Early View

Task Force Report

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


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European Respiratory Society Clinical Practice Guideline:

Palliative care for people with chronic obstructive pulmonary disease or interstitial lung disease

Authors:
Daisy J.A. Janssen¹, Sabrina Bajwah³, Michele Hilton Boon⁴, Courtney Coleman⁵, David C. Currow⁶, Albert Devillers⁷, Chantal Vandendungen⁷, Magnus Ekström⁸, Ron Flewett⁹, Sarah Greenley¹⁰, Mai-Britt Guldin¹¹, Cristina Jácome¹², Miriam J Johnson¹³, Geana Paula Kurita¹⁴,¹⁵, Matthew Maddocks³, Alda Marques¹⁶, Hilary Pinnock¹⁷, Steffen T. Simon¹⁸, Thomy Tonia¹⁹, Kristoffer Marsaa²⁰.

Affiliations
1. Department of Research & Development, Ciro, Horn, The Netherlands
2. Department of Health Services Research and department of Family Medicine, Care and Public Health Research Institute, Faculty of Health Medicine and Life Sciences, Maastricht University, Maastricht, The Netherlands
3. Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London, United Kingdom
4. WiSE Centre for Economic Justice, Glasgow Caledonian University, Glasgow, UK
5. European Lung Foundation, Sheffield, United Kingdom
6. Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, New South Wales, Australia
7. Association Belge Francophone contre la Fibrose Pulmonaire (ABFFP, French-speaking Belgian Association against Pulmonary Fibrosis), Belgium
8. Lund University, Faculty of Medicine, Department of Clinical Sciences Lund, Respiratory Medicine, Allergology and Palliative Medicine, Lund, Sweden
9. Pulmonary Fibrosis Trust, Staffordshire, United Kingdom
10. Institute for Clinical and Applied Health Research, Hull York Medical School, University of Hull, Hull, United Kingdom
11. Research Unit for General Practice, Aarhus, Denmark
12. CINTESIS@RISE, Department of Community Medicine, Health Information and Decision, Faculty of Medicine of University of Porto, Porto, Portugal
13. Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, United Kingdom
14. Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Denmark
15. Multidisciplinary Pain Centre, Department of Anaesthesiology, Pain and Respiratory Support, Neuroscience Centre and Palliative Research Group, Department of Oncology, Centre for Cancer and Organ Diseases, Rigshospitalet, Denmark
16. Respiratory Research and Rehabilitation Laboratory (Lab3R), School of Health Sciences (ESSUA) and Institute of Biomedicine (iBiMEd), University of Aveiro, Aveiro, Portugal
17. Allergy and Respiratory Research Group, Usher Institute, The University of Edinburgh, UK
18. 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
19. Institute of Social and Preventive Medicine, University of Bern, Bern, Switzerland
20. Department of multidisease, Nordsjaellands Hospital, University of Copenhagen, Denmark

Address for correspondence
Prof. Dr. Daisy J.A. Janssen
Dept. of Research & Development, Ciro
Hornerheide 1, 6085 NM, Horn
The Netherlands
E daisyjanssen@ciro-horn.nl
T +31475587686

Abstract
There is increased awareness of palliative care needs in people with chronic obstructive pulmonary disease (COPD) or interstitial lung disease (ILD). This European Respiratory Society (ERS) task force
aimed to provide recommendations for initiation and integration of palliative care into the respiratory care of adult people with COPD or ILD.

The ERS task force consisted of 20 members, including representatives of people with COPD or ILD and informal caregivers. Eight questions were formulated, four in the ‘Population, Intervention, Comparison, Outcome’ (PICO) format. These were addressed with full systematic reviews and application of Grading of Recommendations Assessment, Development and Evaluation (GRADE) for assessing the evidence. Four additional questions were addressed narratively. An ‘evidence-to-decision’ framework was used to formulate recommendations.

The following definition of palliative care for people with COPD or ILD was agreed: A holistic and multidisciplinary, person-centred approach aiming to control symptoms, and improve quality of life of people with serious health-related suffering because of COPD or ILD, and to support their informal caregivers. Recommendations were made regarding people with COPD or ILD and their informal caregivers to: consider palliative care when physical, psychological, social, or existential needs are identified through holistic needs assessment; offer palliative care interventions, including support for informal caregivers, in accordance with such needs; offer advance care planning in accordance with preferences; and integrate palliative care into routine COPD and ILD care. Recommendations should be reconsidered as new evidence becomes available.
INTRODUCTION

Chronic lung diseases are major causes of long-term disability and premature mortality worldwide.[1, 2] Chronic obstructive pulmonary disease (COPD) is a leading cause of death and is predicted to be the fourth cause of death in 2030 worldwide.[1, 3] Although interstitial lung disease (ILD) is less prevalent than COPD, for example idiopathic pulmonary fibrosis is associated with high symptom burden, reduced quality of life and short survival.[4, 5] The present guideline focusses on people with COPD and ILD with serious illnesses, defined as carrying a high risk of death, a negative impact on quality of life and functioning in life roles, and is burdensome in symptoms or caregiver stress.[6] People affected have palliative care needs in physical, psychological, social and spiritual/existential domains, equal to or greater than people with cancer.[5, 7-11] Informal caregivers (any relative, partner, friend, neighbor, or significant other with personal relationship with the person cared for and who provides a broad range of unpaid assistance to the person with COPD or ILD[12]) have a major and complex role. They fulfill many tasks (Online supplement 1),[13-19] and are therefore the main, although often “hidden”, workforce responsible for providing most of daily care.[20] Nevertheless, they generally receive insufficient support.[13-16, 21] A recent systematic review showed that palliative care interventions offered to people with non-malignant diseases resulted in lower symptom burden, fewer visits to the emergency department and fewer hospitalisations.[22] Despite the mentioned benefits, people with COPD or ILD typically do not have access to the palliative care available to people with cancer.[23, 24] Disease trajectories of people with serious COPD or ILD are highly individual and difficult to predict.[25, 26] In COPD, only one third of deaths are due to a pulmonary cause; about one quarter are due to a cardiovascular cause and about one fifth to cancer.[27] In contrast, ILD is a diverse group of respiratory illnesses associated with different likelihoods of survival.[26] This uncertain prognosis, confusion with end-of-life care and not knowing when to initiate palliative care are barriers towards palliative care.[23, 28] The death of people with COPD or ILD is often perceived as unexpected and they are less likely to die at home than people with cancer[29-31], which may affect the bereavement experience.[32, 33] Despite inclusion in disease-specific guidelines and some national statements,[34-37] a European clinical practice guideline on palliative care for people with chronic lung diseases is lacking. Therefore, the European Respiratory Society (ERS) task force for palliative care aimed to provide recommendations for initiation and integration of palliative care for adult people with COPD or ILD and their informal caregivers. Our objectives were to raise awareness and assess the effectiveness of palliative care, provide a clinician-guide to palliative care implementation, and identify knowledge gaps to inform future research. The present guideline is not limited to hospice care, which often refers to care for the dying or...
a location of care in the community.[38] Although for some people supportive care has a more positive association than palliative care, we use the term palliative care, while a well-accepted definition for supportive care is lacking. Moreover, supportive care is sometimes viewed as a component of oncology.[39]

**METHODS**

We used ERS methodology for clinical practice guideline development.[40, 41] (e-figure 1) (see online supplements for details) Co-chaired by DJAJ and KM, the multidisciplinary ERS task force consisted of 20 members, including three representatives of people with COPD or ILD and informal caregivers, and specialists in nursing, respiratory medicine, palliative care, primary care, internal medicine, old age medicine, pulmonary rehabilitation, physiotherapy, psychology, and methodology. Conflicts of interest were declared and managed according to ERS policies. Representatives of people with COPD or ILD and informal caregivers actively participated in the discussions. One of the co-chairs (KM) held two additional meetings with these representatives: one at the start of the process to discuss the aims of the taskforce and expectations and one to discuss their input for formulating recommendations. Following their input, the task force uses ‘person’ with illness instead of ‘patient’ where possible. The senior ERS methodologist (TT) supervised and ensured that all ERS methodological requirements were met, but did not participate in the formulation of questions or recommendations. An information specialist (SG) provided search expertise for all questions. Subgroups of four panellists were formed to work on each question, and the task force held monthly video conferences between November 2020 and September 2022.

**Formulation of questions and outcomes**

Panellists rated 14 potential topics for inclusion in the clinical practice guideline on a five-point Likert scale using an online survey (Qualtrics [Provo, UT]) to identify the most relevant clinical questions on palliative care for people with COPD or ILD. During three meetings, four questions using the PICO framework were defined as well as four complementary narrative questions.[41] (Table 1 and online supplement 1) Each group member then voted, anonymously, on the importance of outcomes of interest for each PICO question, using an online survey and a scoring system of 0 to 9 (1-3 not important; 4-6 important; 7-9 critical for clinical decision making) following GRADE guidance.[42] Scores for each outcome were averaged, presented and those scored as important or critical further discussed during one meeting until group consensus was reached for the final classification of the importance of
outcomes[42] (Online supplement 1). Due to the large number of outcomes, only those deemed as critically important (scoring 7-9) were included.

**Literature searches**

For each question, a search strategy was designed and executed by the information specialist. See online supplement 2 for a summary of the search process and full search strategies for all databases. Initial searches were conducted between February and May 2021 and updated April 19-22, 2022. A standard set of databases were searched for each question: Medline (OVID), Embase (OVID), Cochrane Database of Systematic Reviews and CENTRAL (The Cochrane Library), CINAHL (EBSCOhost), Scopus, Web of Science Core Collection and Epistemonikos with supplementary searches for systematic reviews undertaken in the online CareSearch systematic review collection resource. Search results were screened independently by two panellists for eligibility (see online supplement 1 for inclusion/exclusion criteria). First, systematic reviews were screened. Systematic reviews that provided evidence for at least one of the outcomes of interest for one of the questions were used as a basis to add later studies. If no relevant systematic review was identified for a question, original studies were screened for inclusion. Whenever there were randomised controlled trials (RCTs) available, those were used as the main body of evidence. Relevant articles not included in the initial search could be added by the task force members. For each question, a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram documented the number of studies included and excluded at each step of screening.[43] For narrative questions seven and eight, task force members identified systematic reviews that had comparable aims and objectives to the questions and extracted relevant themes. Then, primary papers were identified that were relevant but not included in the systematic reviews and these were classified as either adding novel insights not identified in the systematic reviews, or corroborating existing themes.

**Evidence syntheses and assessment of the quality of evidence**

The literature review and the evidence profile tables for PICO questions three and four were performed by the University of Liège - Epidémiologie et Economie de la Santé. A recipient of the ERS Fellowship in Guideline Methodology with expertise in Public Health (MHB) conducted the systematic reviews, evidence syntheses and GRADE-assessment for PICO questions five and six. Data from included studies for PICO questions three and four were extracted by one panellist and checked by another. Data from included studies for PICO question five and six were extracted by one panellist and checked by two others. Risk of bias was assessed by one panellist and discussed and agreed with two others. Risk of bias was assessed using the Cochrane Risk of Bias tool (version 1) for RCTs and Joanna Briggs Institute (JBI)
tools for observational studies. Meta-analysis was not possible for any of the PICO questions because of the limited evidence available. GRADE evidence profiles were created for each PICO question using the GRADEpro Guideline Development Tool (https://www.gradepro.org/), and the certainty of evidence was assessed based on the GRADE principles: risk of bias, indirectness, inconsistency, imprecision and publication bias.[44, 45] The GRADE evidence profiles were based on RCTs only, except for question six, for which the only included study had an observational design. The final certainty of outcomes for each question was rated as high, moderate, low or very low.[46]

**Formulating recommendations**

For all questions the evidence-to-decision framework was used to structure the discussions and to document the different factors considered for the recommendations.[47, 48] Apart from the evidence and its certainty other factors considered in this framework included values and preferences of people with illness, resources, feasibility, health equity and acceptability. Draft recommendations were discussed with the task force until consensus was reached. One of the task force chairs (KM), held an additional meeting with representatives of people with COPD or ILD and informal caregivers, and a representative from the European Lung Foundation to discuss in depth their values and preferences concerning each question. Based on GRADE, the strength of the recommendations was rated as either strong (phrased with “We recommend”) or conditional (phrased with “We suggest”).[49, 50]

For the narrative questions, evidence was reviewed narratively to develop recommendations. For question one (definition), data were extracted for each study concerning: what; what for; to whom; by which means; by whom; where; when; and conditional requirements. (Online supplement 3, adapted from Meyer et al.[51]) For question two (when to start), the framework of Philip et al.[52] was used to extract data on referral criteria. For questions seven and eight (implementation), a whole systems approach was used as a framework for analysis[53], relating the findings of included papers to the needs of people with COPD or ILD, professional requirements and service organisation. Findings were then synthesised in a summary text and key themes illustrated in a schema. For all narrative questions, recommendations for research were drafted by the subgroup and discussed within the task force until consensus was reached.

**RESULTS**

The number of studies identified and selected is shown in PRISMA diagrams for each question in e-figures 2 to 8. The evidence profile tables and evidence-to-decision frameworks are shown in online
supplements 3 (question 1-6), 4 (question 7 and 8 COPD), and 5 (question 7 and 8 ILD).
Recommendations are listed in table 1. Table 2 shows recommendations for research.

**Question 1. How do we define palliative care for people with COPD or ILD? (narrative)**

**Recommendation**

We suggest to use the definition for palliative care for people with serious illness due to COPD or ILD as shown in box 1. (conditional recommendation for the suggested definition - very low quality of evidence).

**Justification**

A conditional recommendation was selected based upon the large agreement in the literature on the overall concept of palliative care across the included studies.[54-58]

**Summary of main findings**

Results included three systematic reviews[54-56], a consensus Delphi study guideline[58], and a study using a summary content analysis, environmental scan and rapid review [57].(See online supplement 3) Studies reported that palliative care is a multidisciplinary approach offered to people with illness as well as their family and aiming to improve quality of life. Palliative care is offered in all settings where a person may have a serious illness and needs.

**Other considerations**

In a draft definition based on the extracted findings, a definition of specialist palliative care was missing. Therefore, an additional study was sought to define “specialist palliative care”. This study used a Delphi procedure and concluded that: “specialist palliative care is offered by clinicians who have advanced knowledge of identifying dying, skills to assess and manage complex symptoms to improve quality of life, have advanced communication skills and perform distinct clinical practices (e.g., working with the whole family as the unit of care and providing support in complex bereavement)”. [59] For the current definition we have combined these skills into: “advanced knowledge of and training in palliative care”. ACP is included in the definition and is seen as: “the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate”. [60] Communication should be both effective (including that what is communicated is received and understood) as well as sensitive (be titrated to the needs of the person with COPD or ILD and informal caregiver). Currently, social equity is not included in the identified definitions of palliative care.
Question 2. When to start a palliative care approach in COPD and ILD? (narrative)

Recommendation
We suggest that a palliative care approach should be considered when people with COPD or ILD and their informal caregivers have physical, psychological, social, or spiritual/existential unmet needs. Needs should be actively sought by asking the person with illness or their informal caregiver, but surrogate markers of disease severity and/or health service utilization may help identify those likely to have needs. (conditional recommendation – low quality of evidence).

Justification
Although the evidence level is low, a conditional recommendation was selected that palliative care should start when an unmet need arises.[52, 61-68]

Summary of main findings
The search retrieved one systematic review[52], one observational study[61] and seven qualitative studies[62-68]. Multiple factors can contribute to late palliative care referral and inequitable variation in care. These include the unpredictable course of chronic respiratory disease, personal views of palliative care, and under-recognition of symptoms and concerns.[69] More standardised criteria for when to start a palliative care approach in COPD and ILD would enhance decision-making and consistency in practice. Available studies describe a range of criteria for when to start palliative care, based on either needs or markers of disease severity and/or health service utilisation review.[52] Referral criteria for palliative care in advanced COPD and ILD across the literature (62 articles: 52 COPD, 4 ILD, 6 mixed) are shown in table 3. The common criteria for starting palliative care include, in order of reporting: hospital use; respiratory status; physical or emotional symptoms; functional decline; use of advanced respiratory therapies; and disease progression [52]. Needs-based criteria function similarly across all diagnoses and can be elicited by asking the person with illness or informal caregiver, or in some cases using objective testing. However, their routine use requires clinicians to identify, assess and then respond to needs.[68] Disease-based criteria, e.g., hospital admissions, are often measured in health systems but their relationship to unmet need is dependent on the disease and service delivery context. For example, a new diagnosis of idiopathic pulmonary fibrosis has been suggested as an appropriate time to start palliative care, yet starting palliative care following a diagnosis of mild COPD may raise undue concern among people with COPD and their families about expected speed of progression.[66]
Other considerations

People with illness and informal caregivers are generally more willing to talk about current needs than potential future ones. They see consultations as about treating the ‘here and now’ but would like clinicians to initiate discussions about future care.[65] A structured question guide can help the person with illness to bring up symptoms and concerns which they consider ‘normal’ limitations of disease or which they do not feel can be addressed.[63] Support groups can also help increase readiness for palliative care referral.[61] In primary care, practitioners use verbal and non-verbal indications from people with illness, informal caregivers and health records to identify when to start a palliative care approach. However, without formal screening, recognition of needs may occur late in the disease trajectory by which time it is severe.[64] Most needs will not require specialist palliative care, but potential for benefit depends on the skill-mix and competencies of the care team and delivery structure. The wide range of criteria demonstrates that there is no consensus for when to start a palliative care approach.

Question 3. In people with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (PICO)

Recommendation

In people with COPD, we suggest palliative care interventions including support for informal caregivers should be offered. (conditional recommendation - very low quality of evidence)

Justification

In RCTs, palliative care interventions involving caregivers improved the quality of life and well-being[70-74] of people with COPD. Nevertheless, studies were highly heterogeneous, were often applied to mixed populations (not exclusively composed of people with COPD)[70, 73, 75, 76] and the involvement of and support provided to informal caregivers varied. Serious to very serious limitations were found in the GRADE evaluation.

Summary of main findings

In total 28 studies[68, 70-94] were included, nine of which were RCTs.[70-76, 81, 95]. In RCTs, palliative care interventions involving informal caregivers improved quality of life and well-being of people with COPD [70-74] but did not change symptoms of breathlessness[72, 73], anxiety or depression[71-74, 95]. Outcomes in informal caregivers were not assessed in these studies. Hence, the overall quality of evidence was considered very low for all outcomes.

Other considerations
Additional evidence from non-RCTs has shown that palliative care interventions involving informal caregivers: increased satisfaction with care among people with COPD and informal caregivers with care[75, 76, 84, 85, 89, 90, 96]; enhanced quality of communication[96]; raised awareness of proactive care for and involvement of informal caregivers[77]; decreased symptoms in people with COPD[80, 88]; increased confidence in managing symptoms[90, 91, 96] and reduced the mean number of respiratory emergency department visits[75, 97]. There was no evidence of undesirable effects. Strategies such as promoting more involvement of healthcare professionals in identifying eligible candidates for palliative care interventions, initiatives with patients’ associations, additional information via technology and peer support, might be needed to facilitate involvement of informal caregivers during the implementation of these interventions to real-world settings, according to the available resources.

**Question 4. In people with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (PICO)**

**Recommendation**

In people with ILD, we suggest palliative care interventions including support for informal caregivers should be offered. (conditional recommendation - very low quality of evidence)

**Justification**

The number of available studies is very low, some outcomes of interest were never reported and different instruments have been used to assess the outcomes of interest, leading to very low evidence regarding the use of palliative care interventions involving informal caregivers among people with ILD. Despite this, anxiety and quality of life of people with ILD and burden and depression of informal caregivers was shown to improve with palliative care interventions.[98-100] No serious to very serious limitations were found in the GRADE evaluation.

**Summary of main findings**

In total 11 studies were included[84, 87, 98-106], three of which were RCTs.[98-100] RCTs with palliative care interventions were few and very heterogeneous, often applied to mixed populations (not exclusively people with ILD) and the support offered to informal caregivers varied and included for example telephone contacts with a specialized nurse, group sessions, nurse-led support groups or a booklet to address palliative care needs. Nevertheless, anxiety and quality of life of people with ILD and burden/stress and depression of informal caregivers were found to improve. No harmful or adverse events were reported with any of the interventions.[98-100]

**Other considerations**
Additional evidence from non-RCTs found significant improvements in communication and discussions between people with ILD, informal caregivers and healthcare professionals after palliative care interventions.[84, 101, 102, 105]. Such improvements enabled people with ILD to feel less isolated[99], have better symptom management[101, 103] and, in line with their preferences were less likely to die in hospital[101, 105]. Informal caregivers felt better informed, more prepared, confident and better supported.[100, 103, 105] Satisfaction with care and its acceptability was generally high[98-100], and wishes for earlier access to interventions were expressed. We suggest informal caregivers are involved as early as possible in palliative care interventions implemented in different settings (home, community, hospitals) according to needs and preferences. Strategies such as promoting more involvement of healthcare professionals in identifying people eligible for palliative care interventions, availability of assessment tools, awareness sessions, initiatives with patients’ associations, educational programmes, and additional information via technology and peer support, might be needed to facilitate the involvement of informal caregivers during the implementation of these interventions in real-world settings, according to the available resources.

Question 5. In people with COPD, should Advance care planning (ACP) interventions be used? (PICO)

Recommendation

We suggest that ACP should be offered to people with COPD. (conditional recommendation - low quality of evidence)

Remark: ACP should be periodically revised, respecting individual needs and values of people with COPD and their informal caregivers.

Justification

Evidence was limited but demonstrated beneficial effects of ACP for people with COPD as improving quality of communication with healthcare professionals, increasing follow-up ACP discussions, and decreasing anxiety in informal caregivers.[107] Undesirable effects have not been systematically investigated, but they are considered small and mostly associated with healthcare professionals poorly skilled in ACP undertaking these discussions. The overall quality of evidence was considered as low.

Summary of main findings

Only one study met the eligibility criteria. The selected RCT[107] found that a nurse-led ACP intervention improved the quality of end-of life care communication between people with COPD and their physicians, without causing psychosocial distress in either the person with COPD or the informal caregivers. In addition, the intervention increased the frequency of ACP discussions over the subsequent 6 months.

Other considerations (see also the section in questions 7 and 8 for evidence on implementation)
Nurse-led facilitated ACP is acceptable to people with advanced respiratory disease and is effective in increasing ACP discussions and completion of advance directives. Awareness of symptom burden, readiness to engage in ACP and relevant psychosocial factors may facilitate effective tailoring of ACP interventions and achieve greater uptake.[108] Challenges are how and when ACP should be implemented for people with COPD. The unpredictable trajectory of the disease and the varying readiness of the person with COPD are challenges but also underline the need for timely ACP.[109] Sociocultural factors may play a role in how and when ACP discussions should be conducted. Nevertheless, lack of awareness of culture, religion and spirituality is experienced as a barrier towards ACP discussions with patients with chronic lung diseases.[110] Standardised ACP programmes (e.g., service guidelines and documentation) may facilitate the initiation and ongoing assessment of the plan, but should allow flexibility, respecting personal values and preferences. Healthcare professionals should be trained to conduct ACP discussions including how to address sociocultural factors (such as religion, beliefs and values). Undesirable effects have not been systematically investigated, but mostly appear to be related to poor healthcare professionals’ skills in conducting such discussions. As knowledge is still emerging in this area, studies regarding the effects of ACP in people with COPD and their informal caregivers are necessary.

**Question 6. In people with ILD, should Advance Care planning (ACP) interventions be used? (PICO)**

**Recommendation**

We suggest that ACP should be offered to people with ILD. (conditional recommendation; very low quality of evidence)

Remark: ACP should be periodically revised, respecting individual needs and values of people with ILD and their informal caregivers.

**Justification**

There is limited evidence that ACP may decrease dying in the hospital.[101] We consider it likely that the improved quality of communication seen with ACP in COPD would also be seen in people with ILD. Undesirable effects of ACP have not been systematically investigated, but no major concerns have been reported. The included study was an observational study with serious risk of bias and indirectness, so, the overall quality of evidence was considered very low.

**Summary of main findings**

Only one study met the inclusion criteria.[101] In the selected study a greater percentage of people with ILD who received ACP died at home or hospice compared to those who did not receive ACP.[101]

**Other considerations**
Two additional studies that considered ACP in people with ILD did not meet the inclusion criteria as they investigated ACP as part of a palliative care complex intervention and the independent effect of ACP could not be disaggregated from results. Qualitative data from one of these studies[98] suggested that people with ILD valued the formal ACP process as it allowed them to have important conversations that might not have otherwise been possible. The second study evaluated an ILD disease management programme that included ACP. The quantitative data from this study suggested decreased quality of life and increased anxiety in the intervention group, but these were not supported by the qualitative results. Qualitative data suggested that people with ILD felt less isolated following ACP discussion.[99] The willingness of people with ILD and informal caregivers to partake in ACP may increase over time.[98] There is limited evidence about how and when ACP should be implemented and any undesirable effects. Sociocultural factors may play a role in how and when ACP discussions should be conducted. Acceptability probably varies across different cultures and religions. As evidence is limited in this area, studies regarding the effects of ACP in people with ILD and their informal caregivers are necessary.

Questions 7 and 8. How do we implement palliative care and ACP with routine clinical care for people with COPD and ILD and their informal caregivers? (narrative)

Note: It became clear that it was not appropriate to separate implementation of palliative care and implementation of ACP because ACP was generally considered as a core component of palliative care and there was considerable overlap in papers. We have therefore combined the findings of the two searches. See online supplement 4 and 5 for further details.

Recommendations

We suggest, with regard to people with COPD or ILD and their informal caregivers, services should:

1. integrate palliative care into routine care, explicitly recognising active disease management and palliative care as complementary;
2. provide accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual/existential needs;
3. embed a system within an extended multidisciplinary team where people with COPD or ILD and persistent, unmet palliative care needs have access to specialist palliative care support;
4. foster relationships with trusted healthcare professionals enabling continuity of care;
5. recognise that initiating ACP conversations is challenging and should include analysis of context and timing to offer it. In addition, multi-disciplinary services should prioritise training, clarify responsibilities, and ensure capacity to offer timely ACP, with preferences checked as circumstances change.
(conditional recommendation – low quality of evidence)

Justification

Whilst the lack of rigorous implementation trials mean that the certainty of evidence may be considered as ‘low’, there is consistency in findings across multiple studies with a broad range of methodologies. Our recommendations build on the key emerging themes from this narrative synthesis.

Summary of main findings

Our COPD evidence-base for this question represents data from 221 original studies (13 systematic reviews reporting 175 original papers, plus 46 primary studies not included in the systematic reviews). The ILD evidence-base represents data from 56 primary studies (four systematic reviews reporting 46 original papers, plus 10 primary studies not included in the systematic reviews). See supplement 4 (COPD) and supplement 5 (ILD) for detailed synthesis of findings. In this summary, we have only included references to the systematic reviews and primary papers with novel findings.

