  
qui devraient être mesurés et rapportés de manière cohérente au cours  
de la réadaptation respiratoire des personnes atteintes de BPCO.

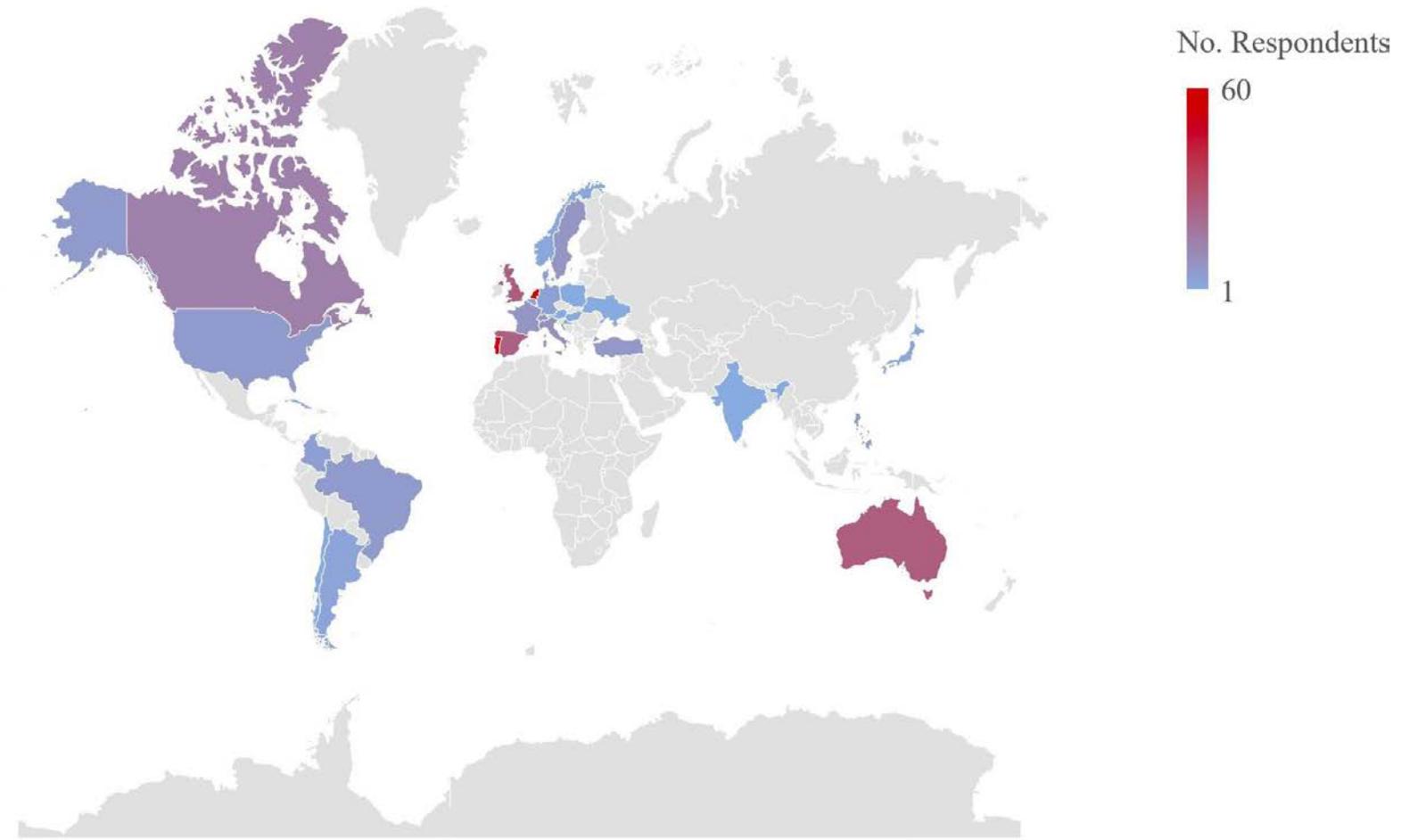
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