



# **La experiencia del paciente que utiliza Terapias Respiratorias a Domicilio en Portugal: un modelo nacional innovador centrado en el paciente**

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# ENTIDADES

Equipo Investigador:



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Centro de Investigação em Tecnologias e Serviços de Saúde, Faculdade de Medicina da Universidade do Porto



Hospital Universitario Clinic Barcelona

Reconocimiento científico:



Sociedade Portuguesa de Pneumologia



Associação Portuguesa de Pessoas com DPOC e outras Doenças Respiratórias Crónicas



Agência Nacional de Inovação

# ¿A QUIÉN SE DIRIGE?

Pacientes que reciben Terapias Respiratorias al  
Domicilio (TRD) y cuidadores



**Oxigenoterapia**

**VNI**



+ 100.000 pacientes con TRD en Portugal

# CALIDAD



**PREM** medida de experiencia reportada por los pacientes

**!** ninguno para evaluar la experiencia de pacientes con TRD

**Desarrollar y validar un PREM para el contexto específico de las TRD.**

# MEJORAS PACIENTE/CUIDADOR

## MACRO

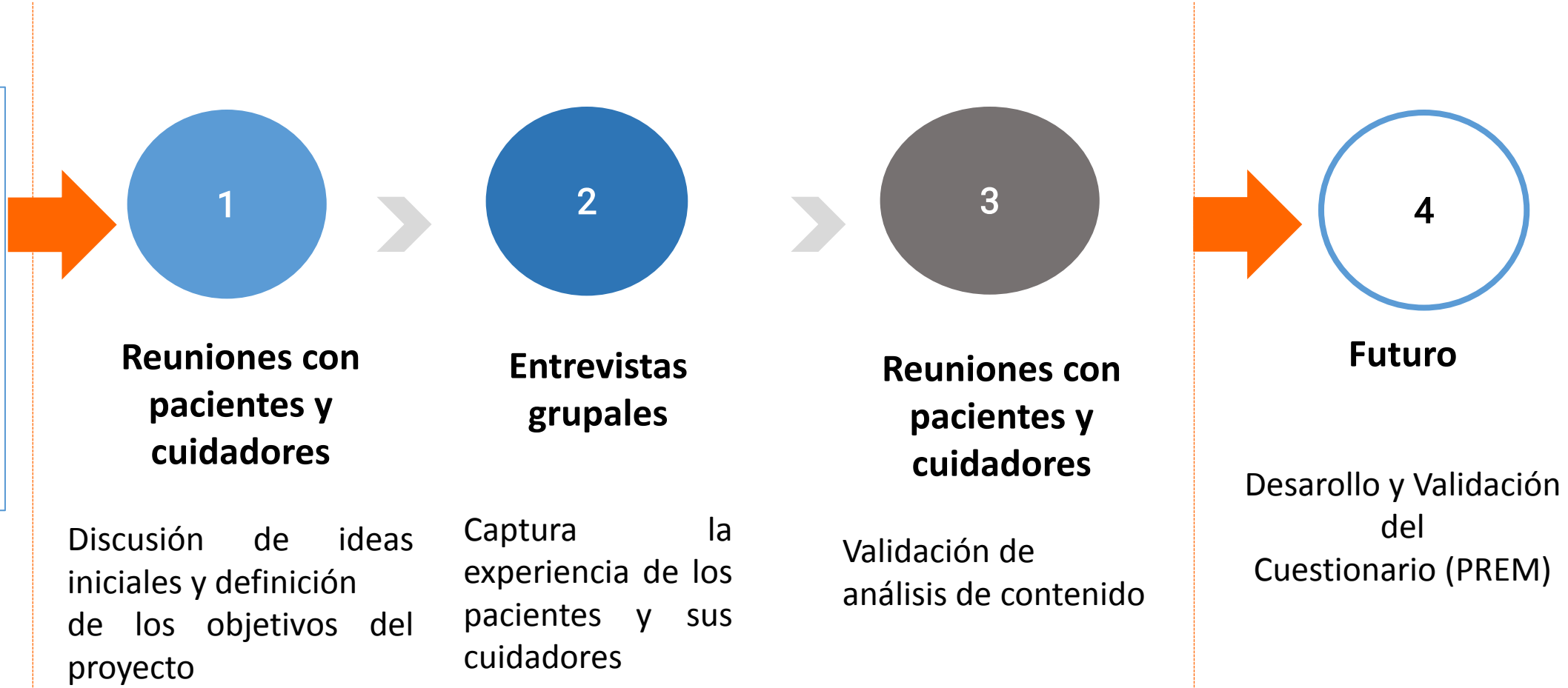
- Indicador de la calidad en la prestación de un servicio de salud especializado
- Contribuir a la identificación de puntos críticos en el proceso asistencial y mejora de los procedimientos (necesidades no cubiertas)
- Apoyará los ciclos de evaluación (Planificar, Estudiar y Actuar)