The findings for COPD and ILD are illustrated in figure 1 and key themes of initiating palliative care, holistic needs assessment, integration with respiratory management, communication, and ACP are described below for each condition. In each theme we first describe the findings for people with COPD (which has the more mature literature) and then contrast with the findings for those with ILD. Key priorities for implementation of palliative care in terms of people with COPD and ILD, healthcare professionals and organisations are shown in tables 4 and 5. These are categorised in terms of people with COPD, healthcare professionals and organisations, a whole systems framework used by five of the systematic reviews in COPD.[68, 111-114]

Theme 1. Initiating a palliative care approach, or referral for palliative care services

Although indicators (e.g., hospitalisation, long-term oxygen therapy, symptom burden) can prompt referral of people with COPD to palliative care services[111-113, 115], some healthcare professionals hesitate to consider a palliative care approach[111, 112] due to the uncertain disease trajectory[111-113, 115, 116], lack of a clear transition to ‘end-of-life’[112, 117], normalisation of living with COPD[113], and lack of professional awareness of the potential role of palliative care.[68, 113] This is compounded by some people’s reluctance to accept a referral to palliative care because of a misunderstood association with cancer and end-of-life[66, 68, 113], though once referred, acceptability is high.[111] There is limited evidence about optimal timing of referral[113], but ‘early’ referral has been recommended[112, 115], defined in one study as when the severity of COPD is classified as ‘moderate’.[66] Some studies have proactively initiated screening (e.g., during a hospitalisation[111, 118]), or searching for prognostic indicators in primary care records.[84, 111]
Similarly, people with ILD are often not referred to palliative care services, or referred too late to address the high levels of unmet need (e.g., 71% within the last month of life[119]). Suggested triggers for palliative care referral in ILD include: oxygen therapy, ventilatory support, uncontrolled symptoms, functional decline, and opioid consideration[101, 119-122] as well as holistic needs (anxiety and depression, loneliness and isolation, and increasing informal caregiver dependence/burden).[101, 121, 123-125] (Table 3) In contrast to the poor prognosis and downward trajectory over time, albeit still seen as uncertain[120, 122], led to calls for a palliative care approach to be incorporated within usual care from soon after diagnosis.[101, 120, 124, 125]

Theme 2. Holistic needs assessment

Holistic assessment of needs (of people with COPD and informal caregivers[115]), is widely described as a crucial first step[68, 111, 113-115, 126], with practical advice that arrangements should be comprehensive[112, 114], accessible (including home-visits)[111], interdisciplinary[114], and coordinated to avoid duplication between support agencies.[127] A multidimensional assessment should not only consider the needs of the person with COPD, informal caregivers and family, but also the timing of support.[114, 128] The validated Support Needs Approach for Patients (SNAP) tool asks people with advanced COPD to identify their support needs[129], but is not yet evaluated clinically. Another available tool is the Integrated Palliative care Outcome Scale (IPOS)[130] to assess physical and emotional symptoms and communication/practical issues. IPOS is used in COPD across diverse settings and is suggested to be valid, reliable and responsive to change.[130]

Similarly for people with ILD, multidisciplinary, holistic needs assessment is preferable to a prognosis-based approach[101, 120, 121, 123, 125], with care plans and goals discussed whilst ambulatory rather than during an acute crisis. Three systematic approaches are described in the literature: a validated needs assessment tool to guide consultations (NAT-ILD)[123], a bespoke clinician supportive care decision aid (SCDAT)[125], and a multidisciplinary collaborative ILD-palliative care bundle.[101] IPOS can also be used in people with ILD.[130]

Theme 3. Integrating palliative care with respiratory management

Several studies in COPD addressed service models in which palliative care was integrated into routine care.[68, 111, 117, 127, 128, 131] This approach recognises disease-modifying management and palliative care as complementary[117, 126], and facilitates early discussions of prognosis, ACP, and holistic care.[66] Strategies to promote integration include joint respiratory/palliative care clinics[84], providing respiratory clinicians with palliative care skills[68], regular inter-professional communication[112, 127], and involvement of a key professional to coordinate multidisciplinary working and information transfer.
between sectors.[117, 126, 131] Raising awareness amongst professionals and the public was important[113, 115], normalising a palliative care approach.[128] Healthcare policy enables these initiatives by supporting organisational change and re-alignment of services.[113, 132, 133]

A needs-based approach was similarly recommended for people with ILD[101, 120, 121, 123, 125], with care coordinated across primary, respiratory (including pulmonary rehabilitation) and specialist palliative care settings, with adequate allied health support to enable care at home (if preferred).[101, 120, 121, 124, 125] Palliative care should be part of multidisciplinary case discussion and a palliative approach triggered by unmet needs, and not seen as a “near-death” intervention.[101, 120, 121, 123-125] Ongoing specialist palliative care for every person with ILD is unnecessary and unsustainable,[125, 134] but needs should be identified systematically to ensure appropriate expertise is involved. Holistic needs assessments involves using an assessment tool and clinical conversation[123, 125, 134], preferably in the ambulatory care setting and not during an acute admission, [123, 125, 134] and consideration caregivers’ needs.[101, 120, 121, 123]

Theme 4. Communication

Communication was a key theme not only among people with COPD, and informal caregivers, but also among healthcare professionals. Strategies to overcome fragmented services[135], included allocating an accessible, named professional able to signpost resources[111, 127, 131, 136], regular multidisciplinary team meetings[114, 127], joint consultations[84], and case management.[115] Most people with COPD value open and honest communication about their prognosis.[96, 112, 113, 131, 133, 136] Digital communication may be useful including phone calls[137], telemonitoring[111], teleconsultations[138], and web-based counselling or support for ACP.[115]

Good communication was also emphasised as crucial for people with ILD. Poor communication between sectors and teams was seen as a major obstacle.[119, 121, 122] Inappropriate optimism, perpetuated by poor communication skills and/or confidence was a problem as healthcare professionals avoided talking about goals of care for fear of “taking away hope”. [119, 121, 139] The concept of palliative care providing a layer of care alongside active treatment was not commonly understood[119-121], and often referrals were seen as a covert message that death was very near.[120, 121]

Theme 5. Advance Care Planning

ACP was uniformly described as central to a palliative care approach in both COPD and ILD.[113, 115] Decisions regarding preferences for end-of-life management in COPD (e.g., ventilation, resuscitation) were influenced by the individual’s prognostic awareness, illness burden, and existential concerns.[140] Systematic ACP provision for people with COPD improved involvement in decision-making[111, 112], and
recording of their wishes, with the caveat that pre-stated wishes could change, and were not always respected. ACP was perceived to be related to improved control, and confidence in self-managing symptoms, but associated changes in unscheduled care and quality of life were variable.

In the context of poor public understanding of COPD, people with COPD often lacked insight into their likely prognosis, and informal caregivers were unprepared for the death. A core function of ACP was to meet information needs, recognising that the needs of people with COPD and informal caregivers may be different. A significant minority avoid discussion about prognosis, even if they wanted information, rarely initiated the conversation. Group sessions (e.g. within pulmonary rehabilitation) were perceived as less threatening than individual discussions, though a few found them ‘depressing’.

Professionals acknowledge the importance of ACP but are unsure when, and how, to start the conversation. They were aware that some people with COPD avoid discussing prognosis, and are afraid of destroying hope by doing so. Therefore, ACP conversations are rarely initiated by professionals, who prefer people with COPD to initiate the discussion, which rarely happens. ACP discussions are best delivered by a trusted healthcare professional, with advanced communication skills and trained in ACP, optimally timed for the patient and including informal carers if wished by the patient. The legal context and place of advance directives was highlighted in one paper. Organisational barriers to incorporating ACP into routine COPD care, include lack of capacity, and no clarity on who is responsible for initiating ACP, or triggers (e.g. hospitalisation) that could indicate appropriate timing. Offers of ACP discussions need to be repeated as preferences change. Use of technology (e.g. a Web-based ACP tool for lung disease) was potentially useful and acceptable.

The findings for COPD were mirrored in the ILD literature. Planning for palliative care at an early stage of the disease with a systematic approach to conversations about disease progression, improving communication about end-of-life needs help people with ILD and informal caregivers manage the uncertainty of illness.
Other considerations

Despite some differences (for example, in the duration of the disease trajectory), the challenges in initiating and delivering an integrated approach to supportive and palliative care for people with COPD and ILD share many features. We have illustrated the considerations for a model of care in a single schema (figure 1) with some differences highlighted. It is important to remember that the evidence base in COPD is far greater than in ILD, and some specific features of ILD care may not be represented in the currently available literature. Research is needed to inform service delivery, specifically implementation of models that integrate palliative care approach into routine care of people with COPD or ILD.

DISCUSSION

The ERS task force evaluated eight questions, including four PICO questions and four narrative questions concerning palliative care for people with COPD or ILD, which were not addressed in previous international guidelines. This resulted in eight conditional recommendations (including a definition for palliative care for people with COPD or ILD), which were based on very low to low quality of evidence. Besides quality of evidence, people with illness and informal caregivers’ values and preferences, resources, feasibility, and acceptability were included into the considerations. In addition, recommendations for future research are provided.

Key findings

There was general agreement in literature that a definition of palliative care for people with serious illness due to COPD or ILD should include components such as: a multidisciplinary and holistic approach; the aim to control symptoms and to improve quality of life; the need to support informal caregivers; and the need to provide palliative care in the place of choice. A needs-based approach is suggested to identify people with serious illness who may benefit from a palliative care approach. These include physical, psychological, social as well as spiritual/existential needs. This is in line with the view of the task force of the European Association for Palliative Care concerning initiation of palliative care in people with chronic heart failure[150]. Moreover, the recent Official ATS/AAHPM/HPNA/SWHPN Policy Statement ‘Palliative Care Early in the Care Continuum among Patients with Serious Respiratory Illness’ also recommends to offer palliative care to people with serious respiratory illnesses using a needs based approach.[151]

Research is needed to explore markers of disease severity and health service utilisation related to palliative care needs and optimal ways to identify and respond to needs. In people with COPD or ILD, we suggest offering palliative care interventions that include support for informal caregivers. These
recommendations were based on very low quality of evidence and, unfortunately, meta-analysis was not possible. However, it is important to realise that there was no evidence of undesirable effects of these palliative care interventions. Moreover, meta-analysis of palliative care interventions in a broader population of chronic non-malignant diseases have shown positive effects on symptom burden, reduced emergency department visits and hospitalisations, but no association with quality of life, which was one of our critical outcomes.[22] A recent systematic review of palliative care interventions in COPD, not limited to those including family caregivers, suggested improved outcomes for people with COPD, but again a meta-analysis was not possible and effects were heterogeneous.[111] Studies are needed to establish the effects of palliative care interventions for people with COPD or ILD involving informal caregivers on critical outcomes such as communication, anxiety, depression, burden for informal caregivers and well-being of the person with illness as well as informal caregiver.

We suggest that ACP should be offered to people with COPD or ILD. However, in both illnesses only one study was selected from the literature, so meta-analyses were not possible. A meta-analysis of ACP in a broader population showed that ACP increased documentation of advance directives and discussions about end-of-life care, but did not include a meta-analysis concerning our other critical outcomes, like experience of end-of-life care, avoidable hospital visits near the end of life, or symptom control at the end of life.[152] Therefore, further research exploring effects of ACP offered to people with COPD or ILD on these outcomes is necessary. Additional research gaps include components of ACP, and cost-effectiveness.

Finally, a schema of components of palliative care services for COPD or ILD was drafted (figure 1), based on a narrative review of the literature about implementation of palliative care and ACP in routine COPD and ILD care. Our ‘whole systems’ approach classified components as those that directly address the needs of the person with COPD or ILD, those that support or upskill the professionals, and organisational strategies that underpin the multidisciplinary service. Not all components will be relevant in all settings, but policy makers and those developing services may wish to consider the components as a ‘pick list’ that they can adopt/adapt to suit their context. Specific targets of future research should be clinical evaluation of holistic need assessment tools, interventions to overcome barriers towards ACP, and implementation of models that integrate a palliative care approach into routine care of people with COPD or ILD. There are regional/national/international differences in access to palliative care services [153, 154], which should be taken into account in studying models of palliative care.
Limitations
There are several limitations concerning the present clinical practice guideline. First, all recommendations are conditional and based on very low to low quality of evidence. Nevertheless, values and preferences of people with COPD or ILD and informal caregivers guided formulation of the recommendations in addition to the quality of the evidence. Second, we could only address eight questions, while the task force identified 14 potential topics for inclusion. Examples of topics that were not addressed and may be relevant for future clinical practice guidelines are symptom management such as palliative treatment of breathlessness, existential needs and bereavement support. Third, two PICO questions explicitly focussed on palliative care interventions involving informal caregivers because of the agreement in the literature concerning the definition of palliative care, as well as agreement among the task force members (including representatives of people with COPD or ILD and informal caregivers). To this end, palliative care interventions not involving informal caregivers were not considered in question three and four of the current guideline, and thereby excluded significant literature regarding effectiveness of palliative care in this population. Importantly, we have sought to synthesise the literature on models of care to provide some insights into how innovative approaches can be implemented. Fourth, social equity was not included in the identified definitions of palliative care. Research among vulnerable people points out that inequity is present in access to palliative care.[155, 156] Surprisingly, social inequity wasn’t found in the literature of questions 7 and 8. Therefore, this may be an important factor to consider in future studies and palliative care definitions. Fifth, in the present guideline, we interpreted ACP according to the definition of the European Association for Palliative Care.[60] Nevertheless, more definitions are available, and ACP can have different legal status around the world.[157, 158] Sixth, in the present guideline, we considered specialized as well as primary palliative care interventions. Although outcomes between these interventions might differ[159], we did not take this into account. Seventh, the literature on palliative care for people with ILD is limited. Therefore, at this moment it is not possible to provide separate recommendations for the diverse group of respiratory illnesses categorized as ILD. By recommending the needs approach instead of a disease-specific approach we believe that palliative care can be adjusted to the personalized needs of people with ILD. Eight, most committee members were palliative care experts from Western European countries. Therefore, perspectives of East and Southern European countries as well as perspectives from clinicians with limited expertise in palliative care were underrepresented.
Conclusion
The task force formulated eight conditional recommendations concerning the definition of palliative care for people with COPD or ILD, when to initiate a palliative care approach for people with COPD or ILD and their informal caregivers, palliative care interventions involving informal caregivers, ACP and the implementation of palliative care interventions and ACP integrated with routine COPD and ILD care. These recommendations were based on very low to low quality of evidence, the values and preferences of people with COPD or ILD and their informal caregivers, resources, feasibility, and acceptability. However, given the consistency of the existing evidence, services should consider providing palliative care in line with these recommendations whilst awaiting further research. As new evidence comes available, these recommendations should be reconsidered and the guideline updated.
AKNOWLEDGEMENTS
The Task Force members would like to thank Mrs. Margaret Ogden for her input as a representative of people with chronic lung diseases in the early stages of this guideline.

CONFLICTS OF INTEREST
DJAJ reports lecture fees from Boehringer Ingelheim (personal), Chiesi (non-personal), AstraZeneca (non-personal) and Abbott (non-personal) within the previous three years outside the submitted work. DC has received intellectual property payments and consultancy fees from Mayne Pharma International Pty Ltd, manufacturers of Kapanol and is a paid adviser to Helsinn Pharmaceuticals. GPK has received grants from Novo Nordisk Foundation, the Danish Cancer Society and European Commission outside the submitted work. HP has received speaker fees from Boehringer Ingelheim, Teva, and Sandoz for non-promotional talks on digital respiratory health and asthma supported selfmanagement. KM reports lectures fees from Astellas Pharma, GlaxoSmithKline, AstraZeneca, Novartis, Boehringer Ingelheim, Kyowa Kirin, Norgine outside the submitted work. All other panellists have no conflicts of interest to report.
FIGURE LEGEND

Figure 1. Schema of components of palliative care services for COPD or ILD

This schema illustrates the consistent themes from the narrative synthesis (Questions 7 and 8). From the left, a range of triggers can help identify people with COPD or ILD who would benefit from a palliative care approach, though there are barriers to be overcome. A standardised, multidisciplinary assessment is the entry point to the palliative care service and an essential prerequisite to planning appropriate care. The components of a palliative care service are classified as relating to the needs and preferences of the person with COPD or ILD and their informal caregiver, the skills and attributes of the healthcare professional, and the organisational considerations. Relief of suffering is the core aim and requires overlap of these three aspects of a palliative care service illustrated as the overlap of the coloured boxes representing components. Communication (between person with COPD or ILD/informal caregiver and healthcare professional, as well as between different professional groups) is a central theme and is illustrated underpinning the whole process. ACP is a key manifestation of the communication between the person with COPD or ILD and their informal caregiver, and the healthcare professional and thus illustrated emerging from the overlap of these two components.

Abbreviations: HCP: healthcare professional; COPD: chronic obstructive lung disease; ILD: interstitial lung disease; ACP: advance care planning; CRD: chronic respiratory disease; LTOT: Long-term oxygen therapy.
REFERENCES


Box 1. Definition of palliative care for people with COPD or ILD

A holistic and multidisciplinary, person-centred approach aiming to control symptoms, and improve quality of life of people with serious health-related suffering because of COPD or ILD, and to support their informal caregivers. Palliative care:

- Is applicable throughout the whole disease trajectory according to need, in conjunction with any disease-modifying therapies.
- Entails symptom assessment and management, psychosocial support for people with COPD or ILD and informal caregivers, addressing spiritual/existential needs, effective and sensitive communication, and determining current goals of care and advance care planning (ACP).
- Is delivered while recognizing and respecting the personal and cultural values and beliefs of the person with illness and their informal caregivers.
- Is offered by healthcare professionals with basic training in palliative care or, if needed, specialists in palliative care at home, in the hospital (in the outpatient clinic, inpatient palliative care unit, ICU, other hospital wards), hospice, long-term care facility or other place of choice of the person with COPD or ILD.
- Is preferably offered by a multidisciplinary team which might include: nurses, social workers, pharmacists, psychologists, physiotherapists, physicians, occupational therapists, and pastoral care workers. Specialist palliative care is offered by clinicians with advanced knowledge of, and training in, palliative care.

Abbreviations: ACP= advance care planning; COPD= chronic obstructive pulmonary disease; ICU=intensive care unit; ILD= interstitial lung disease.
<table>
<thead>
<tr>
<th>Question</th>
<th>Recommendation</th>
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<tbody>
<tr>
<td><strong>2 Narrative</strong> When to start a palliative care approach in COPD and ILD?</td>
<td>We suggest that a palliative care approach should be considered when people with COPD or ILD and their informal caregivers have physical, psychological, social, or spiritual/existential unmet needs. Needs should be assessed using report from the person with illness or their informal caregiver report, but surrogate markers of disease severity and/or health service utilization may help identify those likely to have unmet needs. <em>(conditional recommendation – low quality of evidence?)</em></td>
</tr>
<tr>
<td><strong>3 PICO</strong> In people with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used? <em>(compared to palliative care interventions not involving informal caregivers or no palliative care interventions)</em></td>
<td>In people with COPD, we suggest palliative care interventions including support for informal caregivers should be offered. <em>(conditional recommendation - very low quality of evidence).</em></td>
</tr>
<tr>
<td><strong>4 PICO</strong> In people with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used? <em>(compared to palliative care interventions not involving informal caregivers or no palliative care interventions)</em></td>
<td>In people with ILD, we suggest palliative care interventions including support for informal caregivers should be offered. <em>(conditional recommendation - very low quality of evidence).</em></td>
</tr>
<tr>
<td><strong>5 PICO</strong> In people with COPD, should ACP interventions be used? <em>(compared with no or unstructured forms of advance care planning)</em></td>
<td>We suggest that ACP should be offered to people with COPD. ACP should be periodically revised, respecting individual needs and values of people with COPD and their informal caregivers. <em>(conditional recommendation; low quality of evidence)</em></td>
</tr>
<tr>
<td><strong>6 PICO</strong> In people with ILD, should ACP interventions be used? <em>(compared with no or unstructured forms of advance care planning)</em></td>
<td>We suggest that ACP should be offered to people with ILD. ACP should be periodically revised, respecting individual needs and values of people with ILD and their informal caregivers. <em>(conditional recommendation; very low quality of evidence)</em></td>
</tr>
</tbody>
</table>
| **7 Narrative** How do we implement palliative care with routine clinical care for people with COPD and ILD and their informal caregivers? | We suggest, with regard to people with COPD or ILD and their informal caregivers, services should:  
1. integrate palliative care into routine care, explicitly recognising active disease management and palliative care as complementary;  
2. provide accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual/existential needs; |
<table>
<thead>
<tr>
<th>8 Narrative</th>
<th>How do we implement ACP in routine clinical care for people with COPD and ILD?</th>
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<td></td>
<td>3. embed a system within an extended multidisciplinary team where people with COPD or ILD and persistent, unmet palliative care needs have access to specialist palliative care support;</td>
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<td></td>
<td>4. foster relationships with trusted healthcare professionals enabling continuity of care;</td>
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<td></td>
<td>5. recognise that initiating ACP conversations is challenging, and should include analysis of context and timing to offer it. In addition, multidisciplinary services should prioritise training, clarify responsibilities, and ensure capacity to offer timely ACP, with preferences checked as circumstances change.</td>
</tr>
</tbody>
</table>

(conditional recommendation – low quality of evidence)

**Abbreviations:** ACP= advance care planning; COPD= chronic obstructive pulmonary disease; ICU=intensive care unit; ILD= interstitial lung disease; PICO= Patient, Intervention, Comparison, Outcome.
Table 2. Recommendations for research

<table>
<thead>
<tr>
<th>Topic</th>
<th>We suggest:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition of palliative care</strong></td>
<td>Research on including social equity in the definition of palliative care.</td>
</tr>
</tbody>
</table>
| **When to start palliative care** | Performing studies to:<br>• identify which markers of disease severity and health service utilization most closely relate to palliative care need;  
• elicit the optimal ways for services to identify and respond to needs, including implementing and embedding assessment tools into clinical practice.  
• examine the impact of different models of responding to need using integrated palliative care on people with COPD or ILD and informal caregivers processes and outcomes. |
| **Palliative care interventions** | Performing studies to:<br>• establish the effects (short- and long-term) of palliative care interventions for people with COPD or ILD involving informal caregivers on outcomes considered “critical” by the task force members: Communication within the family and/or with healthcare professionals; Anxiety of informal caregivers; Depression of informal caregivers; Anxiety of people with COPD or ILD; Burden / stress for informal caregivers; Quality of life / well-being of informal caregivers; Quality of life / well-being of people with COPD or ILD; Grief/bereavement/loss experienced by the informal caregiver; Breathlessness of people with COPD or ILD.<br>• study effective components of palliative care interventions for people with COPD or ILD and their informal caregivers.<br>• establish the feasibility and effectiveness of implementing palliative care interventions involving informal caregivers of people with COPD or ILD across different settings (e.g., hospital, long-term facility, home).<br>• define strategies to promote equity of access to palliative care interventions involving informal caregivers of people with COPD or ILD.<br>• establish the cost-effectiveness of palliative care interventions involving informal caregivers of people with COPD or ILD. |
| **ACP interventions**         | Performing studies to:<br>• establish the effects of ACP interventions for people with COPD or ILD on outcomes considered “critical” by the task force members: Communication between people with ILD and healthcare professionals; Concordance between the wishes of people with COPD or ILD and received care at the end of life; Documented discussions between informal caregivers and healthcare professionals about goals of care / advance care planning; Symptom control at the end of life; Experience of end of life care; Avoidable hospital visits near end of life, measured by emergency department attendance without admission; Informal caregivers’ satisfaction with end of life care;<br>• study acceptability and feasibility (how/when initiate) of ACP for people with COPD or ILD and their informal caregivers;<br>• define core and flexible components of ACP for people with COPD or ILD and their informal caregivers;<br>• explore barriers to ACP implementation of ACP for people with COPD or ILD and their informal caregivers;<br>• analyse changes in care preferences and values of people with COPD or ILD over time;<br>• establish cost-effectiveness of ACP for people with COPD or ILD and their informal caregivers. |
| **Implementation of palliative care and ACP** | Performing future studies to:<br>• evaluate holistic needs assessment tools in clinical practice;<br>• develop and evaluate interventions to overcome the barriers preventing initiation of discussions about prognosis and ACP;<br>• implementation of models that integrate a palliative care approach into routine care of people with COPD or ILD. |

**Abbreviations:** ACP= advance care planning; COPD= chronic obstructive pulmonary disease; ILD= interstitial lung disease.
Table 3. Categories of palliative care referral criteria across literature for people with serious illness due to COPD or ILD (with examples) [52, 62]

<table>
<thead>
<tr>
<th>Needs-based criteria</th>
<th>Disease-based / health service utilization criteria</th>
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<tbody>
<tr>
<td>Physical or emotional symptoms (e.g. poor symptom control, breathlessness, pain, weight loss, cachexia)</td>
<td>Hospital use (e.g., admission, frequency of admission, admission for exacerbation)</td>
</tr>
<tr>
<td>Functional decline (e.g. increasing care dependency, low 6-minute walk test or gait speed, unable to meet ADLs)</td>
<td>Respiratory status (e.g., FEV₁ &lt;30% pred., respiratory insufficiency, GOLD stage 3-4)</td>
</tr>
<tr>
<td>Psychosocial (e.g. social needs, supportive counselling, spiritual or existential concerns)</td>
<td>Advanced respiratory therapies (e.g. invasive / non-invasive ventilation, home oxygen use)</td>
</tr>
<tr>
<td>Decision support (e.g. advance care planning, hospice referral, care coordination)</td>
<td>Disease progression (e.g. deteriorating lung function, heart failure, low albumin, multimorbidity)</td>
</tr>
<tr>
<td>Person with illness or informal caregiver request for palliative care</td>
<td>Prognosis (e.g. “surprise question”[160], life expectancy &lt;6-12 months)</td>
</tr>
<tr>
<td>Informal caregiver distress or need for support</td>
<td>Comorbidities (e.g., cancer, renal failure, diabetes)</td>
</tr>
<tr>
<td>Other (e.g. ethical concerns)</td>
<td>New diagnosis (ILD specific)</td>
</tr>
<tr>
<td></td>
<td>End stage care (e.g., terminal care, lack of treatment options)</td>
</tr>
<tr>
<td></td>
<td>Other (e.g., frailty)</td>
</tr>
</tbody>
</table>

Abbreviations: ADLs= Activities of Daily Living; FEV₁= Forced Expiratory Volume in the first second; GOLD= Global Initiative for Chronic Obstructive Lung Disease; ILD= Interstitial Lung Disease.
Table 4. Priorities for implementation of palliative care according to people with COPD, healthcare professionals and organisations

<table>
<thead>
<tr>
<th>People with COPD and informal caregivers</th>
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<tbody>
<tr>
<td>• accessing information about COPD and support services[65, 111, 112, 136]</td>
<td></td>
</tr>
<tr>
<td>• optimising treatment to reduce physical symptoms[66, 68, 111, 112, 115]</td>
<td></td>
</tr>
<tr>
<td>• coping with psychosocial challenges, maintaining enjoyable activities[68, 84, 112]</td>
<td></td>
</tr>
<tr>
<td>• ‘being listened to’ so that their care is appropriately tailored[111, 115]</td>
<td></td>
</tr>
<tr>
<td>• empathy[136],</td>
<td></td>
</tr>
<tr>
<td>• feeling ‘cared for’[65]</td>
<td></td>
</tr>
<tr>
<td>• establishing, maintaining, and in due course closing relationships</td>
<td></td>
</tr>
<tr>
<td>• need for information and practical support (e.g. respite care; resources) (informal caregivers)[115, 117, 136]</td>
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<table>
<thead>
<tr>
<th>Healthcare professionals</th>
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<tbody>
<tr>
<td>• trained in respiratory and palliative care and with access to multidisciplinary generalist and specialist expertise[111-114]</td>
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<tr>
<td>• specific skills include:</td>
<td></td>
</tr>
<tr>
<td>o ability to optimise treatment[112, 115, 117]</td>
<td></td>
</tr>
<tr>
<td>o provide holistic care[68, 112, 114, 115, 117]</td>
<td></td>
</tr>
<tr>
<td>o discuss prognosis and ACP [66, 68, 112-114, 126, 133]</td>
<td></td>
</tr>
<tr>
<td>• lead/co-ordinating professionals could be from any discipline or setting[111-113, 116, 126]</td>
<td></td>
</tr>
<tr>
<td>• continuity of care crucial to build trusting relationships[112, 113, 127, 136]</td>
<td></td>
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</table>

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<tr>
<th>Organisations</th>
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<tbody>
<tr>
<td>• accessible service (often community-based)[111, 112]</td>
<td></td>
</tr>
<tr>
<td>• responsive to individual needs and fluctuating clinical condition[112, 117]</td>
<td></td>
</tr>
<tr>
<td>• adequately resourced with professional time[111, 116]</td>
<td></td>
</tr>
<tr>
<td>• services to meet physical, psychological, social and spiritual care needs,[111, 112, 115, 128, 136] provided by a team including clinical and social care providers, generalists, disease-specific and palliative care specialists</td>
<td></td>
</tr>
<tr>
<td>• availability of ACP documentation to front-line clinical staff to guide decisions (including in an emergency)</td>
<td></td>
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<tr>
<td>• multidisciplinary teams need to be collaborative, coordinated, with good communication and defined referral channels for specialist support.[112, 113, 116, 117, 127, 131]</td>
<td></td>
</tr>
<tr>
<td>• encouraging people and their informal carers to foster relationships with one - or a very few - trusted professionals enabling continuity to be maintained despite the multidisciplinary nature of team[65, 96, 111, 113, 127, 136]</td>
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</table>

**Abbreviations:** ACP= advance care planning; COPD= chronic obstructive pulmonary disease.
Table 5. Priorities for implementation of palliative care according to people with ILD, healthcare professionals and organisations

<table>
<thead>
<tr>
<th>People with ILD and informal caregivers</th>
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<tbody>
<tr>
<td>• access to information and palliative care services\cite{101, 120, 121, 123}:</td>
<td></td>
</tr>
<tr>
<td>o for symptom control</td>
<td></td>
</tr>
<tr>
<td>o to address psycho-social needs</td>
<td></td>
</tr>
<tr>
<td>o for provision of practical help in the home</td>
<td></td>
</tr>
<tr>
<td>o support for informal caregivers</td>
<td></td>
</tr>
<tr>
<td>• clarity about prognosis</td>
<td></td>
</tr>
<tr>
<td>• continuity of care from trusted professionals</td>
<td></td>
</tr>
<tr>
<td>• informal caregivers’ needs should be assessed alongside the needs of the person with ILD (e.g. the validated NAT:ILD \cite{123})</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Healthcare professionals</th>
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</tr>
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<tbody>
<tr>
<td>• trained in \cite{119, 120, 134}:</td>
<td></td>
</tr>
<tr>
<td>o holistic assessment</td>
<td></td>
</tr>
<tr>
<td>o symptom management</td>
<td></td>
</tr>
<tr>
<td>o planning current and future goals of care</td>
<td></td>
</tr>
<tr>
<td>• access to, and support from, specialist palliative care teams</td>
<td></td>
</tr>
<tr>
<td>• using for example \cite{123-125}:</td>
<td></td>
</tr>
<tr>
<td>o a needs assessment tool into routine care</td>
<td></td>
</tr>
<tr>
<td>o multidisciplinary respiratory/palliative integration with case conferences</td>
<td></td>
</tr>
<tr>
<td>o referral checklists/decision aids</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organisations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• service reconfiguration to allow time for:</td>
<td></td>
</tr>
<tr>
<td>o holistic assessment and management</td>
<td></td>
</tr>
<tr>
<td>o multidisciplinary team discussions</td>
<td></td>
</tr>
<tr>
<td>o communication skills training for clinicians, managers and the clinical team</td>
<td></td>
</tr>
<tr>
<td>o adequate flexible resources</td>
<td></td>
</tr>
<tr>
<td>• possible models:</td>
<td></td>
</tr>
<tr>
<td>o linking respiratory/generalists with specialist palliative care teams for mutual education, training and referral\cite{134}</td>
<td></td>
</tr>
<tr>
<td>o a fully integrated collaborative ILD-palliative care service.\cite{101, 124}</td>
<td></td>
</tr>
</tbody>
</table>

**Abbreviation:** ILD= interstitial lung disease.
Identification
Potential triggers:
- Disease progression
- Poor symptom control
- Hospitalisation
- LITOT or ventilation
- Clinician judgement
- Screening
- ILD: at diagnosis

Barriers:
- Uncertain prognosis
- Poor HCP collaboration
- Normalisation of living with COPD
- Lack of awareness
- The word palliative

Holistic needs assessment
Multidisciplinary, structured approach

Palliative care service, integrated with CRD care

ACP
Identify 'triggers' and (repeatedly) offer discussion

Patient ambivalence about discussing prognosis

Trusted relationship

HCP dilemma: ACP important, but unclear when, how and who

Open and honest communication

Continuity

Establish relationship

Multidisciplinary: generalist + specialist

Compassionate

Respiratory trained + palliative care including ACP

Relief of suffering

Optimised treatment

Named key worker

Co-ordinated team

Integration of palliative with respiratory/general care

Proactive collaboration

Adequate time and resources

Supported by policy and management

Organisation

Technology / telecommunication support

Good communication

Person with COPD or ILD/informal caregiver ↔ HCP and HCP ↔ HCP
Online supplement 1

European Respiratory Society Clinical Practice Guideline:

Palliative care for people with chronic obstructive pulmonary disease or interstitial lung disease

PICO questions and outcomes

In- and exclusion criteria for each question
Question 3 (PICO). Palliative care interventions for people with COPD

PICO question:
In people with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (compared to palliative care interventions not involving informal caregivers or no palliative care interventions)

<table>
<thead>
<tr>
<th>Population</th>
<th>People with COPD and their informal caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>Palliative care involving informal caregivers</td>
</tr>
<tr>
<td>Comparison</td>
<td>Palliative care not involving informal caregivers or no palliative care intervention</td>
</tr>
<tr>
<td>Critical Outcomes</td>
<td>1. Communication within the family and/or with healthcare professionals</td>
</tr>
<tr>
<td></td>
<td>2. Anxiety of informal caregivers</td>
</tr>
<tr>
<td></td>
<td>3. Anxiety of people with COPD</td>
</tr>
<tr>
<td></td>
<td>4. Burden / stress for informal caregivers</td>
</tr>
<tr>
<td></td>
<td>5. Depression of the informal caregiver</td>
</tr>
<tr>
<td></td>
<td>6. Depression of people with COPD</td>
</tr>
<tr>
<td></td>
<td>7. Quality of life / well-being of informal caregivers</td>
</tr>
<tr>
<td></td>
<td>8. Quality of life / well-being of people with COPD</td>
</tr>
<tr>
<td></td>
<td>9. Grief/ bereavement/Loss experienced by informal caregivers</td>
</tr>
<tr>
<td></td>
<td>10. Breathlessness of people with COPD</td>
</tr>
<tr>
<td>Outcomes not critical and therefore not assessed</td>
<td>Family adjustment to illness; Coping; Informal caregiver preferences regarding palliative care; Communication within the family and/or with healthcare professionals; Knowledge about the disease of the informal caregiver; Knowledge about the disease of the person with COPD; Connectedness/Intimacy with the partner; Satisfaction of the informal caregiver with the palliative care intervention; Satisfaction of the person with COPD with the palliative care intervention; Personal growth of the informal caregiver; Personal growth of the person with COPD; Stress of...</td>
</tr>
</tbody>
</table>
the person with COPD; Fatigue of the informal caregiver; Fatigue of the person with COPD; Loneliness of the informal caregiver; Loneliness of the person with COPD; Grief/ bereavement/Loss experienced by the person with COPD.