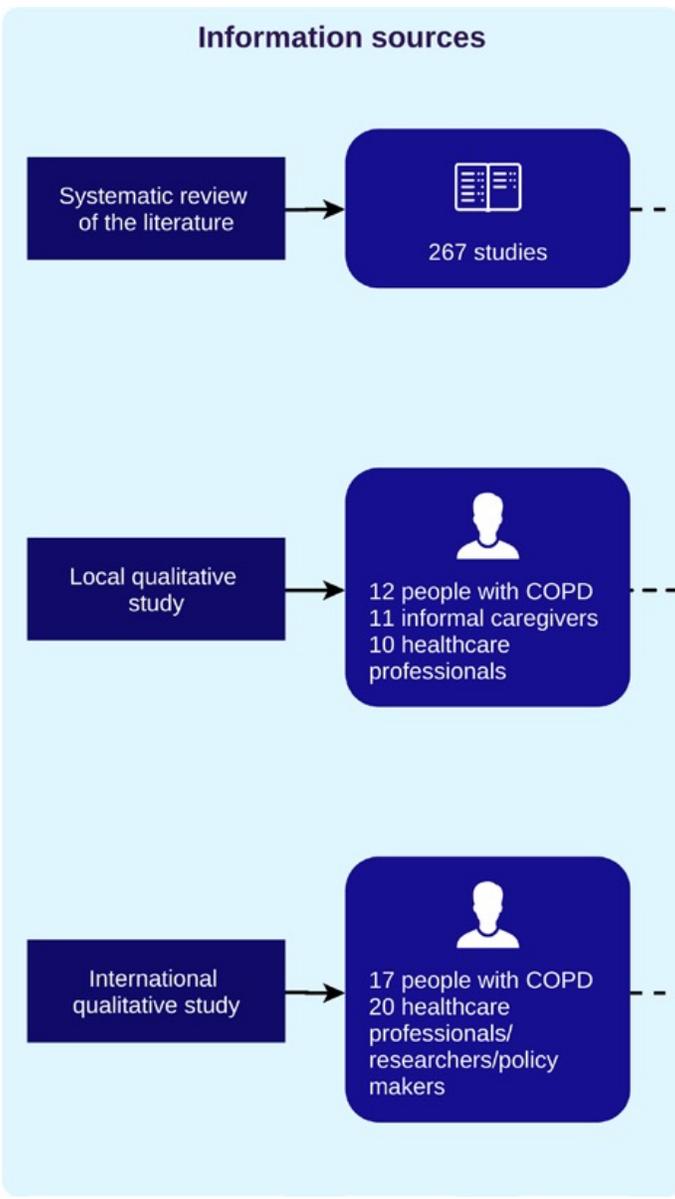
Définir un ensemble de résultats essentiels qui devraient être mesurés et rapportés de manière cohérente au cours de la réadaptation respiratoire des personnes atteintes de BPCO.