## MICRO

- Seguimiento más objetivo de la experiencia individual de los pacientes y cuidadores
- Facilitará la discusión de la experiencia entre pacientes y profesionales
- **Mejor adaptación y cumplimiento** de la terapia

# FOCO EN EL PACIENTE/CUIDADOR







Journal of  
*Clinical Medicine*

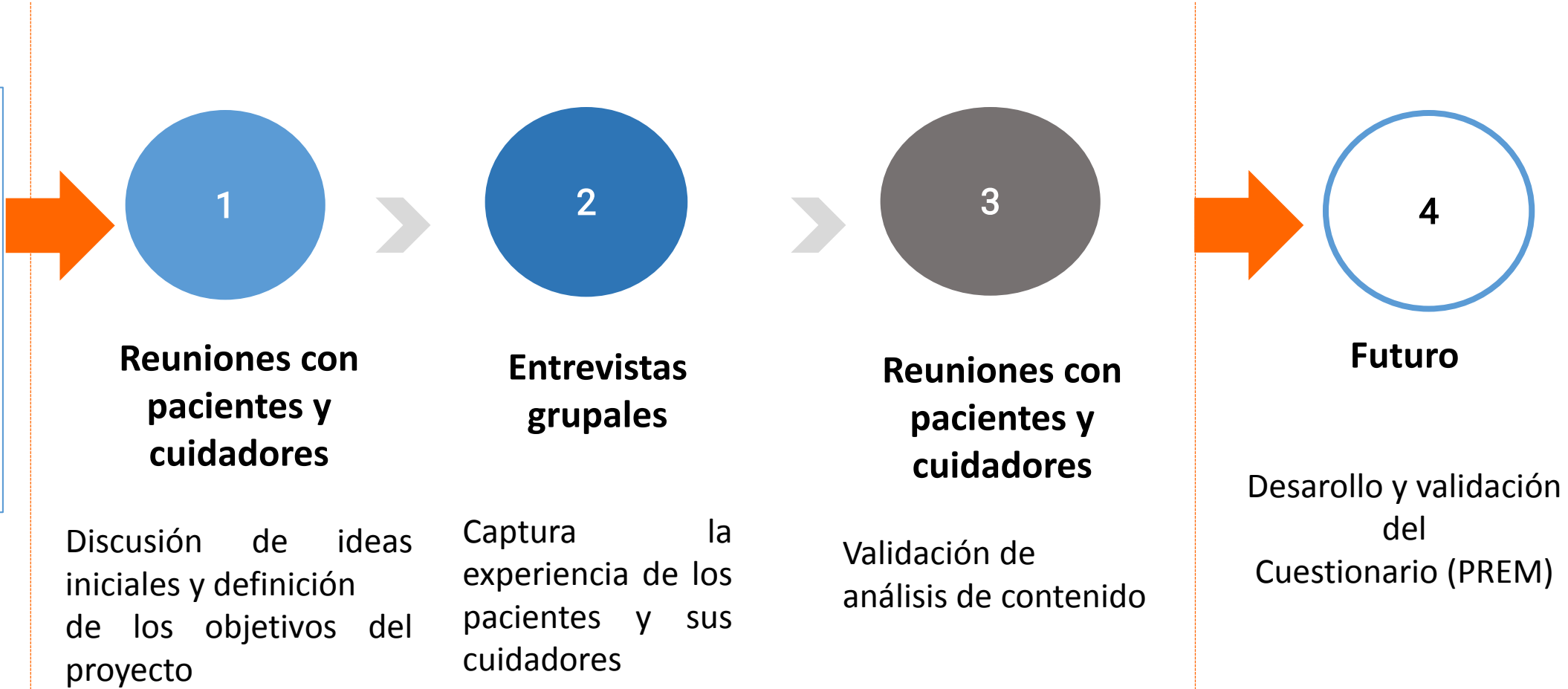


*Review*

## Patient Experience in Home Respiratory Therapies: Where We Are and Where to Go

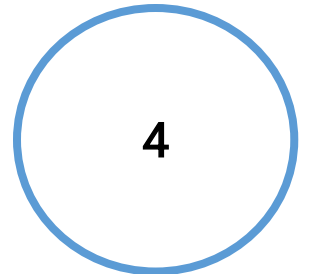
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João Almeida Fonseca <sup>3,7,8</sup>, Joan Escarrabill <sup>9,10,11</sup> and João Carlos Winck <sup>12</sup>

# FOCO EN EL PACIENTE/CUIDADOR





# FOCO EN EL PACIENTE/CUIDADOR



Futuro

Desarrollo y validación  
del  
Cuestionario (PREM)

Disc  
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## Review Patient Experience in Home Respiratory Therapies: Where We Are and Where to Go

Celia Casanova <sup>1,2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35,36,37,38,39,40,41,42,43,44,45,46,47,48,49,50,51,52,53,54,55,56,57,58,59,60,61,62,63,64,65,66,67,68,69,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84,85,86,87,88,89,90,91,92,93,94,95,96,97,98,99,100</sup>,  
Judit Almirall-Ferraz <sup>1,2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35,36,37,38,39,40,41,42,43,44,45,46,47,48,49,50,51,52,53,54,55,56,57,58,59,60,61,62,63,64,65,66,67,68,69,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84,85,86,87,88,89,90,91,92,93,94,95,96,97,98,99,100</sup>,  
Joaquín Martínez-Alfaro <sup>1,2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35,36,37,38,39,40,41,42,43,44,45,46,47,48,49,50,51,52,53,54,55,56,57,58,59,60,61,62,63,64,65,66,67,68,69,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84,85,86,87,88,89,90,91,92,93,94,95,96,97,98,99,100</sup>,  