Detailed description of informal caregiver:
Informal caregivers (any relative, partner, friend, neighbor, or significant other with personal relationship with the person cared for and who provides a broad range of unpaid assistance to the person with COPD or ILD[1]) have a major and complex role. They fulfill many tasks, including: managing and monitoring medication, appointments, and symptoms; ensuring hygiene and nutritional needs are met; encouraging and supporting adherence to treatment recommendations; providing physical, social, psychological and emotional support; recognizing and managing emergency issues; handling equipment; managing care recipient behavior and temperament; handling household- and illness-related finances; and carrying out decision-making and problem-solving.[2-8] They are therefore the main, although often “hidden”, workforce responsible for providing most of daily care.[9] Nevertheless, their different roles require health literacy, disease knowledge, financial security, household conditions, psychological readiness, medical care abilities, among others and yet they generally receive insufficient support.[2-5, 10]

References
**Question 4 (PICO). Palliative care interventions for people with ILD**

**PICO question:**

In people with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used? (compared to palliative care interventions not involving informal caregivers or no palliative care interventions)

<table>
<thead>
<tr>
<th>Population</th>
<th>People with ILD and their informal caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intervention</strong></td>
<td>Palliative care involving informal caregivers</td>
</tr>
<tr>
<td><strong>Comparison</strong></td>
<td>Palliative care not involving informal caregivers or no palliative care intervention</td>
</tr>
<tr>
<td><strong>Critical outcomes</strong></td>
<td>1. Communication within the family and/or with healthcare professionals</td>
</tr>
<tr>
<td></td>
<td>2. Anxiety of informal caregivers</td>
</tr>
<tr>
<td></td>
<td>3. Anxiety of people with ILD</td>
</tr>
<tr>
<td></td>
<td>4. Burden / stress for informal caregivers</td>
</tr>
<tr>
<td></td>
<td>5. Depression of the informal caregivers</td>
</tr>
<tr>
<td></td>
<td>6. Depression of people with ILD</td>
</tr>
<tr>
<td></td>
<td>7. Quality of life / well-being of the informal caregivers</td>
</tr>
<tr>
<td></td>
<td>8. Quality of life / well-being of people with ILD</td>
</tr>
<tr>
<td></td>
<td>9. Grief/ bereavement/loss experienced by the informal caregivers</td>
</tr>
<tr>
<td></td>
<td>10. Breathlessness of people with ILD</td>
</tr>
</tbody>
</table>

**Outcomes not critical and therefore not assessed**

Family adjustment to illness; Coping; Informal caregiver preferences regarding palliative care; Communication within the family and/or with healthcare professionals; Knowledge about the disease of the informal caregiver; Knowledge about the disease of the person with ILD; Connectedness/Intimacy with the partner; Satisfaction of the informal caregiver with the palliative care intervention; Satisfaction of the person with ILD with the palliative care intervention; Personal growth of the informal caregiver; Personal growth of the person with ILD; Stress of the
person with ILD; Fatigue of the informal caregivers; Fatigue of the person with ILD; Loneliness of the informal caregiver; Loneliness of the person with ILD; Grief/bereavement/Loss experienced by the person with ILD.
Question 5 (PICO). Advance care planning interventions for people with COPD

PICO question:

*In people with COPD, should Advance Care Planning (ACP) interventions be used? (compared with no or unstructured forms of advance care planning)*

**Population**  People with COPD

**Intervention**  Advance care planning (ACP)

**Comparison**  No or unstructured forms of ACP

**Critical outcomes**

1. Quality of communication between people with COPD and healthcare professionals
2. Concordance between the wishes of the person with COPD and received care at the end of life
3. Documented discussions between informal caregivers and health professional about goals of care / advance care planning
4. Symptom control at the end of life
5. Experience of end of life care
6. Avoidable hospital visits near end of life, measured by emergency department attendance without admission
7. Informal caregivers’ satisfaction with end of life care

**Outcomes not critical and therefore not assessed**

- Use of interventions with main aim to prolong life; Place of death according to the wish of the person with COPD; Caregiver's experience of end-of-life care; Length of stay in hospital; Concordance in wishes between surrogates and persons with COPD; Awareness among healthcare providers of preferences of people with COPD during end of life and advance decisions.
Question 6 (PICO). Advance care planning interventions for people with ILD

PICO question:

In people with ILD, should Advance Care Planning (ACP) interventions be used? (compared with no or unstructured forms of advance care planning)

<table>
<thead>
<tr>
<th>Population</th>
<th>People with ILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>Advance care planning (ACP)</td>
</tr>
<tr>
<td>Comparison</td>
<td>No or unstructured forms of ACP</td>
</tr>
<tr>
<td>Critical outcomes</td>
<td>1. Quality of communication between person with ILD and healthcare professionals</td>
</tr>
<tr>
<td></td>
<td>2. Concordance between the wishes of the person with ILD and received care at the end of life</td>
</tr>
<tr>
<td></td>
<td>3. Documented discussions between informal caregivers and health professional about goals of care / advance care planning</td>
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<tr>
<td></td>
<td>4. Symptom control at the end of life</td>
</tr>
<tr>
<td></td>
<td>5. Experience of end of life care</td>
</tr>
<tr>
<td></td>
<td>6. Avoidable hospital visits near end of life, measured by emergency department attendance without admission</td>
</tr>
<tr>
<td></td>
<td>7. Informal caregivers’ satisfaction with end of life care</td>
</tr>
</tbody>
</table>

Outcomes: Use of interventions with main aim to prolong life; Place of death according to the wish of the person with ILD; Caregiver's experience of end-of-life care; Length of stay in hospital; Concordance in wishes between surrogates and persons with ILD; Awareness among healthcare providers of preferences of people with ILD during end of life and advance decisions.

Outcomes: not critical and therefore not assessed
In- and exclusion criteria for each question

Question 1

*Inclusion criteria question 1*
- Providing a definition concerning palliative care applicable for people with COPD or ILD
- Systematic review or original study

*Exclusion criteria question 1*
- Letter, protocol or editorial
- Addressing only terminal care
- Addressing only persons with cancer

Question 2

*Inclusion criteria question 2*
- Studies including people with COPD or ILD, caregiver(s), or clinicians providing care for these groups
- Studies reporting on referral criteria, indicators, triggers to start palliative care (generalist or specialist)
- Studies of tools used to screen for and/or assess palliative care needs
- Studies of palliative care interventions (described by authors or fitting definition text)
- Systematic review, clinical trial, observational study, interview/focus groups, case series
- Published in any language

*Exclusion criteria question 2*
- Studies reporting symptoms without an explicit link to palliative care
- Studies including only caregiver(s) (e.g., starting bereavement care)
- Study protocols
- Opinion pieces including narrative reviews, editorials, correspondence.
- Single case studies

Question 3

*Inclusion criteria question 3*
- Studies including palliative care interventions involving informal caregivers of adult people with COPD
- Systematic review or original study
- No language restriction

**Exclusion criteria question 3**
- Studies reporting on measurement properties of tools designed to measure effects of the palliative care interventions
- Interventions targeting only formal caregivers in palliative care
- Studies reporting only on advance care planning interventions involving informal caregivers
- Studies not reporting outcomes of interventions (e.g., protocols, design of study or development intervention etc)
- Case reports

**Question 4**

**Inclusion criteria question 4**
- Studies including palliative care interventions involving informal caregivers of adult people with ILD
- Systematic review or original study
- No language restriction

**Exclusion criteria question 4**
- Studies reporting on measurement properties of tools designed to measure effects of the palliative care interventions
- Interventions targeting only formal caregivers in palliative care
- Studies reporting only on advance care planning interventions involving informal caregivers
- Studies not reporting outcomes of interventions (e.g., protocols, design of study or development intervention etc)
- Case reports

**Question 5**

**Inclusion criteria question 5**
- Studies regarding effects of advance care planning (ACP) on people with chronic obstructive pulmonary disease (COPD)
- Adult people or their representatives
- ACP defined as intervention labelled as ACP by the authors or intervention involving any of:
  - Discussion of values and goals of people with COPD for future medical care and treatment
Clarifying values and goals of people with COPD for future medical care and treatment

- Documenting wishes of people with COPD

- Data are presented specifically for ACP and COPD:
  - In case of complex interventions, it must include and report separate data for ACP
  - In case of mixed samples, it must report separate data for COPD
  - Published work without restriction of year of publication and language

Exclusion criteria question 5

- Studies not reporting outcomes of ACP (e.g., protocols, design of study or development intervention, etc)
- Only abstract published
- Case studies
- Review studies

Question 6

Inclusion criteria question 6

- Studies regarding effects of advance care planning (ACP) on people with Interstitial Lung Disease (ILD)
- Adult people with ILD or their representatives
- ACP defined as intervention labelled as ACP by the authors or intervention involving any of:
  - Discussion of values and goals of people with ILD for future medical care and treatment
  - Clarifying values and goals of people with ILD for future medical care and treatment
  - Documenting wishes of people with ILD
- Data are presented specifically for ACP and ILD:
  - In case of complex interventions, it must include and report separate data for ACP
  - In case of mixed samples, it must report separate data for ILD
  - Published work without restriction of year of publication and language

Exclusion criteria question 6

- Studies not reporting outcomes of ACP (e.g., protocols, design of study or development intervention, etc)
- Only abstract published
- Case studies
- Review studies
Question 7 and 8

Inclusion criteria question 7 and 8

- Systematic reviews or original studies evaluating implementation of palliative care within routine clinical care for people with COPD or ILD and their informal caregivers
- Systematic reviews or original studies evaluating strategies for implementing ACP in routine clinical care for people with COPD and ILD
- In case of mixed samples, it must include people with COPD or ILD and report data relevant to those groups
- Published work without restriction of year of publication and language

Exclusion criteria question 7 and 8

Systematic reviews:

- Generic systematic review, no or limited COPD-specific data
- Highlights needs but no insights into improved care
- Not a systematic review (e.g., clinical review; overview of existing guidelines)
- Not addressing palliative care

Other articles

- No insights into improved care (e.g., description of living with COPD; surveys shortcomings)
- Generic, no insights relevant to COPD or ILD services
- Prediction of mortality post-admission
- Clinical review/perspective
- Protocol, trial registration
- Conference abstract
Online supplement 2

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

Search strategy
Summary of search process

Each question was treated as a separate systematic review with searches developed according to the question. Main search concepts that could be re-used were drafted in OVID Medline using scoping searches, examining the methods of existing relevant systematic reviews, validated search filters (e.g. for palliative care)[1, 2] and tools such as MeSH Analyzer and PubMed PubReminer to research terms. Common concept searches covered COPD and ILD, palliative care, informal caregivers, advance care planning. Draft searches were shared with task force members for comment and edited after feedback before searches were translated for use in other databases.

Most searches were split between a search for systematic reviews addressing the question and a search retrieving other studies. Each question searched the same set of databases and results were downloaded into individual Endnote Libraries for each question and duplicates were removed. Search results after de-duplication were distributed to question subgroups in different formats which included structured bibliographies, compressed Endnote libraries and RIS files to be imported into other softwares.

Where search methods differed from the main process this is indicated below in the search strategy information for each question.
Search strategy question 1
Definition of palliative care (question 1, narrative)

Note: Searches limited to systematic reviews only.
(Initial search date 11 March 2021, all database searches updated 19th April 2022. We searched all database from their inception)

Ovid MEDLINE(R) ALL 1946 to April 19 2022
1. Terminology as Topic/
2. (define* or defining or definition* or conceptualization or conceptualise or terminology or nomenclature).ti.
3. 1 or 2
4. exp advance care planning/
5. exp attitude to death/
6. exp bereavement/
7. death/
8. hospices/
9. life support care/
10. palliative care/ or Palliative Medicine/
11. exp terminal care/ or respite care/
12. terminally ill/
13. palliative$.ti,ab,kw.
14. hospice$.ti,ab,kw.
15. (terminal care or respite care).ti,ab,kw.
16. or/4-15
17. attitude to death.mp.
18. end of life.ti,ab,kw.
19. ((advanced or terminal*) adj (ill* or disease)).ti,ab,kw.
20. supportive care.ti,ab,kw.
21. dying.ti,ab,kw.
22. "last year of life".ti,ab,kw.
23. (limited life adj (expectancy or span*).ti,ab,kw. or life-limiting.mp.
24. 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25. 3 and 24
26. limit 25 to (systematic reviews pre 2019 or systematic reviews)

Ovid Embase 1974 to April 19 2022
1. nomenclature/
2. (define* or defining or definition* or conceptualization or conceptualise or terminology or nomenclature).ti,kw.
3. 1 or 2
4. advance care planning/
5. attitude to death/
6. bereavement/
7. death/
8. hospice/
9. palliative therapy/
10. respite care/
11. terminal care/ or hospice care/
12. exp terminally ill patient/
13. palliative$.af.
14. hospice$.af.
15. (terminal care or respite care).af.
16. supportive care.ti,ab,kw.
17. bereave$.mp.
18. attitude to death.mp.
19. end of life.af.
20. ((advanced or terminal*) adj (ill* or disease)).ti,ab,kw.
22. (limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
23. "last year of life".ti,ab,kw.
24. dying.ti,ab,kw.
25. or/4-24
26. 3 and 25
27. exp review/
28. (literature adj3 review$).ti,ab.
29. exp meta analysis/
30. exp "systematic review"/
31. or/27-30
32. (medline or medlars or embase or pubmed or cinahl or amed or psychlit or psyclit or psychinfo or psycinfo or scisearch or cochrane).ti,ab.
33. RETRACTED ARTICLE/
34. 32 or 33
35. 31 and 34
36. (systematic$ adj2 (review$ or overview)).ti,ab.
37. (meta?anal$ or meta anal$ or meta-anal$ or metaanal$ or metanal$).ti,ab.
38. 35 or 36 or 37
39. 26 and 38
40. limit 39 to conference abstract status
41. 39 not 40

Cochrane Database of Systematic Reviews via The Cochrane Library April 1996 to April 19th 2022

ID | Search
---|---
#1 | MeSH descriptor: [Advance Care Planning] explode all trees
#2 | MeSH descriptor: [Attitude to Death] explode all trees
#3 | MeSH descriptor: [Bereavement] explode all trees
#4 | MeSH descriptor: [Death] this term only
#5 | MeSH descriptor: [Hospices] this term only
#6 | MeSH descriptor: [Life Support Care] this term only
#7 | MeSH descriptor: [Palliative Care] explode all trees
#8 | MeSH descriptor: [Respite Care] explode all trees
#9 | MeSH descriptor: [Terminal Care] explode all trees
#10 | MeSH descriptor: [Terminaly Ill] explode all trees
#11 | (palliat* or hospice*):ti,ab,kw
#12 | ((terminal or supportive) next care):ti,ab,kw
#13 | (respite next care):ti,ab,kw
#14 | (bereave* or dying):ti,ab,kw
#15 | ("attitude to death"):ti,ab,kw
#16 | (((advanced or terminal* or critical*) next (ill* or disease))):ti,ab,kw
#17 | (advance* next care):ti,ab,kw
#18 | ("last year of life" or (limited next (expectanc* or span*)) or life-limiting):ti,ab,kw
#19 | #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18
#20  (define* or defining or definition* or conceptuali?ation or conceptuali?e or terminology or nomenclature):ti
#21  #19 and #20

CINAHL Complete via EBSCOhost 1937 to April 19th 2022
S1   ( (MH "Terminal Care+") or (MH "Palliative Care") or (MH "Attitude to Death") or (MH "Advance Care Planning") or (MH "Respite Care") or (MH "Hospices") or (MH "Life Support Care") )
OR TI ( bereave* or hospice* or "end of life" or "terminally ill" or palliat* ) OR TI ( bereave* or hospice* or "end of life" or "terminally ill" or palliat* )
S2   (TI (systematic* n3 review*)) or (AB (systematic* n3 review*)) or (TI (systematic* n3 bibliographic*)) or (AB (systematic* n3 bibliographic*)) or (TI (systematic* n3 literature)) or (AB (systematic* n3 literature)) or (TI (comprehensive* n3 literature)) or (AB (comprehensive* n3 literature)) or (TI (comprehensive* n3 bibliographic*)) or (AB (comprehensive* n3 bibliographic*)) or (TI (integrative n3 review)) or (AB (integrative n3 review)) or (IN “Cochrane Database of Systematic Reviews”) or (TI (information n2 synthesis)) or (TI (data n2 synthesis)) or (AB (information n2 synthesis)) or (AB (data n2 synthesis)) or (TI (data n2 extract*)) or (AB (data n2 extract*)) or (TI (medline or pubmed or psyclit or cinahl or (psycinfo not “psycinfo database”) or “web of science” or scopus or embase)) or (AB (medline or pubmed or psyclit or cinahl or (psycinfo not “psycinfo database”) or “web of science” or scopus or embase)) or (MH “Systematic Review”) or (MH “Meta Analysis”) or (TI (meta-analy* or metaanaly*)) or (AB (meta-analy* or metaanaly*))
S3   TI define* or defining or definition* or conceptuali?ation or conceptuali?e or terminology or nomenclature
S4   MJ nomenclature
S5   S3 OR S4
S6   S1 AND S2 AND S5

SCOPUS via Scopus.com from inception to April 19th 2022
( TITLE ( palliat* OR hospice* OR respite AND care ) AND TITLE ( define* OR defining OR definiti on* OR conceptuali?ation OR conceptuali?e OR terminology OR nomenclature ) AND TITLE-ABS-
KEY ( systematic AND review OR scoping AND review ) )

Web of Science Core collection (including SCI-EXPANDED 1970 to April 19th 2022)
TITLE: (define* or defining or definition* or conceptuali?ation or conceptuali?e or terminology or nomenclature) AND TOPIC: (palliat* or hospice* or respite care) AND TITLE: ("systematic review" or "scoping review")

Epistemonikos via https://www.epistemonikos.org/en/ from inception to April 19th 2022

title:(define* OR defining OR definition* OR conceptuali?ation OR conceptuali?e OR terminology OR nomenclature) AND title:(palliat* OR hospice* OR end of life)

In addition we reviewed the CareSearch systematic review collection for relevant studies.
Search strategy question 2
When to start a palliative care approach in COPD and ILD (question 2, narrative)

Note: Searches for systematic reviews were performed first, followed by searches for other studies. Both sets of search strategies are listed below
(Initial search date 18-19 March 2021, all database searches updated 19th April 2022. We searched all databases from their inception)

Searches for systematic reviews:

Ovid MEDLINE(R) ALL 1946 to April 19 2022
Search structure: Palliative care [line 42] AND timing/initiation [line 50] AND (ILD or COPD)[Line 80] AND SR filter [line 82 or 110]
1. exp advance care planning/
2. exp attitude to death/
3. exp bereavement/
4. death/
5. hospices/
6. life support care/
7. palliative care/ or Palliative Medicine/
8. exp terminal care/ or respite care/
9. terminally ill/
10. palliat$.af.
11. hospice$.af.
12. (terminal care or respite care).af.
13. or/1-12
14. journal of palliative care.jn.
15. journal of palliative medicine.jn.
16. hospice journal physical psychosocial & pastoral care of the dying.jn.
17. supportive care in cancer.jn.
18. palliative medicine.jn.
19. palliative & supportive care.jn.
20. journal of supportive oncology.jn.
21. journal of social work in end of life & palliative care.jn.
22. journal of pain & symptom management.jn.
23. journal of pain & palliative care pharmacotherapy.jn.
24. international journal of palliative nursing.jn.
25. death studies.jn.
26. death education.jn.
27. american journal of hospice care.jn.
28. american journal of hospice & palliative medicine.jn.
29. omega journal of death & dying.jn.
30. or/14-29
31. 13 or 30
32. bereave$.mp.
33. attitude to death.mp.
34. end of life.af.
35. Advance* Care.af.
36. (advanced or terminal*) adj (ill* or disease)).ti,ab,kw.
37. supportive care.ti,ab,kw.
38. dying.ti,ab,kw.
39. "last year of life".ti,ab,kw.
40. (limited life adj (expectanc* or span*).ti,ab,kw. or life-limiting.mp.
41. or/32-40
42. 31 or 41  [Palliative care concept]
43. "Referral and Consultation"/
44. Time Factors/
45. (timing or time or timely or trigger*).ti,ab,kw.
46. (selection or refer*) adj2 criteria*.ti,ab,kw.
47. Patient Selection/
48. (duration or start* or early or begin or began or initiate or initiation or initiating).ti,ab,kw.
49. Specialization/
50. or/43-49  [Timing/initiation concept]
51. exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
52. emphysema$.mp.
53. (chronic$ adj3 bronchiti$).mp.
54. (obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).mp.
55. COPD.mp.
56. COAD.mp.
57. COBD.mp.
58. AECB.mp.
59. Lung Diseases, Obstructive/
60. or/51-59 [based on Cochrane Airways COPD register search]
61. exp Lung Diseases, Interstitial/
62. exp Pulmonary Fibrosis/
63. (interstitial$ adj3 (lung$ adj3 disease$)).tw.
64. (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumo pathy)).tw.
65. (diffuse* adj3 parenchymal*).tw.
66. alveolitis.mp.
67. exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterans).mp.
68. (goodpasture$ adj syndrome$).mp.
69. granulomatosis.mp.
70. exp Histiocytosis/ or histiocytosis$.mp.
71. exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumonoconiosis.mp. or pneu monoconiosis.mp.
72. bagassosis.mp.
73. (pulmonary$ adj sarcoid$).mp.
74. (pulmonary$ adj fibros$).mp.
75. (wegener$ adj granuloma$).mp.
76. (lung$ adj purpura$).mp.
77. ((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
78. (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
79. or/61-78 [ILD search]
80. 79 or 60 [ILD or COPD]
81. 42 and 50 and 80 [Palliative care AND timing/initiation and COPD/ILD]
82. limit 81 to (systematic reviews pre 2019 or systematic reviews)  [OVID inbuilt SR filter]
83. review.pt.
84. (medline or medlars or embase or pubmed or cochrane).tw,sh.
85. (scisearch or psychinfo or psycinfo).tw,sh.
86. (psychlit or psyclit).tw,sh.
87. cinahl.tw,sh.
88. ((hand adj2 search$) or (manual$ adj2 search$)).tw,sh.
89. (electronic database$ or bibliographic database$ or computeri?ed database$ or online database$).tw,sh.
90. (pooling or pooled or mantel haenszel).tw,sh.
91. (peto or dersimonian or der simonian or fixed effect).tw,sh.
92. (retraction of publication or retracted publication).pt.
93. or/84-92
94. 83 and 93
95. meta-analysis.pt.
96. meta-analysis.sh.
97. (meta-analysis$ or meta analys$ or metaanalys$).tw,sh.
98. (systematic$ adj5 review$).tw,sh.
99. (systematic$ adj5 overview$).tw,sh.
100. (quantitative$ adj5 review$).tw,sh.
101. (quantitative$ adj5 overview$).tw,sh.
102. (quantitative$ adj5 synthesis$).tw,sh.
103. (methodologic$ adj5 review$).tw,sh.
104. (methodologic$ adj5 overview$).tw,sh.
105. (integrative research review$ or research integration).tw.
106. ((qualitative$ adj5 synthesis$) or (scoping adj review)).tw,sh.
108. or/95-107
109. 94 or 108 [BMJ clinical evidence SR filter]
110. 81 and 109 [palliative AND timing/initiation AND COPD/ILD AND BMJ SR filter]
111. 82 or 110 [Search limited to OVID SR filter or BMJ SR filter]

Ovid Embase 1974 to April 19 2022

1. patient referral/
2. patient identification/
3. (timing or time or timely or trigger*).ti,ab,kw.
4. ((selection or refer*) adj2 criteria*).ti,ab,kw.
5. (duration or start* or early or begin or began or initiate or initiation or initiating).ti,ab,kw.
6. or/1-5 [Timing/initiation concept]
7. advance care planning/
8. attitude to death/
9. bereavement/
10. death/
11. hospice/
12. palliative therapy/
13. respite care/
14. terminal care/ or hospice care/
15. exp terminally ill patient/
16. palliat$.af.
17. hospice$.af.
18. (terminal care or respite care).af.
19. supportive care.ti,ab,kw.
20. bereave$.mp.
21. attitude to death.mp.
22. end of life.af.
23. ((advanced or terminal*) adj (ill* or disease)).ti,ab,kw.
25. (limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
26. "last year of life".ti,ab,kw.
27. dying.ti,ab,kw.
28. or/7-27  [palliative care concept]
29. 6 and 28  [timing/initiation AND palliative care]
30. exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
31. emphysema$.mp.
32. (chronic$ adj3 bronchiti$).mp.
33. (obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).mp.
34. COPD.mp.
35. COAD.mp.
36. COBD.mp.
37. AECB.mp.
38. Lung Diseases, Obstructive/
39. or/30-38 [COPD search concept]
40. exp Lung Diseases, Interstitial/
41. exp Pulmonary Fibrosis/
42. (interstitial$ adj3 (lung$ adj3 disease$)).tw.
43. (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
44. (diffuse* adj3 parenchymal*).tw.
45. alveolitis.mp.
46. exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterator).mp.
47. (goodpasture$ adj syndrome$).mp.
48. granulomatosis.mp.
49. exp Histiocytosis/ or histiocytosis$.mp.
50. exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumokoniosis.mp. or pneumonoconiosis.mp.
51. bagassosis.mp.
52. (pulmonary$ adj sarcoid$).mp.
53. (pulmonary$ adj fibros$).mp.
54. (wegener$ adj granuloma$).mp.
55. (lung$ adj purpura$).mp.
56. ((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
57. (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
58. or/40-57 [ILD search concept]
59. 39 or 58 [COPD or ILD]
60. 29 and 59  [Timing/Initiation AND palliative care AND COPD/ILD]
61. exp review/
62. (literature adj3 review$).ti,ab.
63. exp meta analysis/
64. exp "systematic review"/
65. or/61-64
66. (medline or medlars or embase or pubmed or cinahl or amed or amlit or psyclit or psychinfo or psycinfo or scisearch or cochrane).ti,ab.
67. RETRACTED ARTICLE/
68. 66 or 67
69. 65 and 68
70. (systematic$ adj2 (review$ or overview$)).ti,ab.
71. (meta?anal$ or meta anal$ or meta-anal$ or metaanal$ or metanal$).ti,ab.
72. 69 or 70 or 71  [filter for Systematic reviews]
73. 60 and 72  [timing/initiation AND palliative care AND COPD/ILD AND SRs]
74. limit 73 to conference abstract status [retrieve conference abstracts]
75. 73 not 74 [remove conference abstracts]

Cochrane Database of Systematic Reviews 1996 to 19 April 2022 via The Cochrane Library

Palliative care [line #19] AND ILD/COPD [line #47] AND timing/initiation concepts [#56]