- établir un ensemble commun de résultats à mesurer
- conduire à des améliorations de la qualité des soins fournis
- faciliter l'évaluation de la qualité des programmes de réadaptation respiratoire
- faciliter la comparaison et la synthèse des résultats des études

# Méthode

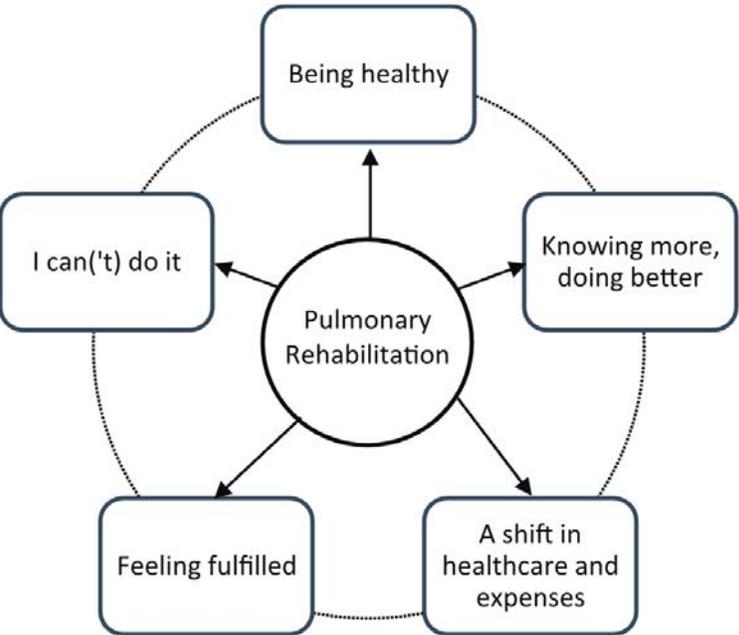
Enquête  
Delphi  
en 2 tours







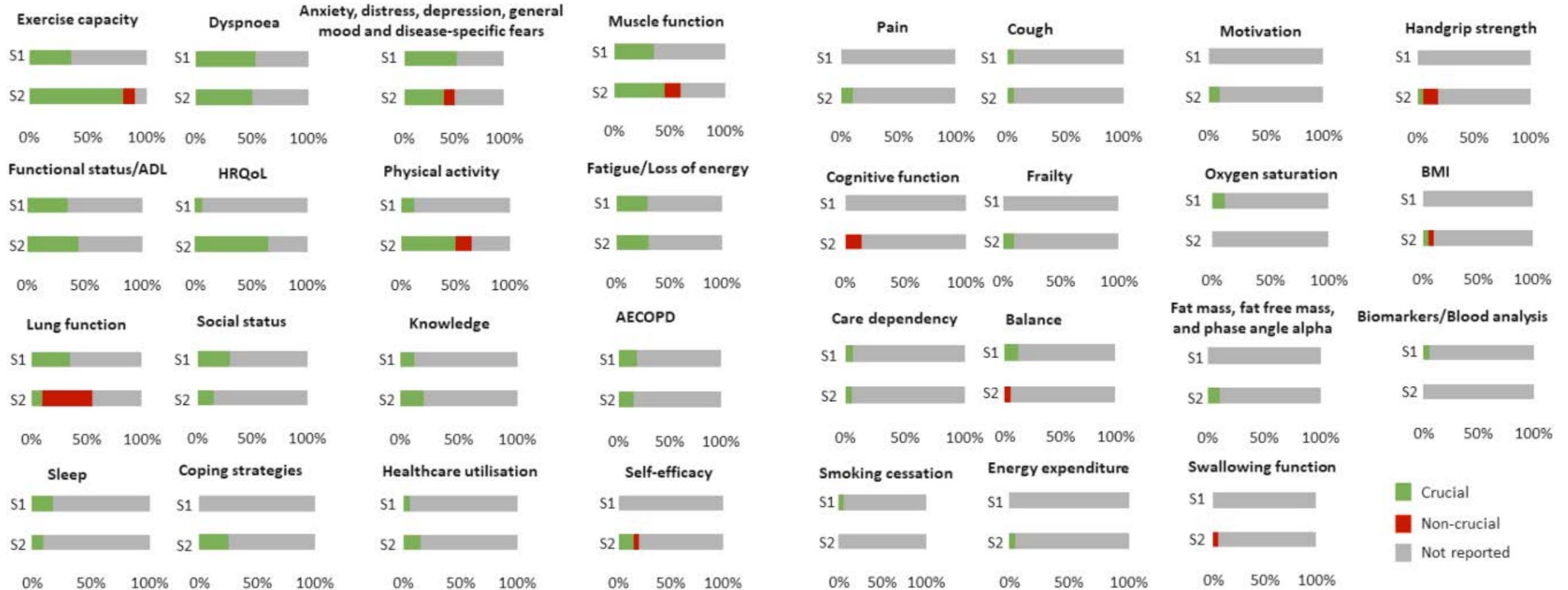
# Triangulated perspectives on outcomes of pulmonary rehabilitation in patients with COPD: a qualitative study to inform a core outcome set