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**Abstract:** The increasing number of patients needing home respiratory therapy (HRT) is improving a major impact on medical, clinical care and healthcare system sustainability. The current challenge is to continue to guarantee access to HRT while maintaining the quality of care. The patient experience is a cornerstone of high-quality healthcare and an emerging area of clinical research. This review approaches the assessment of the patient experience in the context of HRT while highlighting the European contribution to this body of knowledge. This review demonstrates that research in this area is still limited, with the exception of a previous model that incorporates the patient experience as an outcome and no specific patient reported experience measure (PREM) available. This work also shows that Europe is leading the research on HRT practices. The development of a specific PREM and the integration of PREMs into the assessment of prescription models should be clinical research priorities in the next several years.

**Keywords:** Long-term oxygen therapy; home mechanical ventilation; patient reported experience; therapeutic quality of care; healthcare sustainability

**3. Introduction**  
Long-term oxygen therapy (LTO) and/or home mechanical ventilation (HMV) are well-established therapies for patients with chronic respiratory failure, such as those with chronic obstructive pulmonary disease (COPD), neuromuscular diseases, and obstructive sleep apnea (OSA), among others. These

# PRÓXIMOS PASOS

## Difusión

**Cuestionarios  
y/o indicadores  
a nivel  
internacional**

Actividad 4

**Implementación  
del PREM  
desarrollado en  
un contexto real  
de TRD -  
Portugal**

Actividad 3

**Desarrollo y  
validación de un  
PREM**





# Calidad y Mejora continua

**No hacer suposiciones...**

**Hay que perguntar!**

Muchas gracias!

Actuar en lo  
que aporta  
**VALOR !!**