ID  Search
#1   MeSH descriptor: [Advance Care Planning] explode all trees
#2   MeSH descriptor: [Attitude to Death] explode all trees
#3   MeSH descriptor: [Bereavement] explode all trees
#4   MeSH descriptor: [Death] this term only
#5   MeSH descriptor: [Hospices] this term only
#6   MeSH descriptor: [Life Support Care] this term only
#7   MeSH descriptor: [Palliative Care] explode all trees
#8   MeSH descriptor: [Respite Care] explode all trees
#9   MeSH descriptor: [Terminal Care] explode all trees
#10  MeSH descriptor: [Terminally Ill] explode all trees
#11  (palliat* or hospice*):ti,ab,kw
#12  ((terminal or supportive) next care):ti,ab,kw
#13  (respite next care):ti,ab,kw
#14  (bereave* or dying):ti,ab,kw
#15  ("attitude to death"):ti,ab,kw
#16  (((advanced or terminal* or critical*) next (ill* or disease))):ti,ab,kw
#17  (advance* next care):ti,ab,kw
#18  ("last year of life" or (limited next (expectanc* or span*)) or life-limiting):ti,ab,kw
#19  #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15
or #16 or #17 or #18
#20  MeSH descriptor: [Lung Diseases, Interstitial] explode all trees
#21  MeSH descriptor: [Pulmonary Fibrosis] explode all trees
#22  (((interstitial* near/3 (lung* near/3 disease*)):ti,ab,kw
#23  interstitial* near/3 (fibros* or pneumonitis or pneumonia or pneumopathy):ti,ab,kw
#24  diffuse* near/3 parenchymal*:ti,ab,kw
#25  (Alveolitis):ti,ab,kw
#26  MeSH descriptor: [Bronchiolitis Obliterans] explode all trees
#27  (bronchiolitis next obliterans):ti,ab,kw
#28  (goodpasture* NEXT syndrome*):ti,ab,kw
#29  (granulomatosis):ti,ab,kw
#30  MeSH descriptor: [Histiocytosis] explode all trees
#31  (histiocytosis*):ti,ab,kw
#32  MeSH descriptor: [Pneumoconiosis] explode all trees
#33  (pneumoconiosis or pneumokoniosis or pneumonoconiosis):ti,ab,kw
#34  (bagassosis):ti,ab,kw
#35  (pulmonary next (sarcoid* or fibros*)):ti,ab,kw
#36  (wegener* next granuloma*):ti,ab,kw
#37  (lung* adj purpura):ti,ab,kw
#38  (((bird* or farmer* or pigeon* or avian* or budgerigar*) next (lung* or disease*)):ti,ab,kw
#39  #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or
#33 or #34 or #35 or #36 or #37 or #38
#40  MeSH descriptor: [Pulmonary Disease, Chronic Obstructive] explode all trees
#41  (emphysema*):ti,ab,kw
#42  (chronic* near/2 bronchiti*):ti,ab,kw
CINAHL Complete via EBSCOhost  1937 to April 19th 2022

Search structure Palliative care [S1] AND COPD/ILD [S16] AND timing/initiation [S20] and systematic reviews [S22]

S1 ( (MH "Terminal Care+") or (MH "Palliative Care") or (MH "Attitude to Death") or (MH "Advance Care Planning") or (MH "Respite Care") or (MH "Hospices") or (MH "Life Support Care") ) OR TI ( bereave* or hospice* or "end of life" or "terminally ill" or palliat* ) OR TI ( bereave* or hospice* or "end of life" of "terminally ill" or palliat* )

S2 S13 OR S12 OR S3 OR S4 OR S5 OR S6 OR S7 OR S6 OR S5 OR S4 OR S3

S3 TI ( asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis ) OR AB ( asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis )

S4 TI wegener* n1 granuloma* OR AB wegener* n1 granuloma* OR TI ( ((bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)) ) OR AB ( ((bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)) )

S5 TI ( pneumoconiosis or pneumokoniosis or pneumonoconiosis or bagassosis ) OR AB ( pneumoconiosis or pneumokoniosis or pneumonoconiosis or bagassosis ) OR TI ( pulmonary n1 (sarcoid* or fibros*) ) OR AB ( pulmonary n1 (sarcoid* or fibros*) )

S6 TI "bronchiolitis obliterans" OR AB "bronchiolitis obliterans" OR TI ( granulomatosis or "goodpasture* syndrome" ) OR AB ( granulomatosis or "goodpasture* syndrome" )

S7 AB diffuse* n3 parenchymal* OR TI diffuse* n3 parenchymal* OR TI Alveolitis OR AB Alveolitis

S8 TI ( interstitial n2 (lung* or fibros* or pneumo*) ) OR AB ( interstitial n2 (lung* or fibros* or pneumo*) )

S9 (MH "Pneumoconiosis+")

S10 (MH "Histiocytosis+")

S11 (MH "Bronchiolitis Obliterans+")

S12 (MH "Pulmonary Fibrosis+")

S13 (MM "Lung Diseases, Interstitial+")

S14 ( (MH "Pulmonary Disease, Chronic Obstructive+") or (MH "Emphysema") or (MH "Lung Diseases, Obstructive") ) OR TI ( obstruct* n3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*) ) OR AB ( obstruct* n3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*) )

S15 S2 OR S14

S16 S1 AND S15

S17 (MH "Referral and Consultation+")
S18 (MH "Patient Selection")
S19 TI ( timing or time or timely or trigger*) OR AB ( timing or time or timely or trigger*) OR TI ((selection or refer*) n2 criteria*) OR AB ((selection or refer*) n2 criteria*) OR TI ( duration or start* or early or begin or began or initiate or initiation or initiating ) OR AB ( duration or start* or early or begin or began or initiate or initiation or initiating )
S20 S17 OR S18 OR S19
S21 S16 AND S20
S22 (TI (systematic* n3 review*)) or (AB (systematic* n3 review*)) or (TI (systematic* n3 bibliographic*)) or (AB (systematic* n3 bibliographic*)) or (TI (systematic* n3 literature)) or (AB (comprehensive* n3 literature)) or (TI (comprehensive* n3 bibliographic*)) or (AB (comprehensive* n3 bibliographic*)) or (TI (integrative n3 review)) or (AB (integrative n3 review)) or (IN "Cochrane Database of Systematic Reviews") or (TI (information n2 synthesis)) or (TI (data n2 synthesis)) or (AB (information n2 synthesis)) or (AB (data n2 synthesis)) or (TI (data n2 extract*)) or (AB (data n2 extract*)) or (TI (medline or pubmed or psyclit or cinahl or (psycinfo not "psycinfo database") or “web of science” or scopus or embase)) or (AB (medlne or pubmed or psyclit or cinahl or (psycinfo not “psycinfo database”) or “web of science” or scopus or embase)) or (MH “Systematic Review”) or (MH “Meta Analysis”) or (TI (meta-analy* or metanaly*)) or (AB (meta-analy* or metanaly*))
S23 S21 AND S22

Web of Science Core collection (including SCI-EXPANDED 1970 to April 19th 2022)

Search structure: ILD/COPD AND palliative care AND timing/initiation AND Systematic reviews

TOPIC: ("Interstitial lung disease*" OR "parenchymal lung dis*" OR "pulmonary fibrosis" OR "sarcoidosis" OR "interstitial pneumonia" OR "asbestosis" OR "pneumoconiosis" or COPD OR chronic obstructive pulmonary disease) AND TOPIC: ("Terminal care" OR "life support care" OR "palliative care" OR "Advanced care planning" OR "hospice*" OR "Respite care" OR "End-of-life care") AND TOPIC: (timing OR time OR timely OR trigger* OR duration OR start* OR early OR begin OR began OR initiate OR initiation OR initiating) AND TOPIC: ("systematic review" or "meta-analysis" or "scoping review")

Epistemonikos via https://www.epistemonikos.org/en/ from inception to April 19th 2022

Search structure: (ILD or COPD) AND Palliative care AND timing/initiation then limited to systematic reviews

(title:((title:(COPD OR chronic obstructive pulmonary disease OR "Interstitial lung disease*" OR "parenchymal lung dis*" OR "pulmonary fibrosis" OR "sarcoidosis" OR "interstitial pneumonia" OR "asbestosis" OR "pneumoconiosis") OR abstract:(COPD OR chronic obstructive pulmonary disease OR "Interstitial lung disease*" OR "parenchymal lung dis*" OR "pulmonary fibrosis" OR "sarcoidosis" OR "interstitial pneumonia" OR "asbestosis" OR "pneumoconiosis")) AND (title:(palliat* OR hospice*) OR abstract:(palliat* OR hospice*)) AND (title:(timing OR time OR timely OR trigger* OR duration OR start* OR early OR begin OR began OR initiate OR initiation OR initiating) OR abstract:(timing OR time OR timely OR trigger* OR duration OR start* OR early OR begin OR began OR initiate OR initiation OR initiating)) OR abstract:(title:(COPD OR chronic obstructive pulmonary disease OR "Interstitial lung disease*" OR "parenchymal lung dis*" OR "pulmonary fibrosis" OR "sarcoidosis" OR "interstitial pneumonia" OR "asbestosis" OR "pneumoconiosis") OR abstract:(COPD OR chronic obstructive pulmonary disease OR "Interstitial lung disease*" OR "parenchymal lung dis*" OR "pulmonary fibrosis" OR "sarcoidosis" OR "interstitial pneumonia" OR "asbestosis" OR "pneumoconiosis")) AND (title:(palliat* OR hospice*) OR abstract:(palliat* OR hospice*)) AND (title:(timing OR time OR timely OR trigger* OR duration OR start* OR early OR begin
OR began OR initiate OR initiation OR initiating) OR abstract:(timing OR time OR timely OR trigger* OR duration OR start* OR early OR begin OR began OR initiate OR initiation OR initiating))))

SCOPUS via Scopus.com from inception to April 19th 2022
Search structure: ILD/COPD AND palliative care AND timing/initiation AND systematic reviews
( TITLE-ABS-KEY ("Interstitial lung disease" OR "parenchymal lung dis" OR "pulmonary fibrosis" OR "sarcoidosis" OR "interstitial pneumonia" OR "asbestosis" OR "pneumoconiosis" OR copd OR chronic AND obstructive AND pulmonary AND disease ) AND TITLE-ABS-KEY ("Terminal care" OR "life support care" OR "palliative care" OR "Advanced care planning" OR "hospice*" OR "Respite care" OR "End-of-life care") AND TITLE-ABS-KEY ( timing OR time OR timely OR trigger* OR duration OR start* OR early OR begin OR began OR initiate OR initiation OR initiating ) AND TITLE-ABS-KEY ( "systematic review" OR "meta-analysis" OR "scoping review" ))

CareSearch Systematic review collection:

Searches for other studies:

Ovid MEDLINE(R) ALL 1946 to April 19 2022
Search structure: Palliative care[line 42] AND timing/initiation [line 50 and COPD/ILD [line 80]
1. exp advance care planning/
2. exp attitude to death/
3. exp bereavement/
4. death/
5. hospices/
6. life support care/
7. palliative care/ or Palliative Medicine/
8. exp terminal care/ or respite care/
9. terminally ill/
10. palliat$.af.
11. hospice$.af.
12. (terminal care or respite care).af.
13. or/1-12
14. journal of palliative care.jn.
15. journal of palliative medicine.jn.
16. hospice journal physical psychosocial & pastoral care of the dying.jn.
17. supportive care in cancer.jn.
18. palliative medicine.jn.
19. palliative & supportive care.jn.
20. journal of supportive oncology.jn.
21. journal of social work in end of life & palliative care.jn.
22. journal of pain & symptom management.jn.
23. journal of pain & palliative care pharmacotherapy.jn.
24. international journal of palliative nursing.jn.
25. death studies.jn.
26. death education.jn.
27. american journal of hospice care.jn.
28. american journal of hospice & palliative medicine.jn.
29. omega journal of death & dying.jn.
30. or/14-29
31. 13 or 30
32. bereave$.mp.
33. attitude to death.mp.
34. end of life.af.
35. Advance* Care.af.
36. (advanced or terminal*) adj (ill* or disease)).ti,ab,kw.
37. supportive care.ti,ab,kw.
38. dying.ti,ab,kw.
39. "last year of life".ti,ab,kw.
40. (limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
41. or/32-40
42. 31 or 41 [palliative care concept]
43. "Referral and Consultation"/
44. Time Factors/
45. (timing or time or timely or trigger*).ti,ab,kw.
46. ((selection or refer*) adj2 criteria*).ti,ab,kw.
47. Patient Selection/
48. (duration or start* or early or begin or began or initiate or initiation or initiating).ti,ab,kw.
49. Specialization/
50. or/43-49 [timing/initiation concept]
51. exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
52. emphysema$.mp.
53. (chronic$ adj3 bronchiti$).mp.
54. (obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).mp.
55. COPD.mp.
56. COAD.mp.
57. COBD.mp.
58. AECB.mp.
59. Lung Diseases, Obstructive/
60. or/51-59 [COPD concept]
61. exp Lung Diseases, Interstitial/
62. exp Pulmonary Fibrosis/
63. (interstitial$ adj3 (lung$ adj3 disease$)).tw.
64. (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
65. (diffuse* adj3 parenchymal*).tw.
66. alveolitis.mp.
67. exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterans).mp.
68. (goodpasture$ adj syndrome$).mp.
69. granulomatosis.mp.
70. exp Histiocytosis/ or histiocytosis$.mp.
71. exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumokoniosis.mp. or pneumonoconiosis.mp.
72. bagassosis.mp.
73. (pulmonary$ adj sarcoid$).mp.
74. (pulmonary$ adj fibros$).mp.
75. (wegener$ adj granuloma$).mp.
76. (lung$ adj purpura$).mp.
77. ((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
78. (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
79. or/61-78 [ILD search]
80. 79 or 60 [ILD or COPD]
81. 42 and 50 and 80 [Palliative care AND timing and COPD/ILD]
Ovid Embase 1974 to April 19 2022
1. patient referral/
2. patient identification/
3. ((timing or time or timely or trigger*) adj5 (palliat* or refer* or hospice*)).ti,ab,kw.
4. ((selection or refer*) adj2 criteria*).ti,ab,kw.
5. ((duration or start* or early or begin or began or initiate or initiation or initiating) adj5 (palliat* or refer* or hospice*)).ti,ab,kw.
6. or/1-5
7. advance care planning/
8. attitude to death/
9. bereavement/
10. death/
11. hospice/
12. palliative therapy/
13. respite care/
14. terminal care/ or hospice care/
15. exp terminally ill patient/
16. palliat$.ti,ab,kw.
17. hospice*.ti,ab,kw.
18. (terminal care or respite care).ti,ab,kw.
19. supportive care.ti,ab,kw.
20. bereave*.ti,ab,kw.
21. attitude to death.ti,ab,kw.
22. end of life.ti,ab,kw.
23. ((advanced or terminal*) adj (ill* or disease)).ti,ab,kw.
25. (limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
26. "last year of life".ti,ab,kw.
27. dying.ti,ab,kw.
28. or/7-27
29. 6 and 28
30. exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
31. emphysema$.ti,ab,kw.
32. (chronic$ adj3 bronchiti$).ti,ab,kw.
33. (obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).ti,ab,kw.
34. COPD.mp.
35. COAD.mp.
36. COBD.mp.
37. AECB.mp.
38. Lung Diseases, Obstructive/
39. or/30-38 [based on Cochrane Airways COPD register search]
40. exp Lung Diseases, Interstitial/
41. exp Pulmonary Fibrosis/
42. (interstitial$ adj3 (lung$ adj3 disease$)).tw.
43. (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
44. (diffuse* adj3 parenchymal*).tw.
45. alveolitis.mp.
46. exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterans).mp.
47. (goodpasture$ adj syndrome$).mp.
48. granulomatosis.mp.
49. exp Histiocytosis/ or histiocytosis$.mp.
50. exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumokoniosis.mp. or pneumonoconiosis.mp.
51. bagassosis.mp.
52. (pulmonary$ adj sarcoid$).mp.
53. (pulmonary$ adj fibros$).mp.
54. (wegener$ adj granuloma$).mp.
55. (lung$ adj purpura$).mp.
56. ((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
57. (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
58. or/40-57 [ILD search]
59. 39 or 58 [COPD orILD]
60. 29 and 59
61. exp review/
62. (literature adj3 review$).ti,ab.
63. exp meta analysis/
64. exp "systematic review"/
65. or/61-64
66. (medline or medlars or embase or pubmed or cinahl or amed or psychlit or psyclit or psychinfo or psycinfo or scisearch or cochrane).ti,ab.
67. RETRACTED ARTICLE/
68. 66 or 67
69. 65 and 68
70. (systematic$ adj2 (review$ or overview$)).ti,ab.
71. (meta?anal$ or meta anal$ or meta anal$ or metaanal$ or metaanal$).ti,ab.
72. 69 or 70 or 71
73. 60 and 72
74. 60 not 72
75. limit 74 to conference abstract status
76. 74 not 75

CENTRAL via The Cochrane Library
#1 MeSH descriptor: [Advance Care Planning] explode all trees
#2 MeSH descriptor: [Attitude to Death] explode all trees
#3 MeSH descriptor: [Bereavement] explode all trees
#4 MeSH descriptor: [Death] this term only
#5 MeSH descriptor: [Hospices] this term only
#6 MeSH descriptor: [Life Support Care] this term only
#7 MeSH descriptor: [Palliative Care] explode all trees
#8 MeSH descriptor: [Respite Care] explode all trees
#9 MeSH descriptor: [Terminal Care] explode all trees
#10 MeSH descriptor: [Terminally Ill] explode all trees
#11 (palliat* or hospice*):ti,ab,kw
#12 ((terminal or supportive) next care):ti,ab,kw
#13 (respite next care):ti,ab,kw
#14 (bereave* or dying):ti,ab,kw
#15 ("attitude to death"):ti,ab,kw
#16 (((advanced or terminal* or critical*) next (ill* or disease)):ti,ab,kw
#17 (advance* next care):ti,ab,kw
#18 ("last year of life" or (limited next (expectanc* or span*))) or life-limiting):ti,ab,kw
#19 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18
#20 MeSH descriptor: [Lung Diseases, Interstitial] explode all trees
MeSH descriptor: [Pulmonary Fibrosis] explode all trees

#22 ((interstitial* near/3 (lung* near/3 disease*))):ti,ab,kw

#23 interstitial* near/3 (fibros* or pneumonitis or pneumonia or pneumopathy):ti,ab,kw

#24 diffuse* near/3 parenchymal*:ti,ab,kw

#25 (Alveolitis):ti,ab,kw

#26 MeSH descriptor: [Bronchiolitis Obliterans] explode all trees

#27 (bronchiolitis next obliterans):ti,ab,kw

#28 (goodpasture* NEXT syndrome*):ti,ab,kw

#29 (granulomatosis):ti,ab,kw

#30 MeSH descriptor: [Histiocytosis] explode all trees

#31 (histiocytosis*):ti,ab,kw

#32 MeSH descriptor: [Pneumoconiosis] explode all trees

#33 (pneumoconiosis or pneumokoniosis or pneumonoconiosis):ti,ab,kw

#34 (bagassosis):ti,ab,kw

#35 (pulmonary next (sarcoid* or fibros*)):ti,ab,kw

#36 (wegener* next granuloma*):ti,ab,kw

#37 (lung* adj purpura):ti,ab,kw

#38 (((bird* or farmer* or pigeon* or avian* or budgerigar*) next (lung* or disease*)):ti,ab,kw

#39 #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38

#40 MeSH descriptor: [Pulmonary Disease, Chronic Obstructive] explode all trees

#41 (emphysema*):ti,ab,kw

#42 (chronic* near/2 bronchiti*):ti,ab,kw

#43 (obstruct* near/2 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)):ti,ab,kw

#44 (COPD or COAD or COBD or AECB):ti,ab,kw

#45 MeSH descriptor: [Lung Diseases, Obstructive] this term only

#46 #40 or #41 or #42 or #43 or #44 or #45

#47 #39 or #46

#48 #19 and #47

#49 MeSH descriptor: [Referral and Consultation] explode all trees

#50 MeSH descriptor: [Time Factors] explode all trees

#51 MeSH descriptor: [Patient Selection] explode all trees

#52 MeSH descriptor: [Specialization] explode all trees

#53 ((timing or time or timely or trigger*) near/5 (palliat* or refer* or hospice*)):ti,ab,kw

#54 ((duration or start* or early or begin or began or initiate or initiation or initiating) near/5 (palliat* or refer* or hospice)):ti,ab,kw

#55 ((selection or refer*) near/2 criteria):ti,ab,kw

#56 ((timing or time or timely or trigger* or duration or start* or early or begin or began or initiate or initiation or initiating)):ti

#57 #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56

#58 #48 and #57

CINAHL Complete via EBSCOhost 1937 to April 19th 2022
Search structure Palliative care [S1] AND COPD/ILD [S16] AND timing/initiation [S20] and systematic reviews [S22]

S1  ( (MH "Terminal Care") or (MH "Palliative Care") or (MH "Attitude to Death") or (MH "Advance Care Planning") or (MH "Respite Care") or (MH "Hospices") or (MH "Life Support Care") ) OR TI ( bereave* or hospice* or "end of life" or "terminally ill" or palliat* ) OR TI ( bereave* or hospice* or "end of life" or "terminally ill" or palliat* )

S2 S13 OR S12 OR S3 OR S4 OR S5 OR S6 OR S7 OR S6 OR S5 OR S4 OR S3
S3 TI (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis) OR AB (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis)

S4 TI wegener* n1 granuloma* OR AB wegener* n1 granuloma* OR TI (((bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)) OR AB (((bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)))

S5 TI (pneumoconiosis or pneumokoniosis or pneumonoconiosis or bagassosis) OR AB (pneumoconiosis or pneumokoniosis or pneumonoconiosis or bagassosis) OR TI (pulmonary n1 (sarcoid* or fibros*)) OR AB (pulmonary n1 (sarcoid* or fibros*))

S6 TI "bronchiolitis obliterans" OR AB "bronchiolitis obliterans" OR TI (granulomatosis or "goodpasture* syndrome") OR AB (granulomatosis or "goodpasture* syndrome")

S7 AB diffuse* n3 parenchymal* OR TI diffuse* n3 parenchymal* OR TI Alveolitis OR AB Alveolitis

S8 TI (interstitial n2 (lung* or fibros* or pneumo*)) OR AB (interstitial n2 (lung* or fibros* or pneumo*))

S9 (MH "Pneumoconiosis+")

S10 (MH "Histiocytosis+")

S11 (MH "Bronchiolitis Obliterans+")

S12 (MH "Pulmonary Fibrosis+")

S13 (MM "Lung Diseases, Interstitial+")

S14 (MH "Pulmonary Disease, Chronic Obstructive") or (MH "Emphysema") or (MH "Lung Diseases, Obstructive") OR TI (obstruct* n3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)) OR AB (obstruct* n3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*))

S15 S2 OR S14

S16 S1 AND S15

S17 (MH "Referral and Consultation+")

S18 (MH "Patient Selection")

S19 TI (timing or time or timely or trigger*) OR AB (timing or time or timely or trigger*) OR TI (((selection or refer*) n2 criteria*)) OR AB (((selection or refer*) n2 criteria*)) OR TI (duration or start* or early or begin or began or initiate or initiating) OR AB (duration or start* or early or begin or began or initiate or initiating or initiating)

S20 S17 OR S18 OR S19

S21 S16 AND S20

Web of Science Core collection (including SCI-EXPANDED 1970 to April 19th 2022)

Search structure: Palliative care AND initiation AND (ILD or COPD)

TOPIC: ("Interstitial lung disease*" OR "parenchymal lung dis***" OR "pulmonary fibrosis" OR "sarcoidosis" OR "interstitial pneumonia" OR "asbestosis" OR "pneumoconiosis" OR COPD OR chronic obstructive pulmonary disease) AND TOPIC: ("Terminal care" OR "life support care" OR "palliative care" OR "Advanced care planning" OR "hospice***" OR "Respite care" OR "End-of-life care") AND TITLE: (refer* or timing OR time OR timely OR trigger* OR duration OR start* OR early OR begin OR began OR initiate OR initiating OR initiating)

Epistemonikos via https://www.epistemonikos.org/en/ from inception to April 19th 2022

SCOPUS via Scopus.com from inception to April 19th 2022

Search structure: Palliative care AND initiation AND (ILD or COPD)

( TITLE-ABS-KEY ("Interstitial lung disease*" OR "parenchymal lung dis***" OR "pulmonary fibrosis" OR "sarcoidosis" OR "interstitial pneumonia" OR "asbestosis" OR "pneumoconiosis" OR copd OR chronic AND obstructive AND pulmonary AND disease) AND TITLE-ABS-KEY ("Terminal care" OR "life support care" OR "palliat***" OR "Advanced care planning" OR "hospice***" OR "Respite****")
care" OR "End-of-life care" ) AND TITLE ( timing OR time OR timely OR trigger* OR duration OR start* OR early OR begin OR began OR initiate OR initiation OR initiating )
Search strategy question 3
Palliative care interventions for adults with COPD involving informal caregivers (question 3, PICO)

Note: Separate searches were performed for systematic reviews and other studies. The search strategies below do not include a study design filter but the search for systematic reviews included an additional concept/filter for systematic reviews which has been omitted for space. The systematic review concept can be seen in search strategies for Questions 1 and 2 for reference.
(Initial search date 03 February 2021, all database searches updated 20th April 2022. We searched all databases from their inception)

Ovid MEDLINE(R) ALL 1946 to April 20 2022
1. exp advance care planning/
2. exp attitude to death/
3. exp bereavement/
4. death/
5. hospices/
6. life support care/
7. palliative care/ or Palliative Medicine/
8. exp terminal care/ or respite care/
9. terminally ill/
10. palliat$.af.
11. hospice$.af.
12. (terminal care or respite care).af.
13. or/1-12
14. journal of palliative care.jn.
15. journal of palliative medicine.jn.
16. hospice journal physical psychosocial & pastoral care of the dying.jn.
17. supportive care in cancer.jn.
18. palliative medicine.jn.
19. palliative & supportive care.jn.
20. journal of supportive oncology.jn.
21. journal of social work in end of life & palliative care.jn.
22. journal of pain & symptom management.jn.
23. journal of pain & palliative care pharmacotherapy.jn.
24. international journal of palliative nursing.jn.
25. death studies.jn.
26. death education.jn.
27. american journal of hospice care.jn.
28. american journal of hospice & palliative medicine.jn.
29. omega journal of death & dying.jn.
30. or/14-29
31. 13 or 30
32. bereave$.mp.
33. attitude to death.mp.
34. end of life.af.
35. Advance* Care.af.
36. ((advanced or terminal* or critical*) adj (ill* or disease)).ti,ab,kw.
37. supportive care.ti,ab,kw.
38. dying.ti,ab,kw.
39. "last year of life".ti,ab,kw.
40. (limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
41. or/32-40
42. 31 or 41  [Palliative care concept]
43. Caregivers/
44. (caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*).ti,ab,kw.
45. 43 or 44
46. (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*).ti,ab,kw.
47. exp Family/
48. Friends/
49. (friend* or significant other* or most significant person* or next of kin or neighbour* or neighbor* or loved one*).ti,ab,kw.
50. or/46-49
51. (care* or caring or support*).ti,ab,kw.
52. 50 and 51
53. 45 or 52 [caregiver concept]
54. exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
55. emphysema$.mp.
56. (chronic$ adj3 bronchiti$).mp.
57. (obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).mp.
58. COPD.mp.
59. COAD.mp.
60. COBD.mp.
61. AECB.mp.
62. Lung Diseases, Obstructive/
63. or/54-62 [COPD concept]
64. 42 and 53 and 63 [Palliative care AND caregivers AND COPD]

Ovid Embase 1974 to April 20 2022
1. advance care planning/
2. attitude to death/
3. bereavement/
4. death/
5. hospice/
6. palliative therapy/
7. respite care/
8. terminal care/ or hospice care/
9. exp terminally ill patient/
10. palliat$.af.
11. hospice$.af.
12. (terminal care or respite care).af.
13. supportive care.ti,ab,kw.
14. bereave$.mp.
15. attitude to death.mp.
16. end of life.af.
17. ((advanced or terminal* or critical*) adj (ill* or disease*).ti,ab,kw.
18. Advance* Care.af.
19. (limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
20. "last year of life".ti,ab,kw.
21. dying.ti,ab,kw.
22. or/1-21  [Palliative care concept]
23. caregiver/
24. (caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*).ti,ab,kw.
25. 23 or 24
26. (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*).ti,ab,kw.
27. exp family/
28. friend/
29. (friend* or significant other* or most significant person* or next of kin or neighbour* or neighbor* or loved one*).ti,ab,kw.
30. or/26-29
31. (carer* or caring or support*).ti,ab,kw.
32. 30 and 31
33. 25 or 32
[Caregiver concept]
34. chronic obstructive lung disease/
35. obstructive airway disease/
36. chronic bronchitis/
37. lung emphysema/
38. emphysema$.mp.
39. (chronic$ adj3 bronchiti$).mp.
40. (obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).ti,ab,kw.
41. (COPD or COAD or COBD or AECB).mp.
42. or/34-41
[CPD concept]
43. 22 and 33 and 42
44. limit 43 to conference abstract status
45. 43 not 44

Cochrane Database of Systematic Reviews 1996 to 20 April 2022 and CENTRAL via The Cochrane Library
#1 MeSH descriptor: [Caregivers] explode all trees
#2 (caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*).ti,ab,kw
#3 #1 or #2
#4 (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*).ti,ab,kw
#5 MeSH descriptor: [Family] explode all trees
#6 MeSH descriptor: [Friends] this term only
#7 (friend*).ti,ab,kw
#8 (significant next other*).ti,ab,kw
#9 (significant next person*).ti,ab,kw
#10 ("next-of-kin" or "next of kin").ti,ab,kw
#11 (neighbour* or neighbor*).ti,ab,kw
#12 (loved next one*).ti,ab,kw
#13 #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12
#14 (care* or caring or support*).ti,ab,kw
#15 #13 and #14
#16 #3 or #15 Caregiver concept
#17 MeSH descriptor: [Advance Care Planning] explode all trees
#18 MeSH descriptor: [Attitude to Death] explode all trees
#19 MeSH descriptor: [Bereavement] explode all trees
#20 MeSH descriptor: [Death] this term only
#21 MeSH descriptor: [Hospices] this term only
CINAHL Complete via EBSCOhost  1937 to April 20 2022

S1  (MH "Caregivers") OR TI (caregiver* or care-giver* or carer* or "care partner"* or "care provider"*) OR AB (caregiver* or care-giver* or carer* or "care partner"* or "care provider"*) OR TI ((care* or caring or support*) n7 (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*)) OR AB ((care* or caring or support*) n7 (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*))