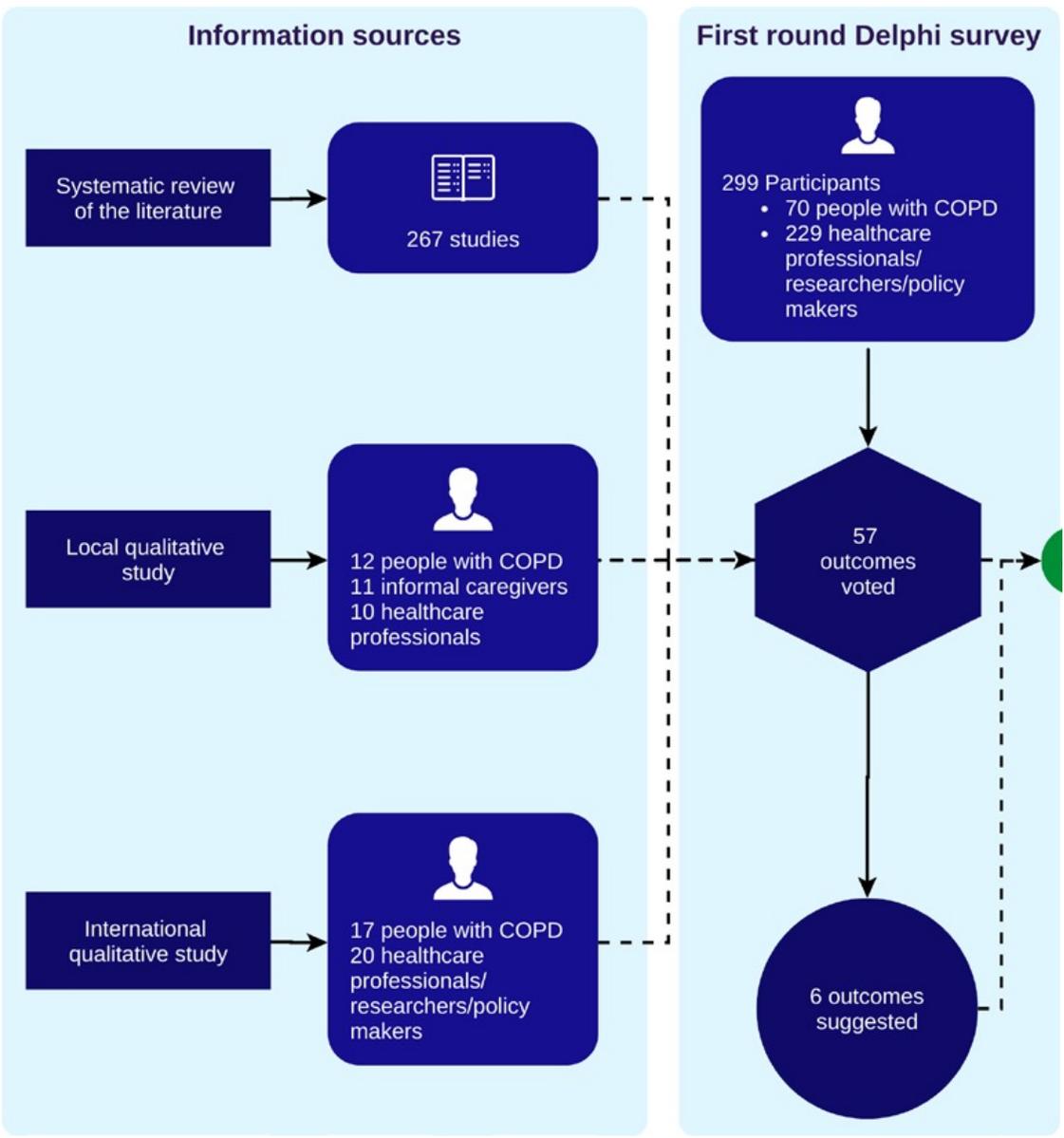


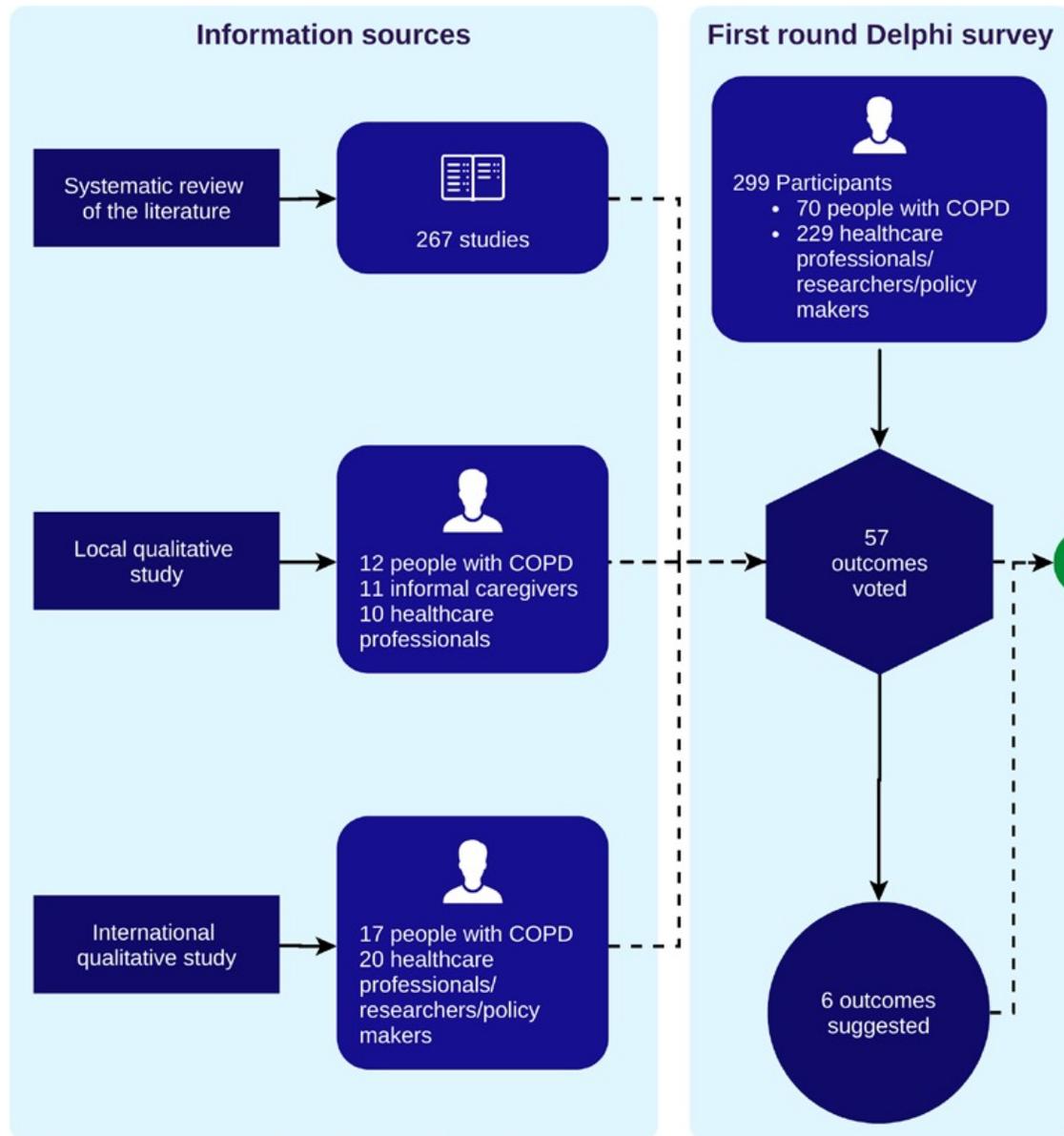
Theme/outcomes	Total, n (%)	Patients, n (%)	Informal carers, n (%)	Health professionals, n (%)
<b>Theme: knowing more, doing better</b>				
<u>Positive outcomes</u>				
Learning about the disease, its management and support network	9 (27%)	3 (25%)	0 (0%)	6 (60%)
Demystifying beliefs and reducing catastrophizing	5 (15%)	1 (8%)	0 (0%)	4 (40%)
Managing burden of disease and care	9 (27%)	1 (8%)	5 (45%)	4 (40%)



