European Respiratory Society Clinical Practice Guideline: Palliative care for people with chronic obstructive pulmonary disease or interstitial lung disease

Daisy J.A. Janssen¹, Sabrina Bajwah², Michele Hilton Boon³, Courtney Coleman⁴, David C. Currow⁵, Albert Devillers⁶, Chantal Vandendungen⁶, Ron Flewett⁷, Magnus Ekström⁸, Sarah Greenley⁹, Mai-Britt Guldin¹⁰, Cristina Jácome¹¹, Miriam J Johnson¹², Geana Paula Kurita^{14,15}, Matthew Maddocks², Alda Marques¹⁵, Hilary Pinnock¹⁶, Steffen T. Simon¹⁷, Thomy Tonia ¹⁸, Kristoffer Marsaa¹⁹

- 1 Department of Research & Development, Ciro, Horn and Department of Health Services Research, Care and Public Health Research Institute, Faculty of Health Medicine and Life Sciences, Maastricht University, Maastricht, The Netherlands.
- 2 Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London, United Kingdom.
- 3 WiSE Centre for Economic Justice, Glasgow Caledonian University, Glasgow, United Kingdom.
- **4** European Lung Foundation, Sheffield, United Kingdom.
- 5 Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, New South Wales, Australia.
- 6 Association Belge Francophone contre la Fibrose Pulmonaire (ABFFP, French-speaking Belgian Association against Pulmonary Fibrosis), Belgium.
- 7 Pulmonary Fibrosis Trust,Staffordshire, United Kingdom.
- 8 Department of Clinical Sciences Lund, Lund University, Faculty of Medicine, Respiratory Medicine, Allergology and Palliative Medicine, Lund, Sweden.
- 9 Institute for Clinical and Applied Health Research, Hull York Medical School, University of Hull, Hull, United Kingdom.
- 10 Research Unit for General Practice, Aarhus, Denmark.
- 11 CINTESIS@RISE, Department of Community Medicine, Health Information and Decision, Faculty of Medicine of University of Porto, Porto, Portugal.

12 – Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, United Kingdom.

13 - Department of Clinical

- Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Denmark.

 14 Multidisciplinary Pain Centre, Department of Anaesthesiology, Pain and Respiratory Support, Neuroscience Centre and Palliative
- Pain and Respiratory Support,
 Neuroscience Centre and Palliative
 Research Group, Department of
 Oncology, Centre for Cancer and
 Organ Diseases, Rigshospitalet,
 Denmark.
 15 Respiratory Research and
- Rehabilitation Laboratory (Lab₃R), School of Health Sciences (ESSUA) and Institute of Biomedicine (iBiMED), University of Aveiro, Aveiro, Portugal.
- 16 Allergy and Respiratory Research Group, Usher Institute, The University of Edinburgh, United Kingdom. 17 – University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine and Center for Integrated Oncology Aachen Bonn Cologne Dusseldorf (CIO ABCD), Germany. 18 – Institute of Social and Preventive Medicine, University of
- Bern, Bern, Switzerland.

 19 Arresoedal Hospice,
 Frederiksrk, Denmark.

FIGURE 1

Methodology used for development of the European Respiratory Society clinical practice guideline. Abbreviation: PICO= Patient, Intervention, Comparison, Outcome.

Chronic respiratory disease (CRD), such as chronic obstructive pulmonary disease (COPD) or interstitial lung disease (ILD), are a leading cause of death (3rd) and disability (6th) worldwide, with high burden for individuals, families and society1-3. Even under optimal pharmacological treatment these people still present many pulmonary (e.g. severe dyspnea), extrapulmonary (e.g., muscle weakness) and behavioural/ lifestyle/risk-factors (e.g., poor family and social support) manifestations4. They often present palliative care needs in physical, psychological, social and spiritual/existential domains, equal to or greater than people with cancer.5-10 Informal carers, i.e., relatives, partners and friends in unpaid roles¹¹ are their main source of support but often feel low priority and abandoned by healthcare professionals¹²⁻²⁰. The CRD population typically does not have access to the palliative care available to people with cancer. The main focus of palliative care is to control symptoms and improve quality of life of people with serious healthrelated suffering, and to support their informal carers. Therefore, this European Respiratory Society taskforce aimed to provide recommendations for initiation and integration of palliative care into the respiratory care of adult people with COPD or ILD.

The panel was composed of 20 members. Eight questions were formulated, four in the 'Population, Intervention, Comparison, Outcome' format and four narrative, tackled as described in Figure 1.

We provided a definition for palliative care and the following recommendations for people with COPD or ILD and their informal carers: consider palliative care when physical, psychological, social, or existential needs are identified through holistic needs assessment; offer palliative care interventions, including advance care planning, in accordance with such needs; integrate palliative care into routine COPD and ILD care.