S2  (MH "Terminal Care") OR TI (MH "Palliative Care") OR (MH "Attitude to Death") OR (MH "Advance Care Planning") OR (MH "Respite Care") OR (MH "Hospices") OR (MH "Life Support Care") OR TI (bereave* or hospice* or "end of life" or "terminally ill" or palliat*) OR TI (bereave* or hospice* or "end of life" or "terminally ill" or palliat*)

S3  (MH "Pulmonary Disease, Chronic Obstructive") OR TI (obstruct* n3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)) OR AB (obstruct* n3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)) OR TI (COPD or COAD or COBD or AECB) OR AB (COPD or COAD or COBD or AECB)

S4  S1 AND S2 AND S3

Web of Science Core collection (including SCI-EXPANDED 1970 to April 20 2022)

TOPIC: (COPD or chronic obstructive pulmonary disease) AND TOPIC: (palliat* or hospice* or respite care) AND TOPIC: (care* or caregiver* or care-giver*)
(title:caregiver* OR carer* OR family OR families) OR abstract:caregiver* OR carer* OR family OR families)) AND (title:palliat* OR hospice* OR end of life OR respite) OR abstract:palliat* OR hospice* OR end of life OR respite)) AND (title:copd OR chronic obstructive pulmonary disease) OR abstract:copd OR chronic obstructive pulmonary disease)

SCOPUS via Scopus.com from inception to April 2022

((TITLE-ABS-KEY ("Chronic Obstructive Pulmonary Disease" OR "COPD" OR "COAD" OR "Chronic Obstructive Airway Disease" OR "Chronic Obstructive Lung Disease" OR "Chronic Airflow Obstruction" OR "Chronic bronchit*" OR "Pulmonary emphysema") ) AND (TITLE-ABS-KEY ("Caregiver*" OR "Carer*" OR "Spouse caregiver" OR "Care partner" OR "Care provider*" OR "Informal care*" OR "family member" OR "family caregiver*" OR "spouse" OR "sibling" OR "next of kin" OR "neighbor" OR "neighbour" OR "friend" OR "most significant person" OR "loved ones") ) AND (TITLE-ABS-KEY ("Terminal care" OR "life support care" OR "palliative care" OR "Advanced care planning" OR "hospice care" OR "Respite care" OR "End-of-life care") ) )

Searches CareSearch Systematic review collection on COPD and Carers:
Search strategy question 4
Palliative care interventions for adults with ILD involving informal caregivers (question 4, PICO)

Note: Separate searches were performed for systematic reviews and other studies. The search strategies below do not include a study design filter but the search for systematic reviews included an additional concept/filter for systematic reviews which has been omitted for space. The systematic review concept can be seen in search strategies for Questions 1 and 2 for reference.
(Initial search date 04 February 2021, all database searches updated 21 April 2022. We searched all databases from their inception)

Ovid MEDLINE(R) ALL 1946 to April 21 2022
1. Caregivers/
2. (caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*).ti,ab,kw.
3. 1 or 2
4. (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*).ti,ab,kw.
5. exp Family/
6. Friends/
7. (friend* or significant other* or most significant person* or next of kin or neighbour* or neighbor* or loved one*).ti,ab,kw.
8. or/4-7
9. (care* or caring or support*).ti,ab,kw.
10. 8 and 9
11. 3 or 10 [caregiver concept]
12. exp advance care planning/
13. exp attitude to death/
14. exp bereavement/
15. death/
16. hospices/
17. life support care/
18. palliative care/ or Palliative Medicine/
19. exp terminal care/ or respite care/
20. terminally ill/
21. palliat$.af.
22. hospice$.af.
23. (terminal care or respite care).af.
24. or/12-23
25. journal of palliative care.jn.
26. journal of palliative medicine.jn.
27. hospice journal physical psychosocial & pastoral care of the dying.jn.
28. supportive care in cancer.jn.
29. palliative medicine.jn.
30. palliative & supportive care.jn.
31. journal of supportive oncology.jn.
32. journal of social work in end of life & palliative care.jn.
33. journal of pain & symptom management.jn.
34. journal of pain & palliative care pharmacotherapy.jn.
35. international journal of palliative nursing.jn.
36. death studies.jn.
37. death education.jn.
38. american journal of hospice care.jn.
39. american journal of hospice & palliative medicine.jn.
40. omega journal of death & dying.jn.
41. or/25-40
42. 24 or 41
43. bereave$.mp.
44. attitude to death.mp.
45. end of life.af.
46. Advance* Care.af.
47. ((advanced or terminal* or critical*) adj (ill* or disease)).ti,ab,kw.
48. supportive care.ti,ab,kw.
49. dying.ti,ab,kw.
50. "last year of life".ti,ab,kw.
51. (limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
52. or/43-51
53. 42 or 52 [palliative care concept]
54. exp Lung Diseases, Interstitial/
55. exp Pulmonary Fibrosis/
56. (interstitial$ adj3 (lung$ adj3 disease$)).tw.
57. (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
58. (diffuse* adj3 parenchymal*).tw.
59. alveolitis.mp.
60. exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterans).mp.
61. (goodpasture$ adj syndrome$).mp.
62. granulomatosis.mp.
63. exp Histiocytosis/ or histiocytosis$.mp.
64. exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumokoniosis.mp. or pneumonoconiosis.mp.
65. bagassosis.mp.
66. (pulmonary$ adj sarcoid$).mp.
67. (pulmonary$ adj fibros$).mp.
68. (wegener$ adj granuloma$).mp.
69. (lung$ adj purpura$).mp.
70. ((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
71. (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
72. or/54-71 [ILD search]
73. 11 and 53 and 72

Ovid Embase 1974 to April 21 2022
1. caregiver/
2. (caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*).ti,ab,kw.
3. 1 or 2
4. (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wive or wives or sibling* or brother* or sister* or mother* or father* or partner*).ti,ab,kw.
5. exp family/
6. friend/
7. (friend* or significant other* or most significant person* or next of kin or neighbour* or neighbor* or loved one*).ti,ab,kw.
8. or/4-7
9. (career* or caring or support*).ti,ab,kw.
10. 8 and 9
11. 3 or 10
12. exp interstitial lung disease/
13. exp lung fibrosis/
14. (interstitial$ adj3 (lung$ adj3 disease$)).tw.
15. (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
16. (diffuse* adj3 parenchymal*).tw.
17. alveolitis.mp.
18. bronchiolitis obliterans/
20. (goodpasture$ adj syndrome$).mp.
21. granulomatosis.mp.
22. exp histiocytosis/
23. histiocytosis$.mp.
24. pneumoconiosis/
25. (pneumoconiosis or pneumokoniosis or pneumonoconiosis).mp.
26. bagassosis.mp.
27. (pulmonary$ adj sarcoid$).mp.
29. (wegener$ adj granuloma$).mp.
30. (lung$ adj purpura).mp.
31. ((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
32. (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
33. or/12-32 [ILD concept]
34. advance care planning/
35. attitude to death/
36. bereavement/
37. death/
38. hospice/
39. palliative therapy/
40. respite care/
41. terminal care/ or hospice care/
42. exp terminally ill patient/
43. palliat$.af.
44. hospice$.af.
45. (terminal care or respite care).af.
46. supportive care.ti,ab,kw.
47. bereave$.mp.
48. attitude to death.mp.
49. end of life.af.
50. ((advanced or terminal* or critical*) adj (ill* or disease$)).ti,ab,kw.
51. Advance* Care.af.
52. (limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
53. "last year of life".ti,ab,kw.
54. dying.ti,ab,kw.
55. or/34-54
56. 11 and 33 and 55
57. limit 56 to conference abstract status
58. 56 not 57

Cochrane Database of Systematic Reviews 1996 to 21 April 2022 and CENTRAL via The Cochrane Library
#1 MeSH descriptor: [Caregivers] explode all trees
#2 (caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*):ti,ab,kw
#3  #1 or #2
#4  (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*):ti,ab,kw
#5  MeSH descriptor: [Family] explode all trees
#6  MeSH descriptor: [Friends] this term only
#7  (friend*):ti,ab,kw
#8  (significant next other*):ti,ab,kw
#9  (significant next person*):ti,ab,kw
#10  ("next-of-kin" or "next of kin"):ti,ab,kw
#11  (neighbour* or neighbor*):ti,ab,kw
#12  (loved next one*):ti,ab,kw
#13  #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12
#14  (care* or caring or support*):ti,ab,kw
#15  #13 and #14
#16  #3 or #15
#17  MeSH descriptor: [Advance Care Planning] explode all trees
#18  MeSH descriptor: [Attitude to Death] explode all trees
#19  MeSH descriptor: [Bereavement] explode all trees
#20  MeSH descriptor: [Death] this term only
#21  MeSH descriptor: [Hospices] this term only
#22  MeSH descriptor: [Life Support Care] this term only
#23  MeSH descriptor: [Palliative Care] explode all trees
#24  MeSH descriptor: [Respite Care] explode all trees
#25  MeSH descriptor: [Terminal Care] explode all trees
#26  MeSH descriptor: [Terminaly Ill] explode all trees
#27  (palliat* or hospice*):ti,ab,kw
#28  ((terminal or supportive) next care):ti,ab,kw
#29  (respite next care):ti,ab,kw
#30  (bereave* or dying):ti,ab,kw
#31  ("attitude to death"):ti,ab,kw
#32  ((advanced or terminal* or critical*) next (ill* or disease)):ti,ab,kw
#33  (advance* next care):ti,ab,kw
#34  ("last year of life" or (limited next (expectanc* or span*)):ti,ab,kw
#35  #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34
#36  MeSH descriptor: [Lung Diseases, Interstitial] explode all trees
#37  MeSH descriptor: [Pulmonary Fibrosis] explode all trees
#38  ((interstitial* near/3 (lung* near/3 disease*)):ti,ab,kw
#39  (diffuse* near/3 parenchymal*:ti,ab,kw
#40  (Alveolitis):ti,ab,kw
#41  (Bronchiolitis Obliterans): explode all trees
#42  (granulomatosis):ti,ab,kw
#43  (Histiocytosis*):ti,ab,kw
#44  (Pulmonary Fibrosis):ti,ab,kw
#45  (Pneumoconiosis):ti,ab,kw
#46  (goodpasture* NEXT syndrome*):ti,ab,kw
#47  (wegener* next granuloma*):ti,ab,kw
#48  (granulomatosis):ti,ab,kw
#49  (granulomatosis):ti,ab,kw
#50  (pulmonary next (sarcoid* or fibros*)):ti,ab,kw
#51  (pulmonary next (sarcoid* or fibros*)):ti,ab,kw
#52  (pulmonary next (sarcoid* or fibros*)):ti,ab,kw
CINAHL Complete via EBSCOhost  1937 to April 21 2022
S1 (MM "Lung Diseases, Interstitial+)")
S2 (MH "Pulmonary Fibrosis+")
S3 (MH "Bronchiolitis Obliterans+")
S4 (MH "Histiocytosis+")
S5 (MH "Pneumoconiosis+")
S6 TI ( interstitial n2 (lung* or fibros* or pneumo*) ) OR AB ( interstitial n2 (lung* or fibros* or pneumo*) )
S7 AB diffuse* n3 parenchymal* OR TI diffuse* n3 parenchymal* OR TI Alveolitis OR AB Alveolitis
S8 TI "bronchiolitis obliterans" OR AB "bronchiolitis obliterans" OR TI ( granulomatosis or "goodpasture* syndrome") OR AB ( granulomatosis or "goodpasture* syndrome")
S9 TI ( pneumoconiosis or pneumokoniosis or pneumoconoiosis or bagassosis ) OR AB ( pneumoconiosis or pneumokoniosis or pneumoconoiosis or bagassosis ) OR TI ( pulmonary n1 (sarcoi* or fibros*) ) OR AB ( pulmonary n1 (sarcoi* or fibros*) )
S10 TI wegener* n1 granuloma* OR AB wegener* n1 granuloma* OR TI ( ((bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)) ) OR AB ( ((bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)) )
S11 TI ( asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis ) OR AB ( asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis )
S12 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11
S13 (MH "Caregivers") OR TI ( caregiver* or care-giver* or carer* or "care partner**" or "care provider**" or "informal care**" ) OR AB ( caregiver* or care-giver* or carer* or "care partner**" or "care provider**" or "informal care**" ) OR TI ( (care* or caring or support*) n2 ( dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner* )) OR AB ( (care* or caring or support*) n2 ( dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner* ) )
S14 ( MH "Terminal Care++") or (MH "Palliative Care") or (MH "Attitude to Death") or (MH "Advance Care Planning") or (MH "Respite Care") or (MH "Hospices") or (MH "Life Support Care") OR TI ( bereave* or hospice* or "end of life" of "terminally ill" or palliat* ) OR TI ( bereave* or hospice* or "end of life" of "terminally ill" or palliat* )
S15 S12 AND S13 AND S14

Web of Science Core collection (including SCI-EXPANDED 1970 to April 21 2022)
TS= ("interstitial lung disease" OR "ILD" OR "parenchymal lung dis**" OR "pulmonary fibrosis" OR "sarcoidosis" OR "connective tissue diseases" OR "interstitial pneumonia" OR "alveolitis" OR "asbestosis" OR "hypersensitivity pneumonitis" OR "pneumoconiosis") AND TS= (Caregiver* OR Carer* OR "Spouse caregiver" OR "Care partner" OR "Care provider**" OR "Informal care**" OR "family member" OR "family caregiver**" OR spouse OR sibling OR "next of kin" OR neighbor* OR neighbour* OR friend* OR "most significant person" OR "loved one**") AND TS= (palliat* or hospice* or respite care)

Epistemonikos via https://www.epistemonikos.org/en/ from inception to April 21 2022 (limited to systematic reviews)
Search strategy question 5
Advance care planning interventions for adults with COPD (question 5, PICO)

Note: After the initial draft searches, the search concepts were revised slightly compared with the standard COPD and ACP search concepts developed at the start of the project to make them more specific for this question.
(Initial search date 25 March 2021, all database searches updated 21 April 2022. We searched all databases from their inception)

Ovid MEDLINE(R) ALL 1946 to April 21 2022
1. exp advance care planning/ or advance directives/ or living wills/
2. (advance* care adj (plan or plans or planning)).ti,ab,kw.
3. (advance* adj (directive* or decision* or statement* or medical plan*)).ti,ab,kw.
4. living will*.ti,ab,kw.
5. Right to Die/
6. right to die.ti,ab,kw.
7. power of attorney.ti,ab,kw.
8. Treatment Refusal/
9. (treatment adj5 (refus* or withhold* or withdraw*)).ti,ab,kw.
10. ((assist* or proxy or substitut*) adj2 (decision making or decision maker*)).ti,ab,kw.
11. ((statement or knowledge or aware*) adj2 wish*).ti,ab,kw.
12. ((end of life or EOL) adj5 (care or discuss* or decision* or plan* or preference* or wish*)).ti,ab,kw.
13. exp Resuscitation Orders/
14. DNR.ti,ab,kw.
15. DNI.ti,ab,kw.
16. ("do not" adj (hospitalise or hospitalize or resuscitate or intubate)).ti,ab,kw.
17. DNH.ti,ab,kw.
18. or/1-17  [Advance care planning concept]
19. exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
20. emphysema$.mp.
22. (chronic* adj3 obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).mp.
23. COPD.mp.
24. COAD.mp.
25. COBD.mp.
26. AECB.mp.
27. or/19-26  [COPD concept]
28. 18 and 27

Ovid Embase 1974 to April 21 2022
1. exp advance care planning/ or advance directives/ or living wills/
2. (advance* care adj (plan or plans or planning)).ti,ab,kw.
3. (advance* adj (directive* or decision* or statement* or medical plan*)).ti,ab,kw.
4. living will*.ti,ab,kw.
5. Right to Die/
6. right to die.ti,ab,kw.
7. power of attorney.ti,ab,kw.
8. Treatment Refusal/
9. (treatment adj5 (refus* or withhold* or withdraw*)).ti,ab,kw.
10. ((assist* or proxy or substitut*) adj2 (decision making or decision maker*)).ti,ab,kw.
11. ((statement or knowledge or aware*) adj2 wish*).ti,ab,kw.
12. ((end of life or EOL) adj5 (care or discuss* or decision* or plan* or preference* or wish*)).ti,ab,kw.
13. exp Resuscitation Orders/
14. DNR.ti,ab,kw.
15. DNI.ti,ab,kw.
16. ("do not" adj (hospitalise or hospitalize or resuscitate or intubate)).ti,ab,kw.
17. DNH.ti,ab,kw.
18. or/1-17
19. exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
20. emphysema$.mp.
22. (chronic* adj3 obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).mp.
23. COPD.mp.
24. COAD.mp.
25. COBD.mp.
26. AECB.mp.
27. or/19-26
28. 18 and 27

Cochrane Database of Systematic Reviews 1996 to April 21 2022 and CENTRAL via The Cochrane Library
#1 MeSH descriptor: [Advance Care Planning] explode all trees
#2 MeSH descriptor: [Right to Die] explode all trees
#3 MeSH descriptor: [Treatment Refusal] this term only
#4 MeSH descriptor: [Resuscitation Orders] explode all trees
#5 ((advance* care next (plan or plans or planning))):ti,ab,kw
#6 ((advance* next (directive* or decision* or statement* or medical plan*))):ti,ab,kw
#7 ("living will**"):ti,ab,kw
#8 ("right to die" or "right-to-die"):ti,ab,kw
#9 ("power of attorney"):ti,ab,kw
#10 ((treatment near/5 (refus* or withhold* or withdraw*))):ti,ab,kw
#11 (((assist* or proxy or substitut*) near/2 (decision making or decision maker*)):ti,ab,kw
#12 (((statement or knowledge or aware*) near/2 wish*)):ti,ab,kw
#13 ((("end of life" or EOL) near/5 (care or discuss* or decision* or plan* or preference* or wish*)):ti,ab,kw
#14 (DNI or DNR or DNH):ti,ab,kw
#15 ("do not" next (hospitalise or hospitalize or resuscitate or intubate)):ti,ab,kw
#16 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15
#17 MeSH descriptor: [Pulmonary Disease, Chronic Obstructive] explode all trees
#18 (emphysema*):ti,ab,kw
#19 (chronic* near/2 bronchiti*):ti,ab,kw
#20 (chronic* near/2 obstruct* near/2 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)):ti,ab,kw
#21 (COPD or COAD or COBD or AECB):ti,ab,kw
#22 #17 or #18 or #19 or #20 or #21
#23 #16 and #22

CINAHL Complete via EBSCOhost 1937 to April 21 2022
S1 (MH "Advance Care Planning")
TOC: (COPD or "chronic obstructive pulmonary disease") AND TOPIC: ("advance* care plan*" or "advance directive*" or "living will*" or "power of attorney" or DNI or DNH or DNI)

Epistemonikos via https://www.epistemonikos.org/en/ from inception to April 21 2022
(title:(COPD OR "chronic obstructive lung" OR "chronic obstructive pulmonary") OR abstract:(COPD OR "chronic obstructive lung" OR "chronic obstructive pulmonary") AND (title: (advance care plan* OR living will* OR advance directive* OR power of attorney OR DNI OR DNH OR DNI) OR abstract:(advance care plan* OR living will* OR advance directive* OR power of attorney OR DNI OR DNH OR DNI))

SCOPUS via Scopus.com from inception to April 21 2022
(TITLE-ABS-KEY ("Chronic Obstructive Pulmonary Disease" OR "COPD" OR "COAD" OR "Chronic Obstructive Airway Disease" OR "Chronic Obstructive Lung Disease" OR "Chronic bronchitis" OR "emphysema") AND TITLE-ABS-KEY ("advance care plan*" OR "advance directive*" OR "living will*" OR "power of attorney" OR dni OR dnh OR dni)) AND (EXCLUDE (DOCTYPE, "ed") OR EXCLUDE (DOCTYPE, "le") OR EXCLUDE (DOCTYPE, "no") OR EXCLUDE (DOCTYPE, "ch") OR EXCLUDE (DOCTYPE, "cp") OR EXCLUDE (DOCTYPE, "sh") OR EXCLUDE (DOCTYPE, "bk"))
Search strategy question 6
Advance care planning interventions for adults with ILD (question 6, PICO)

Note: Note: an initial search combined the searches below with filters for systematic reviews. After no suitable systematic reviews were identified after screening, full searches were undertaken. (Initial search date for systematic reviews 12 February 2021, full search 24 March 2021, all database searches updated 22 April 2022. We searched all databases from their inception)

Ovid MEDLINE(R) ALL 1946 to April 22 2022
1. exp advance care planning/ or advance directives/ or living wills/
2. (advance* care adj (plan or plans or planning)).ti,ab,kw.
3. (advance* adj (directive* or decision* or statement* or medical plan*)).ti,ab,kw.
4. living will*.ti,ab,kw.
5. Right to Die/
6. right to die.ti,ab,kw.
7. Patient Advocacy/
8. ((patient or patients) adj5 (advocat* or advocacy)).ti,ab,kw.
9. power of attorney.ti,ab,kw.
10. Terminal Care/
11. terminal care.ti,ab,kw.
12. Treatment Refusal/
13. exp Withholding Treatment/
14. (treatment adj5 (refus* or withhold* or withdraw*)).ti,ab,kw.
15. ((assist* or proxy or substitut*) adj2 (decision making or decision maker*)).ti,ab,kw.
16. (statement or knowledge or aware*) adj2 wish*).ti,ab,kw.
17. (end of life or EOL) adj5 (care or discuss* or decision* or plan* or preference* or wish*).ti,ab,kw.
18. exp Resuscitation Orders/
19. DNR.ti,ab,kw.
20. DNI.ti,ab,kw.
21. ("do not" adj (hospitalise or hospitalize or resuscitate or intubate)).ti,ab,kw.
22. DNH.ti,ab,kw.
23. or/1-22
24. exp Lung Diseases, Interstitial/
25. exp Pulmonary Fibrosis/
26. (interstitial$ adj3 (lung$ adj3 disease$)).tw.
27. (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
28. (diffuse* adj3 parenchymal*).tw.
29. alveolitis.mp.
30. exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterans).mp.
31. (goodpasture$ adj syndrome$).mp.
32. granulomatosis.mp.
33. exp Histiocytosis/ or histiocytosis$.mp.
34. exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumokoniosis.mp. or pneumonoconiosis.mp.
35. bagassosis.mp.
36. (pulmonary$ adj sarcoid$).mp.
37. (pulmonary$ adj fibros$).mp.
38. (wegener$ adj granuloma$).mp.
40. ((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
41. (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
42. or/24-41 [ILD search]
43. 23 and 42
44. (animals not humans).sh.
45. 43 not 44
46. limit 45 to case reports
47. 45 not 46

**Ovid Embase 1974 to April 22 2022**
1. exp interstitial lung disease/
2. exp lung fibrosis/
3. (interstitial$ adj3 (lung$ adj3 disease$)).tw.
4. (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
5. (diffuse* adj3 parenchymal*).tw.
6. alveolitis.mp.
7. bronchiolitis obliterans/
8. (bronchiolitis adj obliterans).mp.
10. granulomatosis.mp.
11. exp histiocytosis/
12. histiocytosis$.mp.
13. pneumoconiosis/
14. (pneumoconiosis or pneumokoniosis or pneumonoconiosis).mp.
15. bagassosis.mp.
17. (pulmonary$ adj fibros$).mp.
18. (wegener$ adj granuloma$).mp.
20. ((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
21. (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
22. or/1-21 [ILD concept]
23. advance care planning/
24. living will/
25. (advance* adj care adj (plan or plans or planning)).ti,ab,kw.
26. (advance* adj (directive* or decision* or statement* or medical plan*)).ti,ab,kw.
27. living will*.ti,ab,kw.
28. right to die/
29. right to die.ti,ab,kw.
30. patient advocacy/
31. ((patient or patients) adj2 (advocat* or advocacy)).ti,ab,kw.
32. exp "power of attorney"/ or exp "durable power of attorney"/
33. power of attorney.ti,ab,kw.
34. treatment refusal/
35. (treatment adj2 (refus* or withhold* or withdraw*)).ti,ab,kw.
36. ((assist* or proxy or substitut*) adj2 (decision making or decision maker*)).ti,ab,kw.
37. ((statement or knowledge or aware*) adj2 wish*).ti,ab,kw.
38. ((end of life or EOL) adj2 (care or discuss* or decision* or plan* or preference* or wish*)).ti,ab,kw.
39. exp "do not resuscitate order"/
40. DNR.ti,ab,kw.
41. DNI.ti,ab,kw.
42. ("do not" adj (hospitalise or hospitalize or resuscitate or intubate)).ti,ab,kw.
43. DNH.ti,ab,kw.
44. or/23-43
45. 22 and 44
46. limit 45 to conference abstract status
47. 45 not 46
49. 47 not 48
50. case report/
51. case report.ti.
52. 50 or 51
53. 49 and 52
54. 49 not 53

Cochrane Database of Systematic Reviews 1996 to April 22 2022 and CENTRAL via The Cochrane Library
#1 MeSH descriptor: [Lung Diseases, Interstitial] explode all trees
#2 MeSH descriptor: [Pulmonary Fibrosis] explode all trees
#3 ((interstitial* near/3 (lung* near/3 disease*))):ti,ab,kw
#4 interstitial* near/3 (fibros* or pneumonitis or pneumonia or pneumopathy):ti,ab,kw
#5 diffuse* near/3 parenchymal*:ti,ab,kw
#6 (Alveolitis):ti,ab,kw
#7 MeSH descriptor: [Bronchiolitis Obliterans] explode all trees
#8 (bronchiolitis next obliterans):ti,ab,kw
#9 (goodpasture* NEXT syndrome*):ti,ab,kw
#10 (granulomatosis):ti,ab,kw
#11 MeSH descriptor: [Histiocytosis] explode all trees
#12 (histiocytosis*):ti,ab,kw
#13 MeSH descriptor: [Pneumoconiosis] explode all trees
#14 (pneumoconiosis or pneumokoniosis or pneumonoconiosis):ti,ab,kw
#15 (bagassosis):ti,ab,kw
#16 (pulmonary next (sarcoid* or fibros*)):ti,ab,kw
#17 (wegener* next granuloma*):ti,ab,kw
#18 (lung* adj purpura):ti,ab,kw
#19 (((bird* or farmer* or pigeon* or avian* or budgerigar*) next (lung* or disease*)):ti,ab,kw
#20 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19
#21 MeSH descriptor: [Advance Care Planning] explode all trees
#22 MeSH descriptor: [Right to Die] explode all trees
#23 MeSH descriptor: [Patient Advocacy] explode all trees
#24 MeSH descriptor: [Treatment Refusal] this term only
#25 MeSH descriptor: [Resuscitation Orders] explode all trees
#26 ((advance* next care next (plan or plans or planning))):ti,ab,kw
#27 ((advance* next (directive* or decision* or statement* or medical plan*)):ti,ab,kw
#28 ("living will"):ti,ab,kw
#29 ("right to die" or "right-to-die"):ti,ab,kw
#30 (((patient or patients) near/2 (advocat* or advocacy)):ti,ab,kw
#31 ("power of attorney"):ti,ab,kw
#32 (((assist* or proxy or substitut*) near/2 (decision making or decision maker*)):ti,ab,kw
#33 (((statement or knowledge or aware*) near/2 wish*)):ti,ab,kw
#34 ((("end of life" or "end-of-life" or EOL) next (care or discuss* or decision* or plan* or preference* or wish*)):ti,ab,kw
#35 (DNI or DNR or DNH):ti,ab,kw
#36 ("do not" next (hospitalise or hospitalize or resuscitate or intubate)):ti,ab,kw
#37 #21 or #22 or #23 #24 #25 or #26 or #27 or #28 or #29 or #30 or #31 #32 or #33 or #34 or #35 or #36
#38 #20 and #37

CINAHL Complete via EBSCOhost 1937 to April 22 2022
S1 (MH "Advance Care Planning")
S2 (MH "Advance Directives") OR (MH "Durable Power of Attorney") OR (MH "Living Wills") OR (MH "Resuscitation Orders")
S3 (MH "Right to Die")
S4 (MH "Patient Advocacy")
S5 (MH "Terminal Care")
S6 (MH "Treatment Refusal")
S7 (MH "Euthanasia, Passive")
S8 TI advance* care n1 plan* OR AB advance* care n1 plan* OR TI (advance* n1 (directive* or decision* or statement* or medical plan*)) OR AB (advance* n1 (directive* or decision* or statement* or medical plan*)) OR TI "living will*" OR AB "living will*" OR TI ("right to die" or "right-to-die") OR AB ("right to die" or "right-to-die")
S9 TI "power of attorney" OR AB "power of attorney" OR TI ( ((assist* or proxy or substitut*) n2 (decision making or decision maker*)) ) OR AB ( ((assist* or proxy or substitut*) n2 (decision making or decision maker*)) ) OR TI ( ((statement or knowledge or aware*) n2 wish*) ) OR AB ( ((statement or knowledge or aware*) n2 wish*) ) OR TI ( ((end-of-life or "end of life" or EOL) n5 (care or discuss* or decision* or plan* or preference* or wish*)) ) OR AB ( ((end-of-life or "end of life" or EOL) n5 (care or discuss* or decision* or plan* or preference* or wish*)) ) OR TI Resuscitation Order* OR AB Resuscitation Order* OR TI ("do not*" n1 (hospitalise or hospitalize or resuscitate or intubate)) OR AB ("do not*" n1 (hospitalise or hospitalize or resuscitate or intubate))
S10 TI ( DNI or DNH or DNI ) OR AB ( DNI or DNH or DNI )
S11 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10
S12 TI wegener* n1 granuloma* OR AB wegener* n1 granuloma* OR TI ( ((bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)) ) OR AB ( ((bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)) )
S13 TI (pneumoconiosis or pneumokoniosis or pneumonoconiosis or bagassosis) OR AB (pneumoconiosis or pneumokoniosis or pneumonoconiosis or bagassosis) OR TI (pulmonary n1 (sarcoid* or fibros*)) OR AB (pulmonary n1 (sarcoid* or fibros*))
S14 TI "bronchiolitis obliterans" OR AB "bronchiolitis obliterans" OR TI (granulomatosis or "goodpasture* syndrome") OR AB (granulomatosis or "goodpasture* syndrome")
S15 AB diffuse* n3 parenchymal* OR TI diffuse* n3 parenchymal* OR TI Alveolitis OR AB Alveolitis
S16 TI (interstitial n2 (lung* or fibros* or pneumo*)) OR AB (interstitial n2 (lung* or fibros* or pneumo*))
S17 (MH "Pneumoconiosis+")
S18 (MH "Histiocytosis+")
S19 (MH "Bronchiolitis Obliterans+")
S20 (MH "Pulmonary Fibrosis+")
S21 (MM "Lung Diseases, Interstitial+")
S22 S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21
S23 S11 AND S22

Web of Science Core collection (including SCI-EXPANDED 1970 to April 22 2022)
TOPIC: (interstitial lung disease* OR pulmonary fibrosis OR pneumoconiosis OR asbestosis) AND TOPIC: (advance* care planning or advance directive* or living will or power of attorney or DNI or DNH or DNI)
Epistemonikos via https://www.epistemonikos.org/en/ from inception to April 22 2022
(title:(interstitial lung disease* OR pulmonary fibrosis OR pneumoconiosis OR asbestosis) OR 
abstract:(interstitial lung disease* OR pulmonary fibrosis OR pneumoconiosis OR asbestosis)) AND 
title:(advance care plan* OR living will* OR advance directive* OR power of attorney OR DNI OR 
DNH OR DNI) OR abstract:(advance care plan* OR living will* OR advance directive* OR power of 
attorney OR DNI OR DNH OR DNI))

SCOPUS via Scopus.com from inception to April 22 2022
( TITLE-ABS-KEY ( "interstitial lung disease*'" OR "pulmonary fibrosis" OR pneumoconiosis OR 
asbestosis ) AND TITLE-ABS-KEY ( "advance care plan*'" OR "advance directive*'" OR "living will*'" OR 
"power of attorney" OR dni OR dnh OR dni ) )

Browsed Advance Care Planning, Advance Directives and Chronic disease sections of CareSearch 
Search strategy question 7 and 8
How do we implement palliative care with routine clinical care for adults with COPD and ILD and their informal caregivers? (Question7 narrative)

Note: See Supplements 4 and 5 for detailed methodologies after searching. Separate searches for ACP and palliative care were completed for Questions 7 and 8 but the questions were merged and analysis split by population. For Question 7, separate searches were undertaken for systematic reviews and for other studies. The searches were identical apart from the addition of a search filter for systematic reviews which is reproduced below. For the update searches, only the searches for systematic reviews were completed.
(Initial search date 30 April 2021, systematic review searches updated 19th April 2022. We searched all databases from their inception)

Ovid MEDLINE(R) ALL 1946 to April 19 2022
Line 125 is the search for systematic reviews. Line 126 is the search for other studies.