# International perspectives on outcome measurement in pulmonary rehabilitation of people with COPD: A qualitative study





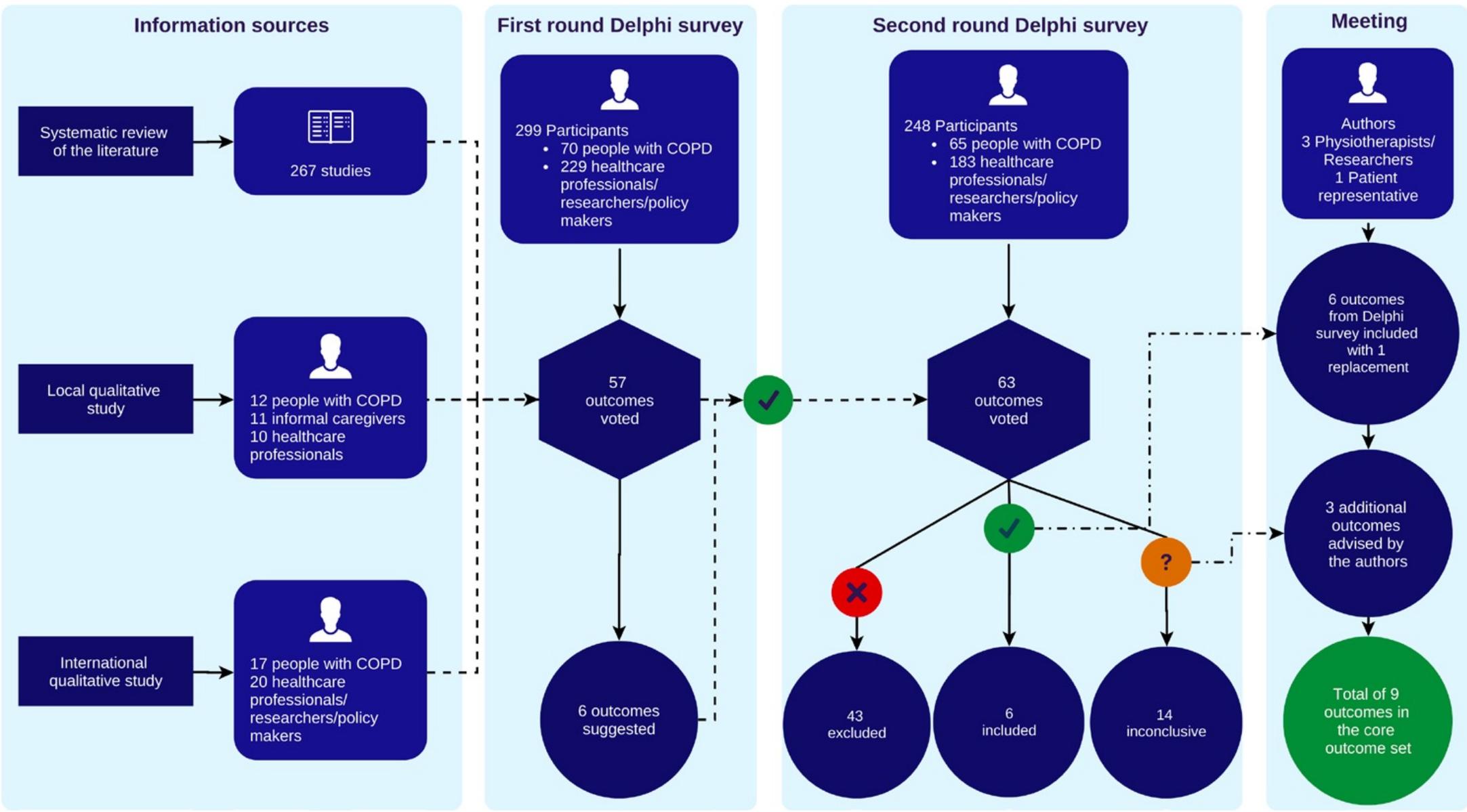


## Professionnels de santé

- 49,2% kinésithérapeutes
- 24,6% médecins

## Evaluation de chaque critère échelle de 1 à 9

- 1-3 : pas si important
- 4-6 : important mais non critique
- 7-9 : critique
- incapable d'évaluer



# Résultats

- Exclusion de l'anxiété et de la dépression
- Fonction respiratoire
  - crucial 80% patients & aidants
  - crucial 22% des soignants
- Fonction des muscles respiratoires
  - crucial 74% des patients & aidants
  - crucial 33% des soignants
- Exacerbations aiguës
  - crucial 59% des patients & aidants
  - crucial 86% des soignants

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## Core outcome set

### Physiological/clinical outcomes

- ✓ Dyspnoea
- ✓ Fatigue
- ✓ Functional exercise capacity
- ✓ Lower limb muscle function

### Life impact outcomes

- ✓ Health-related quality of life
- ✓ Problematic activities of daily living
- ✗ Health behaviours/lifestyle
- ✗ Knowledge about the disease
- ✗ Personal goals

**Table 2** Outcome definitions for the core outcomes, based on available literature and authors' consensus

Outcome	Definition
Dyspnoea	Dyspnoea has been described as a 'subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity'. <sup>52</sup>
Fatigue	Fatigue can be defined as 'a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals' ability to function to their normal capacity'. <sup>53</sup>
Functional exercise capacity	Exercise capacity, and specifically functional exercise capacity can be defined as 'one's maximal potential to realise a functional activity in a standardised environment (eg, walking distance during the 6-minute-walk test)'. <sup>54</sup>
Health-related behaviours/lifestyle	Health-related behaviours can be defined as 'actions taken by individuals that affect health or mortality. These actions may be intentional or unintentional, and can promote or detract from the health of the actor or others'. <sup>55</sup> There are multiple behaviours that are related to lifestyle choices which impact patients health, such as smoking, physical activity and sleep. <sup>55</sup>