1 Caregivers/
2 (caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*).ti,ab,kw.
3 1 or 2
4 (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*).ti,ab,kw.
5 exp Family/
6 Friends/
7 (friend* or significant other* or most significant person* or next of kin or neighbour* or neighbor* or loved one*).ti,ab,kw.
8 or/4-7
9 (care* or caring or support*).ti,ab,kw.
10 8 and 9
11 3 or 10 [caregiver concept]
12 exp advance care planning/
13 exp attitude to death/
14 exp bereavement/
15 death/
16 hospices/
17 life support care/
18 palliative care/ or Palliative Medicine/
19 exp terminal care/ or respite care/
20 terminally ill/
21 palliat$.af.
22 hospice$.af.
23 (terminal care or respite care).af.
24 or/12-23
25 journal of palliative care.jn.
26 journal of palliative medicine.jn.
27 hospice journal physical psychosocial & pastoral care of the dying.jn.
28 supportive care in cancer.jn.
29 palliative medicine.jn.
30 palliative & supportive care.jn.
31 journal of supportive oncology.jn.
32 journal of social work in end of life & palliative care.jn.
33 journal of pain & symptom management.jn.
34 journal of pain & palliative care pharmacotherapy.jn.
international journal of palliative nursing.jn.
dead studies.jn.
american journal of hospice care.jn.
american journal of hospice & palliative medicine.jn.
omega journal of death & dying.jn.
or/25-40
24 or 41
bereave$.mp.
attitude to death.mp.
end of life.af.
Advance* Care.af.
((advanced or terminal*) adj (ill* or disease)).ti,ab,kw.
supportive care.ti,ab,kw.
dying.ti,ab,kw.
"last year of life".ti,ab,kw.
(limited life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
or/43-51
42 or 52 [palliative care concept]
11 and 53 [caregivers AND palliative care]
exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
emphysema$.mp.
(chronic$ adj3 bronchiti$).mp.
(chronic adj3 obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).mp.
COPD.mp.
COAD.mp.
COBD.mp.
AECB.mp.
Lung Diseases, Obstructive/
or/55-63 [COPD]
exp Lung Diseases, Interstitial/
exp Pulmonary Fibrosis/
(interstitial$ adj3 (lung$ adj3 disease$)).tw.
(interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
(diffuse* adj3 parenchymal*).tw.
alveolitis.mp.
exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterator)s.mp.
(goodpasture$ adj syndrome$).mp.
granulomatosis.mp.
exp Histiocytosis/ or histiocytosis$.mp.
exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumokoniosis.mp. or pneumonoconiosis.mp.
bagassosis.mp.
(pulmonary$ adj sarcoid$).mp.
(pulmonary$ adj fibros$).mp.
(wegener$ adj granuloma$).mp.
(lung$ adj purpura$).mp.
((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
(asbestosis or byssiosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
or/65-82 [ILD search]
64 or 83 [COPD or ILD]
(barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance).ti,ab,kw.
(acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity).ti,ab,kw.
(transform* or translat* or transfer* or sustainab* or capacity).ti,ab,kw.
(Institutionalis* or institutionaliz*).ti,ab,kw.
(acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity).ti,ab,kw.
(organizational change*).ti,ab,kw.
(system* adj2 change*).ti,ab,kw.
Organizational Innovation/
Quality Improvement/
exp "diffusion of innovation"/ or implementation science/ or technology transfer/ or Program Evaluation/
((process or program*) adj2 evaluation*).ti,ab,kw.
quality improvement*.ti,ab,kw.
(change adj3 manag*).ti,ab,kw.
(StaRI or SQUIRE).ti,ab,kw.
RE-AIM.ti,ab,kw.
Dynamic Sustainability Framework.ti,ab,kw.
"Practical, Robust Implementation and Sustainability Model".ti,ab,kw.
(CFIR or "Consolidated Framework for Implementation Research").ti,ab,kw.
"Conceptual framework for sustainability of public health programs".ti,ab,kw.
"Sustainability planning model".ti,ab,kw.
"Capacity for sustainability framework".ti,ab,kw.
"Interactive Systems Framework".ti,ab,kw.
"knowledge to action".ti,ab,kw.
"Behavior Change Wheel".ti,ab,kw.
"Exploration Preparation Implementation Sustainment".ti,ab,kw.
"TCU program change model".ti,ab,kw.
"Normalisation Process Theory".ti,ab,kw.
("Promoting Action on Research Implementation in Health Services" or PARIHS).ti,ab,kw.
CRARUM.ti,ab,kw.
KTA.ti,ab,kw.
("Joint Venture Model of Knowledge Utilization" or JVMKU).ti,ab,kw.
("Knowledge Use in Pain Care" or KUPC).ti,ab,kw.
("Advancing Research and Clinical Practice Through Close Collaboration Model" or ARCC).ti,ab,kw.
real world.ti,ab,kw.
routine clinical care.ti,ab,kw.
field effectiveness.ti,ab,kw.
clinical trial, phase iv/
or/85-122 [implementation concept]
54 and 84 and 123 [palliative care AND caregivers AND ILD/COPD AND implementation]
limit 124 to (systematic reviews pre 2019 or systematic reviews)
124 not 125

Ovid Embase 1974 to April 19 2022
Line 120 is the search for systematic reviews. Line 121 is the search for other studies
Set Search Statement
1 caregiver/
(caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*).ti,ab,kw.
1 or 2
(dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*).ti,ab,kw.
exp family/
friend/
(friend* or significant other* or most significant person* or next of kin or neighbour* or neighbor* or loved one*).ti,ab,kw.
or/4-7
(carer* or caring or support*).ti,ab,kw.
8 and 9
3 or 10 [caregiver concept]
advance care planning/
attitude to death/
bereavement/
death/
hospice/
palliative therapy/
respite care/
terminal care/ or hospice care/
exp terminally ill patient/
palliat$.af.
hospice$.af.
(friend care or respite care).af.
supportive care.ti,ab,kw.
bereave$.mp.
attitude to death.mp.
end of life.af.
((advanced or terminal* or critical*) adj (ill* or disease)).ti,ab,kw.
Advance* Care.af.
(limitated life adj (expectanc* or span*)).ti,ab,kw. or life-limiting.mp.
"last year of life".ti,ab,kw.
dying.ti,ab,kw.
or/12-32 [palliative care concept]
11 and 33 [palliative care AND caregivers]
chronic obstructive lung disease/
obstructive airway disease/
chronic bronchitis/
lung emphysema/
emphysema$.mp.
(chronic$ adj3 bronchiti$).mp.
(obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).ti,ab,kw.
(COPD or COAD or COBD or AECB).mp.
or/35-42 [COPD based on Cochrane Airways]
exp interstitial lung disease/
ex lung fibrosis/
(interstitial$ adj3 (lung$ adj3 disease$)).tw.
(interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
(diffuse* adj3 parenchymal*).tw.
alveolitis.mp.
bronchiolitis obliterans/
(bronchiolitis adj obliterans).mp.
(goodpasture$ adj syndrome$).mp.
granulomatosis.mp.
exp histiocytosis/
histiocytosis$.mp.
pneumoconiosis/
(pneumoconiosis or pneumokoniosis or pneumonoconiosis).mp.
bagassosis.mp.
(pulmonary$ adj sarcoid$).mp.
(pulmonary$ adj fibros$).mp.
(wegener$ adj granuloma$).mp.
(lung$ adj purpura).mp.
((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
(asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
or/44-64 [ILD concept]
43 or 65 [COPD or ILD]
(barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance).ti,ab,kw.
(acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity).ti,ab,kw.
(transform* or translat* or transfer* or sustainab* or capacity).ti,ab,kw.
(Institutionalis* or institutionaliz*).ti,ab,kw.
(implement* or integrat*).ti,ab,kw.
(dissemin* or adopt* or practice* or diffus*).ti,ab,kw.
organizational change*.ti,ab,kw.
(system* adj2 change*).ti,ab,kw.
implementation science/
exp program evaluation/
((process or program*) adj2 evaluation*).ti,ab,kw.
quality improvement*.ti,ab,kw.
(change adj3 manag*).ti,ab,kw.
(StaRI or SQUIRE).ti,ab,kw.
RE-AIM.ti,ab,kw.
Dynamic Sustainability Framework.ti,ab,kw.
"Practical, Robust Implementation and Sustainability Model".ti,ab,kw.
(CFIR or "Consolidated Framework for Implementation Research").ti,ab,kw.
"Conceptual framework for sustainability of public health programs".ti,ab,kw.
"Sustainability planning model".ti,ab,kw.
"Capacity for sustainability framework".ti,ab,kw.
"Interactive Systems Framework".ti,ab,kw.
"knowledge to action".ti,ab,kw.
"Behavior Change Wheel".ti,ab,kw.
"Exploration Preparation Implementation Sustainment".ti,ab,kw.
"TCU program change model".ti,ab,kw.
"Normalisation Process Theory".ti,ab,kw.
("Promoting Action on Research Implementation in Health Services" or PARIHS).ti,ab,kw.
CRARUM.ti,ab,kw.
KTA.ti,ab,kw.
("Joint Venture Model of Knowledge Utilization" or JVMKU).ti,ab,kw.
("Knowledge Use in Pain Care" or KUPC).ti,ab,kw.
("Advancing Research and Clinical Practice Through Close Collaboration Model" or ARCC).ti,ab,kw.
real world.ti,ab,kw.
routine clinical care.ti,ab,kw.
field effectiveness.ti,ab,kw.
phase 4 clinical trial/
or/67-103 [implementation concept]
34 and 66 and 104 [palliative care AND caregivers AND ILD/COPD AND implementation]
limit 105 to conference abstract status
105 not 106
exp review/
literature adj3 review$.ti,ab.
exp meta analysis/
exp "systematic review"/
or/108-111
medline or medlars or embase or pubmed or cinahl or amed or psychlit or psyclit or psychinfo or psycinfo or scisearch or cochrane).ti,ab.
RETRACTED ARTICLE/
113 or 114
116 and 115
systematic$.ti,ab,kw
(metaanal$ or meta anal$ or meta-ana$ or metaanal$ or metanal$).ti,ab.
116 or 117 or 118
107 and 119 [systematic review search]
107 not 120 [search for other results]

Cochrane Database of Systematic Reviews 1996 to 19 April 2022 and CENTRAL via The Cochrane Library to 30 April 2021
#1 MeSH descriptor: [Diffusion of Innovation] explode all trees
#2 (barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance):ti,ab,kw
#3 (acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity):ti,ab,kw
#4 (transform* or translat* or transfer* or sustainab* or capacity):ti,ab,kw
#5 (Institutionalis* or institutionaliz*):ti,ab,kw
#6 (implement* or integrat*):ti,ab,kw
#7 (dissemin* or adopt* or practice* or diffus*):ti,ab,kw
#8 ((process or program*) near/2 evaluation*):ti,ab,kw
#9 MeSH descriptor: [Program Evaluation] explode all trees
#10 (StaRI or SQUIRE):ti,ab,kw
#11 (real next world):ti,ab,kw
#12 ("routine clinical care"):ti,ab,kw
#13 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12
#14 MeSH descriptor: [Advance Care Planning] explode all trees
#15 MeSH descriptor: [Attitude to Death] explode all trees
#16 MeSH descriptor: [Bereavement] explode all trees
#17 MeSH descriptor: [Death] this term only
#18 MeSH descriptor: [Hospices] this term only
#19 MeSH descriptor: [Life Support Care] this term only
#20 MeSH descriptor: [Palliative Care] explode all trees
#21 MeSH descriptor: [Respite Care] explode all trees
#22 MeSH descriptor: [Terminal Care] explode all trees
#23 MeSH descriptor: [Terminally Ill] explode all trees
#24 (palliat* or hospice*):ti,ab,kw
#25 ((terminal or supportive) next care):ti,ab,kw
#26 (respite next care):ti,ab,kw
#27 (bereave* or dying):ti,ab,kw
#28 ("attitude to death":ti,ab,kw
#29 (((advanced or terminal* or critical*) next (ill* or disease)):ti,ab,kw
#30 (advance* next care):ti,ab,kw
#31 ("last year of life" or (limited next (expectanc* or span*)) or life-limiting):ti,ab,kw
#32 #14 or #15 or #16 or #17 or #18 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31
#33 MeSH descriptor: [Caregivers] explode all trees
#34 (caregiver* or care-giver* or carer* or care partner* or care provider* or informal care*):ti,ab,kw
#35 #33 or #34
#36 (dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner*):ti,ab,kw
#37 MeSH descriptor: [Family] explode all trees
#38 MeSH descriptor: [Friends] this term only
#39 (friend*):ti,ab,kw
#40 (significant next other*):ti,ab,kw
#41 (significant next person*):ti,ab,kw
#42 ("next-of-kin" or "next of kin"):ti,ab,kw
#43 (neighbour* or neighbor*):ti,ab,kw
#44 (loved next one*):ti,ab,kw
#45 #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44
#46 (care* or caring or support*):ti,ab,kw
#47 #45 and #46
#48 #35 or #47
#49 MeSH descriptor: [Lung Diseases, Interstitial] explode all trees
#50 MeSH descriptor: [Pulmonary Fibrosis] explode all trees
#51 (((interstitial* near/3 (lung* near/3 disease*)):ti,ab,kw
#52 interstitial* near/3 (fibros* or pneumonitis or pneumonia or pneumopathy):ti,ab,kw
#53 diffuse* near/3 parenchymal*:ti,ab,kw
#54 (Alveolitis):ti,ab,kw
#55 MeSH descriptor: [Bronchiolitis Obliterans] explode all trees
#56 (bronchiolitis next obliterans):ti,ab,kw
#57 (goodpasture* NEXT syndrome*):ti,ab,kw
#58 (granulomatosis):ti,ab,kw
#59 MeSH descriptor: [Histiocytosis] explode all trees
#60 (histiocytosis*):ti,ab,kw
#61 MeSH descriptor: [Pneumoconiosis] explode all trees
#62 (pneumoconiosis or pneumokoniosis or pneumonoconiosis):ti,ab,kw
#63 (bagassosis):ti,ab,kw
#64 (pulmonary next (sarcoid* or fibros*)):ti,ab,kw
#65 (wegener* next granuloma*):ti,ab,kw
#66 (lung* adj purpura):ti,ab,kw
#67 (((bird* or farmer* or pigeon* or avian* or budgerigar*) next (lung* or disease*)):ti,ab,kw
#68 #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67
#69 MeSH descriptor: [Pulmonary Disease, Chronic Obstructive] explode all trees
#70 (emphysema*):ti,ab,kw
#71 (chronic* near/2 bronchiti*):ti,ab,kw
#72 (obstruct* near/2 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)):ti,ab,kw
CINAHL Complete via EBSCOhost  1937 to April 19th 2022

Line S31 is the search for systematic reviews. Line S29 is the search for other studies

S1  ( (MH "Terminal Care") or (MH "Palliative Care") or (MH "Attitude to Death") or (MH "Advance Care Planning") or (MH "Respite Care") or (MH "Hospices") or (MH "Life Support Care") ) OR TI ( bereave* or hospice* or "end of life" of "terminally ill" or palliat* ) OR TI ( bereave* or hospice* or "end of life" of "terminally ill" or palliat* )

S2  (MH "Caregivers") OR TI ( caregiver* or care-giver* or carer* or "care partner*" or "care provider*" or "informal care*" ) OR AB ( caregiver* or care-giver* or carer* or "care partner*" or "care provider*" or "informal care*" ) OR TI ( ( care* or caring or support* ) n2 ( dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner* ) ) OR AB ( ( care* or caring or support* ) n2 ( dependents or families or family or parent* or relative* or spouse* or spousal or husband* or wife or wives or sibling* or brother* or sister* or mother* or father* or partner* ) )

S3  S1 AND S2

S4  ( (MH "Pulmonary Disease, Chronic Obstructive") or (MH "Emphysema") or (MH "Lung Diseases, Obstructive") ) OR TI ( ( obstruct* n3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)) ) OR AB ( ( obstruct* n3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)) ) OR TI ( COPD or COAD or COBD or AECB ) OR AB ( COPD or COAD or COBD or AECB )

S5  TI ( asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthropsilicosis or silicotuberculosis ) OR AB ( asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthropsilicosis or silicotuberculosis )

S6  TI wegener* n1 granuloma* OR AB wegener* n1 granuloma* OR TI ( (bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*)) ) OR AB ( (bird* or farmer* or pigeon* or avian* or budgerigar*) n1 (lung* or disease*))

S7  TI ( pneumoconiosis or pneumokoniosis or pneumonoconiosis or bagassosis ) OR AB ( pneumoconiosis or pneumokoniosis or pneumonoconiosis or bagassosis ) OR TI ( pulmonary n1 (sarcoid* or fibros*) ) OR AB ( pulmonary n1 (sarcoid* or fibros*) )

S8  TI "bronchiolitis obliterans" OR AB "bronchiolitis obliterans" OR TI ( granulomatosis or "goodpasture* syndrome" ) OR AB ( granulomatosis or "goodpasture* syndrome" )

S9  AB diffuse* n3 parenchymal* OR TI diffuse* n3 parenchymal* OR TI Alveolitis OR AB Alveolitis

S10  TI ( interstitial n2 (lung* or fibros* or pneumo*) ) OR AB ( interstitial n2 (lung* or fibros* or pneumo*) )

S11  (MH "Pneumoconiosis+")

S12  (MH "Histiocytosis+")

S13  (MH "Bronchiolitis Obliterans+")

S14  (MH "Pulmonary Fibrosis+")

S15  (MM "Lung Diseases, Interstitial+")

S16  S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

S17  S4 OR S16

S18  S3 AND S17

S19  (MH "Program Evaluation")

S20  TI ( dissemin* or adopt* or practice* or diffus* ) OR AB ( dissemin* or adopt* or practice* or diffus* )

S21  TI ( implement* or integrat* ) OR AB ( implement* or integrat* )

S22  TI ( Institutionalis* or institutionaliz* ) OR AB ( Institutionalis* or institutionaliz* )
S23  TI ( transform* or translat* or transfer* or sustainab* or capacity ) OR AB ( transform* or translat* or transfer* or sustainab* or capacity )
S24  TI ( acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity ) OR AB ( acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity )
S25  TI ( barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance ) OR AB ( barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance )
S26  (MH "Program Implementation")
S27  (MH "Diffusion of Innovation") OR (MH "Implementation Science")
S28  S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27
S29  S18 AND S28
S30  (TI (systematic* n3 review*)) or (AB (systematic* n3 review*)) or (TI (systematic* n3 bibliographic*)) or (AB (systematic* n3 bibliographic*)) or (TI (scoping n3 review)) or (AB (scoping n3 review)) or (TI (systematic* n3 literature)) or (AB (systematic* n3 literature)) or (TI (comprehensive* n3 literature)) or (AB (comprehensive* n3 literature)) or (TI (comprehensive* n3 bibliographic*)) or (AB (comprehensive* n3 bibliographic*)) or (TI (integrative n3 review)) or (AB (integrative n3 review)) or (JN "Cochrane Database of Systematic Reviews") or (TI (information n2 synthesis)) or (TI (data n2 synthesis)) or (AB (information n2 synthesis)) or (AB (data n2 synthesis)) or (TI (data n2 extract*)) or (AB (data n2 extract*)) or (TI (medline or pubmed or psyclit or cinahl or (psycinfo not "psycinfo database") or "web of science" or scopus or embase)) or (AB (medline or pubmed or psyclit or cinahl or (psycinfo not "psycinfo database") or "web of science" or scopus or embase)) or (MH "Systematic Review") or (MH "Meta Analysis") or (TI (meta-analy* or metaanaly*)) or (AB (meta-analy* or metaanaly*))

Web of Science Core collection (including SCI-EXPANDED 1970 to April 19th 2022)

TOPIC: (dissemin* or adopt* or practice* or diffus* or implement* or integrat* or acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity or barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance) AND TOPIC: (COPD or chronic obstructive pulmonary disease OR interstitial lung disease* OR pulmonary fibrosis OR pneumoconiosis OR asbestosis) AND TOPIC: (palliat* OR hospice* OR end of life OR respite care) AND TOPIC: (carer* OR caregiver* OR care-giver* OR "family member" OR "family caregiver*" OR spouse OR sibling OR "next of kin" OR neighbor* OR neighbour* OR friend* OR "most significant person" OR "loved one"*)

Epistemonikos via https://www.epistemonikos.org/en/ from inception to April 19th 2022
(title:(dissemin* OR adopt* OR practice* OR diffus* OR implement* OR integrat* OR acceptab* OR appropriat* OR uptake OR embed* OR adher* OR usage OR engagement OR fidelity OR barrier* OR constraint* OR facilitator* OR enabler* OR feasib* OR maintenance) OR abstract:(dissemin* OR adopt* OR practice* OR diffus* OR implement* OR integrat* OR acceptab* OR appropriat* OR uptake OR embed* OR adher* OR usage OR engagement OR fidelity OR barrier* OR constraint* OR facilitator* OR enabler* OR feasib* OR maintenance)) AND (title:(COPD OR chronic obstructive pulmonary disease OR interstitial lung disease* OR pulmonary fibrosis OR pneumoconiosis OR asbestosis) OR abstract:(COPD OR chronic obstructive pulmonary disease OR interstitial lung disease* OR pulmonary fibrosis OR pneumoconiosis OR asbestosis)) AND (title:(palliat* OR hospice* OR end of life OR respite care) OR abstract:(palliat* OR hospice* OR end of life OR respite care)) AND (title:(carer* OR caregiver* OR care-giver* OR "family member" OR "family caregiver*" OR spouse OR sibling OR "next of kin" OR neighbor* OR neighbour* OR friend*) OR abstract:(carer* OR caregiver* OR care-giver* OR "family member" OR "family caregiver*" OR spouse OR sibling OR "next of kin" OR neighbor* OR neighbour* OR friend*))

SCOPUS via Scopus.com from inception to April 19th 2022
(TITLE-ABS-KEY (palliat* OR hospice* OR end AND of AND life OR respite AND care) AND
TITLE-ABS-KEY (carer* OR caregiver* OR care-giver* OR "family member" OR "family caregiver*" OR spouse OR sibling OR "next of kin" OR neighbor* OR neighbour* OR friend* OR "most significant person" OR "loved one*"
) AND
TITLE-ABS-KEY (copp OR "chronic obstructive pulmonary disease" OR "interstitial lung disease*" OR "pulmonary fibrosis" OR pneumoconiosis OR asbestosis) AND
TITLE-ABS-KEY (dissemin* OR adopt* OR practice* OR diffus* OR implement* OR integrat* OR acceptab* OR appropriat* OR uptake OR embed* OR adher* OR usage OR engagement OR fidelity OR barrier* OR constraint* OR facilitator* OR enabler* OR feasib* OR maintenance) AND
TITLE (review))
Question 8 (narrative)
How do we implement ACP in routine clinical care for adults with COPD and ILD?

Note: please see Online supplement 4 for more detail about the subsequent merging of Questions 7 and 8

Separate searches for palliative care and ACP were completed for Questions 7 and 8 but the questions were merged and analysis split by population. For Question 8, separate searches were undertaken for systematic reviews and for other studies. The searches were identical apart from the addition of a search filter for systematic reviews which is reproduced below. For the update searches, only the searches for systematic reviews were completed.

(Initial search date 04 May 2021, systematic review searches updated 20 April 2022. We searched all databases from their inception)

Ovid MEDLINE(R) ALL 1946 to April 2022

The search for systematic review is line 94, the search for other studies is line 95

1 exp advance care planning/ or advance directives/ or living wills/
2 (advance* care adj (plan or plans or planning)).ti,ab,kw.
3 (advance* adj (directive* or decision* or statement* or medical plan*)).ti,ab,kw.
4 living will*.ti,ab,kw.
5 Right to Die/
6 right to die.ti,ab,kw.
7 Patient Advocacy/
8 ((patient or patients) adj5 (advocat* or advocacy)).ti,ab,kw.
9 power of attorney.ti,ab,kw.
10 Terminal Care/
11 terminal care.ti,ab,kw.
12 Treatment Refusal/
13 exp Withholding Treatment/
14 (treatment adj5 (refus* or withhold* or withdraw*)).ti,ab,kw.
15 ((assist* or proxy or substitut*) adj2 (decision making or decision maker*)).ti,ab,kw.
16 ((statement or knowledge or aware*) adj2 wish*).ti,ab,kw.
17 ((end of life or EOL) adj5 (care or discuss* or decision* or plan* or preference* or wish*)).ti,ab,kw.
18 exp Resuscitation Orders/
19 DNR.ti,ab,kw.
20 DNI.ti,ab,kw.
21 ("do not" adj (hospitalise or hospitalize or resuscitate or intubate)).ti,ab,kw.
22 DNH.ti,ab,kw.
23 or/1-22
24 (barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance).ti,ab,kw.
25 (acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity).ti,ab,kw.
26 (transform* or translat* or transfer* or sustainab* or capacity).ti,ab,kw.
27 (Institutionalis* or institutionaliz*).ti,ab,kw.
28 (implement* or integrat*).ti,ab,kw.
29 (dissemin* or adopt* or practice* or diffus*).ti,ab,kw.
30 organ?ational change*.ti,ab,kw.
31 (system* adj2 change*).ti,ab,kw.
32 Organizational Innovation/
33 Quality Improvement/
34 exp "diffusion of innovation"/ or implementation science/ or technology transfer/ or Program Evaluation/
((process or program*) adj2 evaluation*).ti,ab,kw.
quality improvement*.ti,ab,kw.
(change adj3 manag*).ti,ab,kw.
(StaRI or SQUIRE).ti,ab,kw.
RE-AIM.ti,ab,kw.
Dynamic Sustainability Framework.ti,ab,kw.
"Practical, Robust Implementation and Sustainability Model".ti,ab,kw.
(CFIR or "Consolidated Framework for Implementation Research").ti,ab,kw.
"Conceptual framework for sustainability of public health programs".ti,ab,kw.
"Sustainability planning model".ti,ab,kw.
"Capacity for sustainability framework".ti,ab,kw.
"Interactive Systems Framework".ti,ab,kw.
"knowledge to action".ti,ab,kw.
"Behavior Change Wheel".ti,ab,kw.
"Exploration Preparation Implementation Sustainment".ti,ab,kw.
"TCU program change model".ti,ab,kw.
"Normalisation Process Theory".ti,ab,kw.
("Promoting Action on Research Implementation in Health Services" or PARIHS).ti,ab,kw.
CRARUM.ti,ab,kw.
KTA.ti,ab,kw.
("Joint Venture Model of Knowledge Utilization" or JVMKU).ti,ab,kw.
("Knowledge Use in Pain Care" or KUPC).ti,ab,kw.
("Advancing Research and Clinical Practice Through Close Collaboration Model" or ARCC).ti,ab,kw.
real world.ti,ab,kw.
routine clinical care.ti,ab,kw.
field effectiveness.ti,ab,kw.
clinical trial, phase iv/
or/24-61 [implementation concept]
exp pulmonary disease, chronic obstructive/ or asthma-chronic obstructive pulmonary disease overlap syndrome/ or bronchitis, chronic/ or pulmonary emphysema/
emphysema$.mp.
(chronic$ adj3 bronchiti$).mp.
(chronic adj3 obstruct$ adj3 (pulmonary or lung$ or airflow$ or bronch$ or respirat$)).mp.
COPD.mp.
COAD.mp.
COBD.mp.
AECB.mp.
Lung Diseases, Obstructive/
or/63-71 [COPD]
exp Lung Diseases, Interstitial/
exp Pulmonary Fibrosis/
(interstitial$ adj3 (lung$ adj3 disease$)).tw.
(interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
(diffuse* adj3 parenchymal*).tw.
alveolitis.mp.
exp Bronchiolitis Obliterans/ or (bronchiolitis adj obliterator$s).mp.
(goodpasture$ adj syndrome$).mp.
granulomatosis.mp.
exp Histiocytosis/ or histiocytosis$.mp.
exp Pneumoconiosis/ or pneumoconiosis.mp. or pneumokoniosis.mp. or pneumonoconiosis.mp.
bagassosis.mp.
(pulmonary$ adj sarcoid$).mp.
(pulmonary$ adj fibros$).mp.
wegener$ adj granuloma$).mp.
lung$ adj purpura).mp.
((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
(asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
or/73-90 [ILD search]
72 or 91
23 and 62 and 92 [ACP and implementation and COPD/ILD]
limit 93 to (systematic reviews pre 2019 or systematic reviews)
93 not 94

Ovid Embase 1974 to April 20 2022
Line 106 is the search for systematic reviews, line 107 is the search for other studies
1 advance care planning/
2 living will/
3 (advance* care adj (plan or plans or planning)).ti,ab,kw.
4 (advance* adj (directive* or decision* or statement* or medical plan*)).ti,ab,kw.
5 living will*.ti,ab,kw.
6 right to die/
7 right to die.ti,ab,kw.
8 exp "power of attorney"/ or exp "durable power of attorney"/
9 power of attorney.ti,ab,kw.
10 treatment refusal/
11 (treatment adj3 (refus* or withdraw*)).ti,ab,kw.
12 ((assist* or proxy or substitut*) adj2 (decision making or decision maker*)).ti,ab,kw.
13 ((statement or knowledge or aware*) adj2 wish*).ti,ab,kw.
14 ((end of life or EOL) adj3 (care or discuss* or decision* or plan* or preference* or wish*)).ti,ab,kw.
15 exp "do not resuscitate order"/
16 DNR.ti,ab,kw.
17 DNI.ti,ab,kw.
18 ("do not" adj (hospitalise or hospitalize or resuscitate or intubate)).ti,ab,kw.
19 DNH.ti,ab,kw.
20 or/1-19
21 chronic obstructive lung disease/
22 chronic bronchitis/
23 lung emphysema/
24 emphysema$.ti,ab,kw.
25 (chronic$ adj3 bronchiti$).ti,ab,kw.
26 (chronic adj3 obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).ti,ab,kw.
27 (COPD or COAD or COBD or AECB).ti,ab,kw.
28 or/21-27
29 exp interstitial lung disease/
30 exp lung fibrosis/
31 (interstitial$ adj3 (lung$ adj3 disease$)).tw.
32 (interstitial$ adj3 (fibros$ or pneumonitis or pneumonia or pneumopathy)).tw.
(diffuse* adj3 parenchymal*).tw.
alveolitis.mp.
bronchiolitis obliterans/
(bronchiolitis adj obliterans).mp.
(goodpasture$ adj syndrome$s).mp.
granulomatosis.mp.
exp histiocytosis/
histiocytosis$ .mp.
pneumoconiosis/
(pneumoconiosis or pneumokoniosis or pneumonoconiosis).mp.
bagassosis.mp.
(pulmonary$ adj sarcoid$).mp.
(pulmonary$ adj fibros$).mp.
(wegener$ adj granuloma$).mp.
(lung$ adj purpura).mp.
((bird$ or farmer$ or pigeon$ or avian$ or budgerigar$) adj (lung$ or disease$)).mp.
(asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis).mp.
or/29-49 [ILD concept]
28 or 50 [COPD or ILD]
20 and 51 [ACP and COPD/ILD]
(barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance).ti,ab,kw.
(acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity).ti,ab,kw.
(transform* or translat* or transfer* or sustainab* or capacity).ti,ab,kw.
(Institutionalis* or institutionaliz*).ti,ab,kw.
(implementation* or integrat*).ti,ab,kw.
(dissemin* or adopt* or practice* or diffus*).ti,ab,kw.
organizational change*.ti,ab,kw.
(system* adj2 change*).ti,ab,kw.
implementation science/
exp program evaluation/
((process or program*) adj2 evaluation*).ti,ab,kw.
quality improvement*.ti,ab,kw.
(change adj3 manag*).ti,ab,kw.
(StaRI or SQUIRE).ti,ab,kw.
RE-AIM.ti,ab,kw.
Dynamic Sustainability Framework.ti,ab,kw.
"Practical, Robust Implementation and Sustainability Model".ti,ab,kw.
(CFIR or "Consolidated Framework for Implementation Research").ti,ab,kw.
"Conceptual framework for sustainability of public health programs".ti,ab,kw.
"Sustainability planning model".ti,ab,kw.
"Capacity for sustainability framework".ti,ab,kw.
"Interactive Systems Framework".ti,ab,kw.
"knowledge to action".ti,ab,kw.
"Behavior Change Wheel".ti,ab,kw.
"Exploration Preparation Implementation Sustainment".ti,ab,kw.
"TCU program change model".ti,ab,kw.
"Normalisation Process Theory".ti,ab,kw.
("Promoting Action on Research Implementation in Health Services" or PARIHS).ti,ab,kw.
CRARUM.ti,ab,kw.
KTA.ti,ab,kw.
("Joint Venture Model of Knowledge Utilization" or JVMKU).ti,ab,kw.
("Knowledge Use in Pain Care" or KUPC).ti,ab,kw.
("Advancing Research and Clinical Practice Through Close Collaboration Model" or ARCC).ti,ab,kw.
real world.ti,ab,kw.
routine clinical care.ti,ab,kw.
field effectiveness.ti,ab,kw.
phase 4 clinical trial/
or/53-89 [implementation concept]
52 and 90
limit 91 to conference abstract status
91 not 92
exp review/
literature adj3 review$.ti,ab.
exp meta analysis/
exp "systematic review"/
or/94-97
(medline or medlars or embase or pubmed or cinahl or amed or psychlit or psyclit or psychinfo or psycinfo or scisearch or cochrane).ti,ab.
COPD or COAD or COBD or AECB:ti,ab,kw
#17 or #18 or #19 or #20 or #21
#16 and #22
MeSH descriptor: [Diffusion of Innovation] explode all trees
(barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance):ti,ab,kw
(acceptab* or appropriat* or uptake or embed* or adher* or usage or engagement or fidelity):ti,ab,kw
(transform* or translat* or transfer* or sustainab* or capacity):ti,ab,kw
(Institutionalis* or institutionaliz*):ti,ab,kw
(implment* or integrat*):ti,ab,kw
(disemmin* or adopt* or practice* or diffus*):ti,ab,kw
((process or program*) near/2 evaluation*):ti,ab,kw
MeSH descriptor: [Program Evaluation] explode all trees
(StaRI or SQUIRE):ti,ab,kw
(real next world):ti,ab,kw
("routine clinical care"):ti,ab,kw
#24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35
#23 and #36
MeSH descriptor: [Lung Diseases, Interstitial] explode all trees
MeSH descriptor: [Pulmonary Fibrosis] explode all trees
((interstitial* near/3 (lung* near/3 disease*)):ti,ab,kw
interstitial* near/3 (fibros* or pneumonitis or pneumonia or pneumopathy):ti,ab,kw
diffuse* near/3 parenchymal*:ti,ab,kw
(Alveolitis):ti,ab,kw
MeSH descriptor: [Bronchiolitis Obliterans] explode all trees
(bronchiolitis next obliterans):ti,ab,kw
MeSH descriptor: [Histiocytosis] explode all trees
(granulomatosis):ti,ab,kw
MeSH descriptor: [Histiocytosis] explode all trees
(histiocytosis*):ti,ab,kw
MeSH descriptor: [Pneumoconiosis] explode all trees
(pneumoconiosis or pneumokoniosis or pneumonoconiosis):ti,ab,kw
(bagassosis):ti,ab,kw
(pulmonary next (sarcoid* or fibros*)):ti,ab,kw
(wegener* next granuloma*):ti,ab,kw
(lung* adj purpura):ti,ab,kw
(((bird* or farmer* or pigeon* or avian* or budgerigar*) next (lung* or disease*)):ti,ab,kw
#38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56
#57 #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56
#58 #57 and #16 and #36
#59 #58 or #37

CINAHL Complete via EBSCOhost 1937 to April 20 2022
S1 (MH "Advance Care Planning")
S2 (MH "Advance Directives") OR (MH "Durable Power of Attorney") OR (MH "Living Wills") OR (MH "Resuscitation Orders")
S3 (MH "Right to Die")
S4 (MH "Patient Advocacy")
S5 (MH "Terminal Care")
S6 (MH "Treatment Refusal")
S7 (MH "Euthanasia, Passive")
S33 TI (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis) OR AB (asbestosis or byssinosis or siderosis or silicosis or berylliosis or anthracosilicosis or silicotuberculosis)

S34 S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33

S35 S22 OR S34

S36 S11 AND S21 AND S35

S37 (TI (systematic* n3 review*)) or (AB (systematic* n3 review*)) or (TI (systematic* n3 bibliographic*)) or (AB (systematic* n3 bibliographic*)) or (TI (scoping n3 review)) or (AB (scoping n3 review)) or (TI (systematic* n3 literature)) or (AB (systematic* n3 literature)) or (TI (comprehensive* n3 literature)) or (AB (comprehensive* n3 literature)) or (TI (comprehensive* n3 bibliographic*)) or (AB (comprehensive* n3 bibliographic*)) or (TI (integrative n3 review)) or (AB (integrative n3 review)) or (JN "Cochrane Database of Systematic Reviews") or (TI (data n2 synthesis)) or (AB (data n2 synthesis)) or (TI (information n2 synthesis)) or (AB (information n2 synthesis)) or (TI (data n2 extract*)) or (AB (data n2 extract*)) or (TI (medline or pubmed or psyclit or cinahl or (psycinfo not “psycinfo database") or “web of science” or scopus or embbase)) or (AB (medline or pubmed or psyclit or cinahl or (psycinfo not “psycinfo database") or “web of science” or scopus or embbase)) or (MH “Systematic Review") or (MH "Meta Analysis") or (TI (meta-analy* or metaanaly*)) or (AB (meta-analy* or metaanaly*))

S38 S36 and S37

Web of Science Core collection (including SCI-EXPANDED 1970 to April 2022)

TOPIC: (COPD or “chronic obstructive pulmonary disease” or interstitial lung disease* OR pulmonary fibrosis OR pneumoconiosis OR asbestosis) AND TOPIC: (“advance* care plan*” or "advance directive*" or "living will*" or "power of attorney" or DNI or DNH or DNI) AND TOPIC: (dissemin* or adopt* or practice* or diffus* or implement* or integrat* or acceptab* or appropriat* or uptake or embed* or adher* or usage OR engagement or fidelity OR barrier* or constraint* or facilitator* or enabler* or feasib* or maintenance)

Epistemonikos via https://www.epistemonikos.org/en/ from inception to April 2022

(ttitle:(dissemin* OR adopt* OR practice* OR diffus* OR implement* OR integrat* OR acceptab* OR appropriat* OR uptake OR embed* OR adher* OR usage OR engagement or fidelity OR barrier* or constraint* OR facilitator* OR enabler* OR feasib* OR maintenance)) AND (title:(advance* care plan*)) OR abstract:(advance* care plan*)) AND (title:(copd OR chronic obstructive OR interstitial lung) OR abstract:(copd OR chronic obstructive OR interstitial lung))

SCOPUS via Scopus.com from inception to April 2022

(TITLE-ABS-KEY ("Chronic Obstructive Pulmonary Disease" OR "COPD" OR "COAD" OR "Chronic Obstructive Airway Disease" OR "Chronic Obstructive Lung Disease" OR "Chronic bronchit*" OR "emphysema" OR "interstitial lung disease*" OR "pulmonary fibrosis" OR pneumoconiosis OR asbestosis) AND TITLE-ABS-KEY ("advance care plan*" OR "advance directive*" OR "living will*" OR "power of attorney" OR dni OR dnh OR dni) AND TITLE-ABS-KEY ( dissemin* OR adopt* OR practice* OR diffus* OR implement* OR integrat* OR acceptab* OR appropriat* OR uptake OR embed* OR adher* OR usage OR engagement OR fidelity OR barrier* OR constraint* OR facilitator* OR enabler* OR feasib* OR maintenance) )

CareSearch Systematic review collection on Advance Care Plans:
References
Online supplement 3

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

Evidence summary tables and GRADE evidence profiles
Evidence to decision frameworks
<table>
<thead>
<tr>
<th>Author, year</th>
<th>What</th>
<th>What for</th>
<th>To whom</th>
<th>By which means</th>
<th>By whom</th>
<th>Where</th>
<th>When</th>
<th>Conditional requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Van Mechelen et al 2013 [1]</td>
<td>Complex interventions, holistic and multidisciplinary approach</td>
<td>Pain and symptom control and quality of life</td>
<td>People suffering from an irreversible disease that is reinforcing the normal decline of their health status and will ultimately lead to death.</td>
<td>Holistic and multidisciplinary approach. Symptom relief through the administration of drugs.</td>
<td>Multidisciplinary team</td>
<td>Home, nursing home, hospital, palliative care unit, hospice</td>
<td>No consensus about the attributes of palliative care regarding the illness (progressive, incurable, far-advanced or just advanced, life-threatening and/or active)</td>
<td>Holistic and multidisciplinary approach</td>
</tr>
<tr>
<td>Bausewein 2012 [2]</td>
<td>Multidisciplinary approach</td>
<td>Pain and symptom management, psychosocial and family support, and (advance) care planning</td>
<td>People with advanced disease in clinical trials</td>
<td>Personal encounters; Complex intervention: pain and symptom management; psychosocial and family support; advance care planning; decision making; establishing goals of care; action plan; end-of-life care; referral to other services</td>
<td>Multiprofessional palliative care teams with varying professions (palliative care nurses, social workers, pharmacists, psychologists or physiotherapists, palliative care physician, occupational therapist)</td>
<td>Outpatient clinic, inpatient palliative care unit, ICU, other wards, home – place of patient choice</td>
<td>From newly diagnosed people to failure of specific drug treatments or interventions, which acted as surrogates to identify life-threatening and incurable stage of disease</td>
<td>Evidence-based guidelines Professional qualifications and training</td>
</tr>
<tr>
<td>Hui et al 2013 [3]</td>
<td>Interdisciplinary care</td>
<td>Improving people’ quality of life and</td>
<td>People with life-limiting illness; debate whether people with</td>
<td>Quality of life and symptom control, interdisciplinary care, by addressing physical emotional,</td>
<td>Interdisciplinary team</td>
<td>Home, hospital, daycare centre and</td>
<td>Throughout the disease trajectory</td>
<td>The provision of patient care by a single discipline comprised of a</td>
</tr>
</tbody>
</table>

Evidence summary table for question 1
<table>
<thead>
<tr>
<th>Radbruch et al 2020 [4]</th>
<th>Active holistic care</th>
<th>Improve quality of life of people with illness, their families, and their caregivers; intends neither to hasten nor to postpone death.</th>
<th>Individuals across all ages with serious health-related suffering because of severe illness and especially those near the end of life; their caregiver and bereaved</th>
<th>Prevention, early identification, comprehensive assessment, and management of physical issues, psychological distress, spiritual distress, and social needs.</th>
<th>Professionals with basic palliative care training; specialist palliative care training with a multiprofessional team</th>
<th>Applicable throughout all health care settings and in all levels (primary to tertiary)</th>
<th>Applicable throughout the course of an illness according to the patient needs in conjunction with disease-modifying therapies whenever needed</th>
<th>Delivered recognizing and respecting the cultural values and beliefs of the patient and family; An integral component of education (basic to specialist) and continuing education and research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Xiao et al 2021 [5]</td>
<td>Team approach to address the needs of clients and their families</td>
<td>Improve quality of life throughout the illness trajectory of patient and family;</td>
<td>Clients and their families facing complications associated with life-limiting and serious illness</td>
<td>Prevention and relief of suffering by means of early identification and effective assessment and treatment of pain</td>
<td>Team Specialized palliative care providers</td>
<td>Not reported</td>
<td>From early stages of the illness to end-of-life.</td>
<td>Not reported</td>
</tr>
</tbody>
</table>
reinforce the person's autonomy; give clients and families a greater sense of control; and other problems (including those that are physical, psychosocial, and spiritual)

Data were extracted for each study concerning: what (the essence of palliative care, its object or matter); what for (the aims of palliative care, or outcomes); to whom (the person with illness, consumers, beneficiaries, target group, population); by which means (the (set of) interventions or measures used within palliative care); by whom (the people delivering palliative care, especially the different professional groups); where (the location in which palliative care is delivered or should be delivered); when (the period of time in which palliative care is delivered or should be delivered along the continuum of care); and conditional (on specified conditions under which palliative care should be delivered). (adapted from Meyer et al. [6])

References Evidence summary table for question 1
**Evidence to decision framework for question 1**

**How do we define palliative care for people with COPD or ILD?**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Judgement</th>
<th>Research evidence</th>
<th>Additional considerations</th>
</tr>
</thead>
</table>
| Priority         | Is the problem a priority? | ○ No  
○ Probably no  
○ Probably yes  
● Yes  
o Varies  
o Don't know | Palliative care aims to improve quality of life of persons with serious illness. Palliative care is rarely offered or very late to persons with COPD or ILD.  
Reported reasons for this are: the uncertain disease trajectory, lack of a clear transition to 'end-of-life', normalization of living with COPD, lack of professional awareness of the potential role of palliative care, and a focus of persons with cancer. [1-5]  
A definition of palliative care for persons with serious COPD or ILD could increase awareness of the possibility of palliative care for people with serious COPD or ILD. | There is a need to incorporate social inequality in health into the definitions of palliative care.  
Views of representatives of people with COPD or ILD and informal caregivers:  
The definition of palliative care should reflect that it is not just about end-of-life care. The perception of what palliative care is needs to change. All persons with COPD or ILD are different. |
| Certainty of evidence | What is the overall certainty of the evidence for using the suggested definition? | ● Very Low  
o Low  
o Moderate  
o High  
o No included studies | We identified five studies that addressed the definition of palliative care relevant for this guideline. [6-10] | The fact that there are few studies may reflect the need for everyone to follow the same definition.  
The development within the definitions over a period of 30 years raises the need for further work to achieve an internationally broad accepted definition. |
| Current practice | | Current practice is characterized by the fragmentation of efforts so that palliative care is not integrated into standard respiratory medicine. [1] This creates a great risk that palliative care is offered based on coincidences and local initiatives and not based on systematic needs assessment. [11, 12] | The word life-threatening illness may have contributed to the focus in the understanding of initiation of palliative care being based on the prognosis of imminent death and not on needs assessment.  
In the upcoming years, palliative care will be triggered by the word serious illness. This can lead to a shift from prognosis-based understanding to need-based understanding. |
<table>
<thead>
<tr>
<th>Values</th>
<th>Is there important uncertainty about or variability in how much people value the main outcomes?</th>
<th>A recognized definition could lead to a common understanding of what palliative care is and where, what for, and to whom it should be offered. [1, 11-13]</th>
<th>Although there are minor differences between the found definitions, they all share the core concepts (involvement of persons with illness and informal caregivers and overall focus on improving quality of life). View of representatives of persons with COPD or ILD and informal caregivers: Palliative care should also be available at times when you might feel lonely or depressed – not just at the end of life. It is very important to involve informal caregivers from the initiation of palliative care. Healthcare professionals need to explore how people with COPD, ILD, and informal caregivers are really feeling/coping. Palliative care should broadly be the same for both persons with COPD and ILD. To achieve this, integration between routine care and palliative care is needed and should be included in the definition.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefits and harms</td>
<td>How substantial are the benefits of the suggested definition compared to harms?</td>
<td>Currently, people with serious COPD or ILD rarely receive timely palliative care. [1, 11-13] An internationally recognized definition of palliative care for people with COPD or ILD could potentially facilitate implementation of palliative care and thus result in large benefits. [1, 12, 14, 15]</td>
<td>The definition of palliative care is of crucial importance for implementing palliative care in clinical practice, especially in deciding who should be offered palliative care and when. Finding a useful and easy-to-understand definition will benefit healthcare professionals as well as persons with serious illness and their informal caregivers.</td>
</tr>
<tr>
<td>Equity</td>
<td>What would be the impact on health equity?</td>
<td>No available studies</td>
<td>If this guideline’s definition of palliative care is introduced systematically, it will require systematic symptom and needs screening. Furthermore, understanding of symptoms and needs is expanded to include physical,</td>
</tr>
<tr>
<td>Acceptability</td>
<td>Is the intervention acceptable to key stakeholders?</td>
<td>No available studies</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------------------</td>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Increased</td>
<td>psychological, social and existential/spiritual dimensions.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Varies</td>
<td>This systematic approach might ensure greater equality in health care.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>● Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Don't know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

We expect that an international definition of palliative care can be accepted, as was the WHO definition from 2002. Nevertheless, it will be challenging to develop one that will be accepted worldwide and will be clinically applicable in all settings – it is likely that core components will be accepted, but some components might need to be adapted in specific situations. Also, translating the definition into different languages and maintaining the meaning will be challenging.
How do we define palliative care for people with COPD or ILD?

<table>
<thead>
<tr>
<th>TYPE OF RECOMMENDATION</th>
<th>Strong recommendation against the intervention</th>
<th>Conditional recommendation against the intervention</th>
<th>Conditional recommendation for either the intervention or the alternative</th>
<th>Conditional recommendation for the suggested definition</th>
<th>Strong recommendation for the intervention</th>
</tr>
</thead>
</table>
| Recommendation         | We suggest that palliative care for people with serious illness due to COPD or ILD is defined as: A holistic and multidisciplinary, person-centred approach aiming to control symptoms, and improve quality of life of people with serious health-related suffering because of COPD or ILD, and to support their informal caregivers. Palliative care:  
• Is applicable throughout the whole disease trajectory according to need, in conjunction with any disease-modifying therapies.  
• Entails symptom assessment and management, psychosocial support for people with COPD or ILD and informal caregivers, addressing spiritual/existential needs, effective and sensitive communication, and determining current goals of care and advance care planning (ACP).  
• Is delivered while recognizing and respecting the personal and cultural values and beliefs of the person with illness and their informal caregivers.  
• Is offered by healthcare professionals with basic training in palliative care or, if needed, specialists in palliative care at home, in the hospital (in the outpatient clinic, inpatient palliative care unit, ICU, other hospital wards), hospice, long-term care facility or other place of choice of the person with COPD or ILD.  
• Is preferably offered by a multidisciplinary team which might include: nurses, social workers, pharmacists, psychologists, physiotherapists, physicians, occupational therapists, and pastoral care workers. Specialist palliative care is offered by clinicians with advanced knowledge of, and training in, palliative care. |
| Justification          | Although the evidence level is low, a conditional recommendation for the suggested definition was selected based upon the large agreement in the literature on the overall concept of palliative care. |
| Subgroup considerations| In this guideline, we see palliative care as an approach independent of the different disease trajectories that COPD and ILD have. The specific palliative treatment is of course based on the clinical situation of the person with COPD or ILD and may therefore be different between a slowly progressive COPD and a rapidly progressive ILD. |
| Implementation consideration | A worldwide accepted definition of palliative care is crucial for palliative care to be recognized by international organizations, local healthcare organizations, healthcare professionals, persons with serious illness due to COPD or ILD and their informal caregivers. |
| Monitoring and evaluation | The development of palliative care over the years requires monitoring, evaluation and where needed adaptation of the definition of palliative care for persons with serious illness due to COPD or ILD. |
| Research priorities    | Future research could examine what influences health professionals' understanding of what palliative care is, as well as the impact of new definitions into both research and clinical work. An important research question is also persons with COPD or ILD and informal caregivers' understanding of what palliative care is and from where they get their knowledge. Lastly, we call for future research to address palliative care and social inequality. |
References for Evidence to decision framework for question 1

<table>
<thead>
<tr>
<th>Author/year</th>
<th>Study design</th>
<th>Participants</th>
<th>Main findings</th>
</tr>
</thead>
</table>
| Philips et al. 2021 (1) | Systematic review             | 62 articles across COPD (n=52), 4 ILD (n=4) and mixed chronic respiratory disease (n=6) | • 62 articles identified referral criteria to palliative care in advanced non-malignant respiratory disease.  
• Of 18 categories for referral criteria these were broadly grouped according to “needs-based” and “disease-based”  
• The most common criteria were hospital use (69% of papers), indicators of poor respiratory status (47%), physical and emotional symptoms (37%), functional decline (29%), need for advanced respiratory therapies (27%), and disease progression (26%). |
| Zou et al. 2019 (2)  | Observational study           | People with Idiopathic pulmonary fibrosis (n=828)                           | • Of the study population, 178 (22%) took part in at least one support group meeting, focusing on patient and informal caregiver education and support. This group were typically youngers, lived closer to the centre, and had more outpatient appointment visits.  
• Support group participation led to higher frequency of palliative care referral (35% vs 19%) and lower mortality (Hazard Ratio 0.59 95%CI 0.40-0.86). |
| Iyer et al. 2020 (3) | Qualitative interview study   | Clinicians (n=12) providing care for people with COPD, from pulmonary medicine (n=6) and palliative care (n=6) | • Clinicians agreed that early palliative care could add value to disease-focused COPD care, but stressed the need for consensus on referral criteria.  
• Potential referral criteria fitted the framework proposed in the Philips review and most had already been identified.  
• Cachexia and poor nutritional status was highlighted as an additional referral criteria, beyond those covered previously, to start palliative care. |
| Kendall et al. 2018 (4) | Qualitative interview and focus group study | People with severe COPD post exacerbation (n=14), informal caregivers (n=3), health professionals (n=28) | • Only a minority of problems that people with COPD described had been revealed to nurses during an assessment as part of the research context.  
• Needs felt by people were shaped by their perceptions, e.g. of ageing and disease, and knowledge of available support from services. Often these hindered people expressing perceived need to a healthcare professional.  
• Some people with COPD preferred to accept care from family members rather than health professionals and agencies.  
• Professionals were aware of the discrepancy between observed needs and the help could give and the person with COPD was willing to accept. |
| Claessen et al. 2013 (5) | Qualitative interview study   | General Practitioners (n=20) providing care for people with chronic respiratory disease | • General Practitioners reported that a combination of signals, often subtle, from people with chronic respiratory diseases, informal caregivers and clinicians made them identify palliative care needs.  
• In chronic respiratory disease awareness of palliative care need can arise gradually. |
and late in the disease trajectory (relative to other diseases e.g. cancer) when care needs become intensive and contacts more frequent.

<table>
<thead>
<tr>
<th>Study (Reference)</th>
<th>Study Design</th>
<th>Participants</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Tavares et al. 2020 (6) | Qualitative interview study | People with COPD (n=33) | - People preferred to discuss palliative care with clinicians they perceive to have greater levels of competency and authority in care, and with who they have an established relationship.  
- People often deferred discussions about the future, waiting for significant deterioration in their condition, or until clinicians initiate these discussions. |
| Iyer et al. 2018 (7) | Qualitative interview study | People with COPD (n=10) and their informal caregivers (n=10) | - Participants favoured incorporating palliative care in the moderate stage of disease.  
- People with COPD and families reported that starting palliative care in mild COPD may raise undue concerns among about the expected speed of disease progression. |
| Gysels et al. 2008 (8) | Qualitative interview study | People with moderate to severe COPD (n=18) | - People report low or poor access to services for breathlessness. This was due the slow and surreptitious onset of breathlessness, social stigma related to breathlessness, and health care services ‘discrediting’ the experience of the person with COPD.  
- The invisibility metaphor captures the experience of breathlessness. It can be disguised when at rest but manifests at the slightest exertion, people try to keep it hidden from others, and services are often not responsive to it. |
| Fu et al. 2021 (9) | Qualitative interview study | People with COPD (n=20), informal caregivers (n=6), health professionals (n=25) | - Health professionals were unclear as to when to discuss palliative care, leading to hesitation and fragmented care.  
- A standardized screening and needs assessment tool is required to improve timely palliative care in the care of people with COPD. |

References Evidence summary table for question 2


## Evidence to decision framework for question 2

**When should a palliative care approach be started in COPD and ILD?**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Judgement</th>
<th>Research evidence</th>
<th>Additional considerations</th>
</tr>
</thead>
</table>
| Priority             | Is the problem a priority?  
○ No  
○ Probably no  
○ Probably yes  
● Yes  
○ Varies  
○ Don’t know | There is recognition around the lack of standardised criteria for when to start a palliative care approach in COPD and ILD.                                                                                     | As recognized in narrative question 1, it is difficult to know when to introduce palliative care approach, but important to get this right if people with COPD or ILD and informal caregivers are to be able to access palliative care in a timely manner. |
| Certainty of evidence | What is the overall certainty of the evidence for starting palliative care as suggested?  
○ Very Low  
● Low  
○ Moderate  
○ High  
○ No included studies | Results included one systematic review [1] one observational study [2] and six qualitative studies [3-8]. The systematic review [1] on referral criteria for palliative care in advanced COPD and ILD identified 62 articles (52 COPD, 4 ILD, 6 mixed). Although there is wide variation in the specific criteria, most are based on needs of people with COPD or ILD or on markers of disease severity and/or health service utilization that are seen to indicate a likelihood of need. Studies since the systematic review identified some new criteria, e.g. cachexia, but again these could be easily categorized as based on need of people with COPD or ILD [3]. | The research evidence is largely descriptive. Without data linking the criteria for when to start palliative care to outcomes, there is low certainty on which criteria are effective in reducing burden of disease. |
| Current practice     | Multiple factors currently contribute to late palliative care referral. These include the unpredictable course of chronic respiratory disease, views of palliative care of professionals and people with COPD or ILD, and under-recognition of symptoms and concerns [1]. Clinicians use signals from people with COPD or ILD, informal caregivers and health records to identify when to start a palliative care approach. However, without formal screening, recognition of need can occur gradually and late in the disease trajectory [4, 7]. | There is wide variation in practice, internationally, nationally and regionally. |
Encouraging use of people with illness and informal caregiver support groups can also help increase readiness for specialist palliative care referral [2].