Health-related quality of life	Health-related quality of life refers to the 'aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment' <sup>56</sup> or 'a component of the broader concept of quality of life that is defined as satisfaction with health'. <sup>2</sup>
Knowledge about the disease	The definition of health literacy used by the WHO was adapted for this outcome that is, the ability of individuals to gain access to, understand and use information about the disease in ways which promote and maintain good health. <sup>57 58</sup>
Lower limb muscle function	Muscle dysfunction is defined as 'the loss of at least one of the two main muscle properties: strength and endurance'. <sup>59 60</sup> Although muscle endurance and other properties might be important to assess, <sup>61</sup> it was consensual that lower limb muscle strength should be the core outcome assessed, as it is the most studied muscle characteristic in COPD, has a clear prognostic value, can be improved with PR and is easily measured. <sup>59 62</sup>
Personal goals	Personal goals were defined as goals that patients aim to achieve with PR and are set by themselves.
Problematic activities of daily living	Activities of daily living are meaningful tasks of everyday life that can be basic (eg, eating, dressing, bathing) or instrumental that is, associated with independent living (eg, transportation, shopping, managing money, housework). <sup>63 64</sup>
COPD, chronic obstructive pulmonary disease; PR, pulmonary rehabilitation.	

# Conclusion

Grande hétérogénéité sur les critères d'évaluation d'une réadaptation respiratoire

Discordances entre ce qui est perçu comme crucial par patients/aidants et soignants

Pas d'outil défini pour évaluer chaque critère retenu

# Touloulous dans les rues de Cayenne en 2007





# Merci de votre attention

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