<table>
<thead>
<tr>
<th>Values</th>
<th>Is there important uncertainty about or variability in how much people value the main outcomes?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Important uncertainty or variability</td>
</tr>
<tr>
<td></td>
<td>Possibly important uncertainty or variability</td>
</tr>
<tr>
<td></td>
<td>Probably no important uncertainty or variability</td>
</tr>
<tr>
<td></td>
<td><strong>Not important uncertainty or variability</strong></td>
</tr>
<tr>
<td></td>
<td>No known undesirable outcomes</td>
</tr>
</tbody>
</table>

There is recognition that more standardised criteria for when to start a palliative care approach in COPD and ILD would enhance decision making and practice [1, 6, 9]. Views of representatives of people with COPD or ILD and informal caregivers: When to start palliative care is very individual to each person with COPD or ILD and informal caregiver, and links to their understanding of it. It can be important to ‘plant the seed’ early on, but not right at the point of diagnosis.

<table>
<thead>
<tr>
<th>Benefits and harms</th>
<th>How substantial are the benefits of starting palliative care as suggested compared to harms?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Trivial</td>
</tr>
<tr>
<td></td>
<td>Small</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td>Large</td>
</tr>
<tr>
<td></td>
<td>Varies</td>
</tr>
<tr>
<td></td>
<td><strong>Don’t know</strong></td>
</tr>
</tbody>
</table>

There is an absence of data linking criteria for when to start palliative care to health care outcomes. Although, from randomized controlled trial data from people with other advanced illnesses (e.g., cancer, heart failure) and observational data in people with COPD and ILD indicate a clear net benefit from starting palliative care interventions, we have no robust data yet in people with COPD and ILD.

<table>
<thead>
<tr>
<th>Equity</th>
<th>What would be the impact on health equity?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Reduced</td>
</tr>
<tr>
<td></td>
<td><strong>Probably reduced</strong></td>
</tr>
<tr>
<td></td>
<td>Probably no impact</td>
</tr>
<tr>
<td></td>
<td>Probably increased</td>
</tr>
<tr>
<td></td>
<td>Increased</td>
</tr>
<tr>
<td></td>
<td>Varies</td>
</tr>
</tbody>
</table>

No available studies Widespread recognition that more standardised criteria for when to start a palliative care approach would reduce inequities in current practice.
### Acceptability

<table>
<thead>
<tr>
<th>Option</th>
<th>Acceptability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td></td>
</tr>
<tr>
<td>Is the intervention acceptable to key stakeholders?</td>
<td></td>
</tr>
<tr>
<td>○ No</td>
<td></td>
</tr>
<tr>
<td>○ Probably no</td>
<td></td>
</tr>
<tr>
<td>● Probably yes</td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
</tr>
<tr>
<td>○ Don't know</td>
<td></td>
</tr>
</tbody>
</table>

Most of the suggested criteria were acceptable to key stakeholder across the studies. People with COPD or ILD and informal caregivers are generally more willing to talk about current needs than future ones [8]. Regarding starting palliative care at diagnosis, a new diagnosis of Interstitial Pulmonary Fibrosis has been suggested as an appropriate time to start palliative care [1], yet starting palliative care following a diagnosis of mild COPD may raise undue concern among people with COPD and families about expected speed of progression [5].

### Views of representatives of people with COPD or ILD and informal caregivers:
Health professionals should always be sensitive to the feelings each person has, and give regular opportunities to discuss palliative care options.

### When should a palliative care approach be started in COPD and ILD?

<table>
<thead>
<tr>
<th>TYPE OF RECOMMENDATION</th>
<th>Strong recommendation against the intervention</th>
<th>Conditional recommendation against the intervention</th>
<th>Conditional recommendation for either the intervention or the alternative</th>
<th>Conditional recommendation for the suggested intervention</th>
<th>Strong recommendation for the intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendation</td>
<td>A palliative care approach should be considered when people with COPD or ILD and their informal caregivers have physical, psychological, social, or spiritual/existential needs. Needs should be assessed using person with COPD or ILD or informal caregiver report but markers of disease severity and/or health service utilisation may help identify those likely to have unmet needs. (conditional recommendation, low quality of evidence)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Justification</td>
<td>Although the evidence level is low, a conditional recommendation was selected based upon the general agreement in the literature that palliative care should start when need is identified.</td>
<td></td>
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<tr>
<td>Subgroup considerations</td>
<td>Consistent with this guideline, we generally see palliative care as an approach independent of the different disease trajectories that COPD and ILD. Criteria based on the point of initial diagnosis may differ based on the type and typical trajectory of disease.</td>
<td></td>
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<tr>
<td>Implementation consideration</td>
<td>The routine use of needs-based criteria for when to start palliative care will require clinicians to identify, assess and then respond to unmet needs and this does not always occur in practice. Tools to help embed screening into respiratory services are available. Disease-based, e.g. lung function parameters, and health service utilisation criteria, e.g. hospital admissions, are more often measured in health systems.</td>
<td></td>
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<tr>
<td>Monitoring and evaluation</td>
<td>As health systems and services evolve, and as palliative care becomes more integrated with respiratory care services, the criteria for when to start (specialist) palliative care may change subtly. This may be especially true for the health service utilization markers and how they serve as indicators of palliative care need.</td>
<td></td>
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<tr>
<td>Research priorities</td>
<td>The wide range of criteria demonstrates that consensus for when to start a palliative care approach is not yet in place.</td>
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</tr>
</tbody>
</table>
As a priority therefore, research studies should identify which markers of disease severity and health service utilisation most closely relate to palliative care need, then elicit the optimal ways for services to identify and respond to needs, including implementing and embedding assessment tools into clinical practice. Closely related to this, research studies should examine the impact of different models of responding to need using integrated palliative care on person with COPD or ILD and informal caregiver processes and outcomes.

References for Evidence to decision framework for question 2

Evidence summary tables for question 3
Grading of Recommendations, Assessment, Development and Evaluations (GRADE) evaluation of PICO question number 3 – “In people with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used?” (n=9).

<table>
<thead>
<tr>
<th>Certainty assessment</th>
<th>Results</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study design</td>
<td>No of studies</td>
<td>No of participants</td>
<td>Summary</td>
</tr>
<tr>
<td>Anxiety informal caregivers</td>
<td>RCT</td>
<td>1</td>
<td>Very serious¹</td>
</tr>
<tr>
<td>Anxiety people with COPD</td>
<td>RCT</td>
<td>5</td>
<td>Very serious¹</td>
</tr>
<tr>
<td>Depression people with COPD</td>
<td>RCT</td>
<td>5</td>
<td>Very serious¹</td>
</tr>
<tr>
<td>QoL/wellbeing people with COPD</td>
<td></td>
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</tr>
<tr>
<td>6</td>
<td>RCT</td>
<td>Very serious¹</td>
<td>Serious⁶</td>
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<tr>
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<td></td>
<td>Results were not significant (intervention vs control), with the exception of:</td>
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<tr>
<td></td>
<td></td>
<td>• A better performance on the Physical Functioning, General Health and Vitality domains of the SF-36 after 9 months of follow-up in one study for intervention participants [8]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• An improvement on the Mastery subscale of the CRDQ in two studies in the intervention participants [1, 9]</td>
<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>2</td>
<td>RCT</td>
<td>Very serious¹</td>
<td>Not Serious⁷</td>
</tr>
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<tr>
<td></td>
<td></td>
<td>Both studies did not report significant results, although breathlessness did decrease slightly in both intervention and control groups [1, 9]</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>No studies report on outcomes:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Communication with family and/or healthcare professional</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Burden/stress informal caregiver</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>QoL/wellbeing informal caregiver</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Grief/bereavement informal caregiver</td>
<td></td>
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</tr>
</tbody>
</table>

Abbreviations: NA = not applicable
1 – At least one domain in Cochrance RoB tool judged at high risk of bias for all studies
2 - Sample not exclusively of people with COPD
3 – Trial inadequately powered and small sample size
4 – Sample not exclusively of people with COPD and interventions not homogeneous
5 – Likely underpowered trials (small sample sizes) and large uncertainty around point estimates
6 – Serious because of disagreement between absence of effect and significant effects
7 – The two studies did not measure exactly the same outcomes within “breathlessness”
References for Evidence summary table for question 3


**Evidence to decision framework for question 3**

**Should (intervention) vs. (control) be used for?**

*In people with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used?*

<table>
<thead>
<tr>
<th><strong>POPULATION:</strong></th>
<th>People with COPD and their informal caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INTERVENTION:</strong></td>
<td>Palliative care involving informal caregivers</td>
</tr>
<tr>
<td><strong>COMPARISON:</strong></td>
<td>Palliative care not involving informal caregivers or no palliative care intervention</td>
</tr>
</tbody>
</table>
| **MAIN OUTCOMES:** | 1. Communication within the family and/or with healthcare professionals  
2. Anxiety of informal caregivers  
3. Anxiety of people with COPD  
4. Burden / stress for informal caregivers  
5. Depression of the informal caregiver  
6. Depression of people with COPD  
7. Quality of life / well-being of informal caregivers  
8. Quality of life / well-being of people with COPD  
9. Grief/ bereavement/Loss experienced by informal caregivers  
10. Breathlessness of people with COPD |
| **SETTING:** | No restriction |
| **PERSPECTIVE:** | Population |
| **BACKGROUND:** | Chronic obstructive pulmonary disease (COPD) imposes tremendous daily challenges not just to people with COPD but also to informal caregivers [1]. The trajectory of the disease involves recurrent acute exacerbations, often requiring hospital admissions [2]; uncertainty about the prognosis [3]; multiple highly distressing symptoms (such as breathlessness, fatigue, and pain), which are frequently undertreated [4, 5]; and multimorbidity, with substantial illness burden for people with COPD and families [6]. A large number of people with COPD need informal care [7] and as the disease progresses care dependency tends to increase [7-9]. Informal caregivers are the main, although often «hidden», workforce responsible for providing most of daily care, from practical (medication or symptom management) to more complex support (e.g. educational, emotional) [10]. Palliative care could have a key role to improve the quality of life of those with COPD and support their informal caregivers however, this dyad, i.e., person with COPD-informal caregiver, is not often seen as a target group for palliative care, [11] despite the extension of care to the informal caregivers being embedded in definitions of palliative care [12]. |

| **CONFLICT OF INTERESTS:** | All panelists declared no conflicts of interest. |

**ASSESSMENT**

**Problem**

Is the problem a priority?

<table>
<thead>
<tr>
<th><strong>JUDGEMENT</strong></th>
<th><strong>RESEARCH EVIDENCE</strong></th>
<th><strong>ADDITIONAL CONSIDERATIONS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>○ No</td>
<td>Palliative care demand for people with non-malignant lung disease is high [13]. Nevertheless, people with COPD receive less palliative care at the end of life, than those with lung cancer, despite a relatively similar</td>
<td></td>
</tr>
</tbody>
</table>
Informal caregivers provide most of the daily care to people with COPD. At advanced stages, the average number of caregiving hours per day, has been found to be 12.7h \[7\]. Their multiplicity of roles, together with changes in family dynamics and financial responsibilities, indicate a need for informal caregivers to also be included in palliative care interventions to acquire specific knowledge and develop a wide range of skills to support themselves and their loved ones with COPD \[9, 11\]. Palliative care interventions therefore aim to improve the quality of life of people with COPD and to support their informal caregivers.

### Desirable Effects

**How substantial are the desirable anticipated effects?**

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trivial</td>
<td>- Anxiety of informal caregivers: Greater reduction of anxiety in the intervention group compared to the control group (not statistically significant) [14].</td>
<td>Further attention is needed to understand how palliative care interventions involving informal caregivers contribute to change, which will require not just an efficacy or effectiveness perspective, assessed with randomized controlled trials, but also other study designs to generate new knowledge and reduce decision makers uncertainty [20].</td>
</tr>
<tr>
<td>Small</td>
<td>- Anxiety of people with COPD: No significant difference in the evolution of the anxiety experienced by people with COPD between intervention and control groups [14-18]. Anxiety levels in general remained largely stable over the course of the studies in both groups.</td>
<td>The following evidence was found in non-RCT and qualitative studies exploring the effects of palliative care interventions involving informal caregivers:</td>
</tr>
<tr>
<td>Moderate</td>
<td>- Depression of people with COPD: No significant difference in the evolution of depression between the intervention and control groups, neither within each group over the duration of the follow-up periods [14-18].</td>
<td>High quality communication was found to be greatly valued by people with COPD and informal caregivers [21], was inversely related to informal caregivers burden, and their proactive involvement in palliative care has been advocated [22].</td>
</tr>
<tr>
<td>Large</td>
<td>- Quality of life / well-being of people with COPD: Significant improvements in favour of the intervention group in at least one domain [14, 15, 19]. Significant improvements in at least one domain in both groups [14, 18] and no differences between groups [15, 18].</td>
<td>People with COPD have reported high levels of satisfaction with care [23-29], and these levels were higher when compared with usual care [23, 25], but also with their informal caregivers and healthcare professionals [26, 27, 29]. Informal caregivers also reported high levels of satisfaction with care [26, 27, 29]; and both, people with COPD and informal caregivers, have expressed the wish to have access to the intervention earlier [26-29].</td>
</tr>
<tr>
<td>Varies</td>
<td>- Breathlessness of people with COPD: No significant differences between groups [14, 16].</td>
<td>Significantly fewer symptoms of dyspnoea [30, 31], anxiety, and better sleep quality have</td>
</tr>
<tr>
<td>Don’t know</td>
<td>No data was found on the following outcomes: Communication within the family and/or with healthcare professionals; Burden / stress for informal caregivers; Depression of the informal caregiver; Quality of life / well-</td>
<td></td>
</tr>
</tbody>
</table>
being of the informal caregiver; Grief/bereavement/Loss experienced by the informal caregiver.

been reported in the intervention group than in control groups after palliative care involving caregivers [31].

People with COPD and informal caregivers also value strategies to deal with breathlessness and education focusing on their needs [32].

No significant differences between groups have been found for symptoms of depression, pain or quality of life after palliative care involving informal caregivers [31].

Undesirable Effects
How substantial are the undesirable anticipated effects?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Large</td>
<td>No harmful or adverse events were reported for any intervention.</td>
<td>Adding other team members, assessments and monitoring to an already complex, often fragmented system might be ineffective if not planned carefully to be introduced according to the different settings and needs.</td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
<td>In practice, implementation of palliative care interventions involving informal caregivers need conversations which are often time-consuming. It may be difficult for people with COPD and informal caregivers to synthesize diverse information during a single visit. Hence, the number of visits might need to increase slightly, which might pose a burden for people with COPD and informal caregivers.</td>
</tr>
<tr>
<td>○ Small</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Trivial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Certainty of evidence
What is the overall certainty of the evidence of effects?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Very low</td>
<td>Based on GRADE assessment.</td>
<td>Nine RCTs were found applying multiple, multifaceted and interdisciplinary interventions. Hence, pooling of results was not appropriate. None of the interventions explicitly stated that it aimed to involve informal caregivers, instead included them as they were available. Often studies included samples that were not exclusively composed of people with COPD and their informal caregivers [19, 23, 25, 33].</td>
</tr>
<tr>
<td>○ Low</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ High</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ No included studies</td>
<td></td>
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</tr>
</tbody>
</table>
### JUDGEMENT | RESEARCH EVIDENCE | ADDITIONAL CONSIDERATIONS
---|---|---
○ Important uncertainty or variability  
○ Possibly important uncertainty or variability  
○ Probably no important uncertainty or variability  
○ No important uncertainty or variability | No evidence was found. | Evidence from non-RCT and qualitative studies shows that palliative care is a holistic and multidisciplinary person-centered approach highly valued by people with COPD and by their informal caregivers for the optimal management of the disease (symptoms, psychosocial, communication) [23, 25-29, 32, 34-39].  
Views of representatives of people with COPD or ILD and informal caregivers:  
The integration of informal caregivers is much relevant as they see informal caregivers as the main person communicating with the palliative care team.

### Balance of effects  
Does the balance between desirable and undesirable effects favor the intervention or the comparison?

| JUDGEMENT | RESEARCH EVIDENCE | ADDITIONAL CONSIDERATIONS |
---|---|---|
○ Favors the comparison  
○ Probably favors the comparison  
○ Does not favor either the intervention or the comparison  
○ Probably favors the intervention  
○ Favors the intervention  
○ Varies  
○ Don’t know | Palliative care interventions involving informal caregivers seem to favor the quality of life and well-being and do not change symptoms of anxiety and depression in people with COPD.  
No harmful or adverse events were reported with any of the interventions. | Additional evidence from non-RCT and qualitative studies exploring the effects of palliative care interventions involving informal caregivers have shown:  
Increased satisfaction among people with COPD and informal caregivers by the intervention [23, 25-29, 38];  
Quality communication being highly valued by people with COPD and informal caregivers [21] and inversely related to informal caregivers burden [22];  
Need for proactive care for and involvement of informal caregivers’ [22];  
Fewer symptoms of dyspnoea [30, 31], anxiety levels, and better sleep quality in people with COPD of the intervention group than in control groups [31];  
Increased confidence managing symptoms [28, 40];  
Significant reduction in the mean number of emergency department respiratory presentations [23, 39].

### Resources required
### How large are the resource requirements (costs)?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Large costs</td>
<td>No evidence sought and found.</td>
<td>Additional evidence from RCT and non-RCT shows no difference or lower healthcare costs per person after palliative care interventions for people with COPD [41]. In an economic value analysis of palliative and end-of-life care interventions across various settings, where RCT and non-RCT studies of people with COPD were included, substantial savings to the health system, including a decrease in total healthcare costs, resource use and improvement in outcomes for people with and informal caregivers were suggested [42]. Probably costs will be associated with the local situation, content and design of the palliative care intervention. We have considered costs (e.g., developing support material for informal caregivers) and cost-savings (e.g., visits to the emergency department, hospital admissions, medical appointments).</td>
</tr>
<tr>
<td>○ Moderate costs</td>
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<td></td>
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<tr>
<td>○ Negligible costs and savings</td>
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<tr>
<td>○ Moderate savings</td>
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<td></td>
</tr>
<tr>
<td>○ Large savings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Don’t know</td>
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</table>

### Certainty of evidence of required resources

**What is the certainty of the evidence of resource requirements (costs)?**

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Very low</td>
<td>No evidence sought or found.</td>
<td>No specific search about this topic was conducted.</td>
</tr>
<tr>
<td>○ Low</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Moderate High</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ No included studies</td>
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</tr>
</tbody>
</table>

### Cost effectiveness

**Does the cost-effectiveness of the intervention favor the intervention or the comparison?**

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Favors the comparison</td>
<td>No evidence was sought or found.</td>
<td>A mixed methods RCT found in its quantitative cost-effectiveness analysis no significant differences in the reduction of the primary outcome (‘distress due to breathlessness’) when compared to standard care but high positive impacts were reported in the qualitative analyses [43]. Additional evidence from non-RCT and qualitative studies [38, 41] has shown an increased satisfaction with services at 60 days and significantly fewer emergency department visits, hospital days, skilled nursing facility days, and physician visits in those who received palliative care which integrated informal caregivers with a 45%</td>
</tr>
<tr>
<td>○ Probably favors the comparison</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Does not favor either the intervention or the comparison</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably favors the intervention</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
average decrease in costs compared with the control group [24]. A reduction in 52.4% of healthcare usage at 12 months after palliative care has been reported in a single group cohort study. [39] Increased satisfaction and decreased healthcare utilization have also been reported in semi-structured interviews after a palliative care intervention. [38]

**Equity**

What would be the impact on health equity?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Reduced</td>
<td>No evidence was found.</td>
<td>There is inequity access of people with COPD to palliative care interventions within primary care interventions [44, 45]. Symptom prevalence is similar among people with COPD being cared in nursing homes or in specialist palliative care. Yet, symptom assessment, symptom relief medication, end-of-life discussions, and bereavement support are more likely to occur in specialist palliative care. [46] Additionally, equity access to palliative care might be challenged by differences in socio-economic levels, social, cultural and religious backgrounds. Therefore, these need to be taken into consideration in the future. Indeed, palliative care interventions for people with COPD involving informal caregivers will need to be tailored to different groups, according to their needs, culture, religion among other factors, to optimize outcomes of people with COPD and informal caregivers.</td>
</tr>
<tr>
<td>o Probably reduced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Probably no impact</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Probably increased</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Increased</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Acceptability**

Is the intervention acceptable to key stakeholders?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>o No</td>
<td>No evidence was found.</td>
<td>The recognition of the need to involve informal caregivers in palliative care interventions as well as to provide access to this fundamental treatment to people with COPD has been widely recognised [6, 34, 47]. Moreover, available evidence suggests higher satisfaction with those who received palliative care which integrated informal caregivers compared with the control group [24, 38, 41].</td>
</tr>
<tr>
<td>o Probably no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Views of representatives of people with COPD or ILD and informal caregivers:
For people with COPD and informal caregivers, palliative care continues to be associated with end of life and cancer and sometimes they associate it with assisted dying/euthanasia. Some may need support to reframe their understanding of palliative care and to know when palliative care is suitable.

### Feasibility
Is the intervention feasible to implement?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ No</td>
<td>No evidence was found.</td>
<td>Introduction of palliative care interventions with informal caregivers should be guided by the complexity of symptoms and concerns, rather than prognosis, to improve outcomes of people with COPD and informal caregivers [6]. Nevertheless, fragmented health systems, with lack of time, often focus on the prognosis (difficult to establish given the unpredictable nature of COPD and difficulty in predicting survival), lack of healthcare professionals to perform a comprehensive assessment and time to discuss palliative care, and local regulatory constraints might be barriers to provide access to palliative care interventions of people with COPD and their informal caregivers [6, 48, 49]. Please see question 7 for further details.</td>
</tr>
<tr>
<td>□ Probably no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### SUMMARY OF JUDGEMENTS

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>No</th>
<th>Probably no</th>
<th>Probably yes</th>
<th>Yes</th>
<th>Varies</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>DESIRABLE EFFECTS</td>
<td>Trivial</td>
<td>Small</td>
<td>Moderate</td>
<td>Large</td>
<td>Varies</td>
<td>Don’t know</td>
</tr>
<tr>
<td>UNDESIRABLE EFFECTS</td>
<td>Large</td>
<td>Moderate</td>
<td>Small</td>
<td>Trivial</td>
<td>Varies</td>
<td>Don’t know</td>
</tr>
<tr>
<td>CERTAINTY OF EVIDENCE</td>
<td>Very low</td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
<td>Varies</td>
<td>No included studies</td>
</tr>
<tr>
<td>VALUES</td>
<td>Important uncertainty or variability</td>
<td>Possibly important uncertainty or variability</td>
<td>Probably no important uncertainty or variability</td>
<td>No important uncertainty or variability</td>
<td>Varies</td>
<td>Don’t know</td>
</tr>
<tr>
<td>BALANCE OF EFFECTS</td>
<td>Favors the comparison</td>
<td>Probably favors the comparison</td>
<td>Does not favor either the intervention or the comparison</td>
<td>Probably favors the intervention</td>
<td>Favors the intervention</td>
<td>Varies</td>
</tr>
<tr>
<td>RESOURCES REQUIRED</td>
<td>Large costs</td>
<td>Moderate costs</td>
<td>Negligible costs and savings</td>
<td>Moderate savings</td>
<td>Large savings</td>
<td>Varies</td>
</tr>
<tr>
<td>CERTAINTY OF EVIDENCE OF REQUIRED RESOURCES</td>
<td>Very low</td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
<td>Varies</td>
<td>No included studies</td>
</tr>
<tr>
<td>COST EFFECTIVENESS</td>
<td>Favors the comparison</td>
<td>Probably favors the comparison</td>
<td>Does not favor either the intervention or the comparison</td>
<td>Probably favors the intervention</td>
<td>Favors the intervention</td>
<td>Varies</td>
</tr>
<tr>
<td>EQUITY</td>
<td>Reduced</td>
<td>Probably reduced</td>
<td>Probably no impact</td>
<td>Probably increased</td>
<td>Increased</td>
<td>Varies</td>
</tr>
<tr>
<td>ACCEPTABILITY</td>
<td>No</td>
<td>Probably no</td>
<td>Probably yes</td>
<td>Yes</td>
<td>Varies</td>
<td>Don’t know</td>
</tr>
<tr>
<td>FEASIBILITY</td>
<td>No</td>
<td>Probably no</td>
<td>Probably yes</td>
<td>Yes</td>
<td>Varies</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

### TYPE OF RECOMMENDATION

| Strong recommendation | Conditional recommendation | Conditional recommendation for either the | Conditional recommendation for the intervention | Strong recommendation for the intervention |
CONCLUSIONS

Recommendation

In people with COPD, we suggest palliative care interventions including support for informal caregivers should be offered. (conditional recommendation - very low quality of evidence).

Justification

Palliative care interventions found were very heterogeneous, often applied to a mixture of populations (not exclusively composed of people with COPD) and support to informal caregivers varied. Nevertheless, quality of life of people with COPD improved. Moreover, outcomes of informal caregivers were not assessed, but they reported the need to be involved in palliative care interventions. Additional evidence found from non-randomised controlled trials and qualitative studies, showed probable beneficial effects and no evidence for undesirable effects. Nevertheless, the number of available studies is limited and outcomes of interest were rarely assessed, leading to very low quality evidence regarding the use of palliative care interventions involving informal caregivers for people with COPD.

Subgroup considerations

Not applicable.

Implementation considerations

We suggest to involve informal caregivers as early as possible in palliative care interventions implemented in different settings (community, hospitals, home) according to people with COPD and informal caregivers’ needs and preferences. Strategies such us promoting more involvement of healthcare professionals on identifying eligible candidates for palliative care interventions, awareness sessions, initiatives with patients’ associations, educational programmes, availability of psychometrically-sound assessment tools and additional information via technology and peer support, might be needed to facilitate involvement of informal caregivers’ during the implementation of these interventions to real-world settings, according to the available resources.

Please see questions 7 and 8 for more implementation details.

Monitoring and evaluation

We suggest monitoring the involvement of informal caregivers in the palliative care interventions offered to people with COPD and measure the impact of interventions on outcomes for informal caregivers.

Research priorities

1. Establish the effects (short- and long-term) of palliative care interventions involving informal caregivers on multiple outcomes, namely on those considered “critical” by the panel members:

Communication within the family and/or with healthcare professionals; Anxiety of informal caregivers; Anxiety of people with COPD; Burden / stress for informal caregivers; Depression of informal caregivers;
Depression of people with COPD; Quality of life / well-being of informal caregivers; Quality of life / well-being of people with COPD; Grief/ bereavement/Loss experienced by informal caregivers; Breathlessness of people with COPD.

2. Study effective components of palliative care interventions for people with COPD and their informal caregivers.

3. Establish the feasibility and effectiveness of implementing palliative care interventions involving informal caregivers of people with COPD across different settings (e.g., hospital, long-term-facility, homes).

4. Define strategies to promote equity of access to palliative care interventions involving informal caregivers of people with COPD.

5. Establish the cost-effectiveness of palliative care interventions involving informal caregivers of people with COPD.

References for Evidence to decision framework for question 3

12. WHO. Palliative care. 2020 [cited; Available from:]


Evidence summary table for question 4

Grading of Recommendations, Assessment, Development and Evaluations (GRADE) evaluation of PICO question number 4 – “In people with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used?” (n=3).

<table>
<thead>
<tr>
<th>N° of studies</th>
<th>Study design</th>
<th>RoB</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other</th>
<th>No of participants</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>RCT</td>
<td>Very serious¹</td>
<td>Not serious</td>
<td>Not serious</td>
<td>Serious³</td>
<td>/</td>
<td>66</td>
<td>Bajwah et al and Lindell et al (2010) did not find a significant effect of the intervention on anxiety.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>N° of studies</th>
<th>Study design</th>
<th>RoB</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other</th>
<th>No of participants</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>RCT</td>
<td>Very serious¹</td>
<td>Not serious²</td>
<td>Not serious</td>
<td>Serious³</td>
<td>/</td>
<td>150</td>
<td>Bajwah et al found a decrease in anxiety in the intervention group and a slight increase in the control group. This difference was borderline significant. Lindell et al (2010) and Lindel et al (2021) did not find a significant difference post-intervention.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>N° of studies</th>
<th>Study design</th>
<th>RoB</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other</th>
<th>No of participants</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>RCT</td>
<td>Very serious¹</td>
<td>Not serious²</td>
<td>Not serious</td>
<td>Serious³</td>
<td>/</td>
<td>128</td>
<td>Burden experienced by the caregiver remained stable in the study from Bajwah et al and Lindell et al (2021). Lindell et al (2010) however did find significantly lower burden in the intervention group compared to the control group post-intervention.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>N° of studies</th>
<th>Study design</th>
<th>RoB</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other</th>
<th>No of participants</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>RCT</td>
<td>Very serious¹</td>
<td>Not serious²</td>
<td>Not serious</td>
<td>Serious³</td>
<td>/</td>
<td>66</td>
<td>Bajwah et al found a decrease (improvement) in depression in the intervention group and a slight increase (deterioration) in the control group. This difference was borderline significant. Lindell et (2010) al did not find a significant difference post-intervention.</td>
</tr>
<tr>
<td></td>
<td>Depression people with ILD</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>RCT</td>
<td>Very serious¹</td>
<td>Not serious</td>
<td>Not serious</td>
<td>Serious³</td>
<td>/</td>
<td>150</td>
<td>Bajwah et al found a borderline effect of the intervention on depression, but the other two studies did not found a significant effect</td>
</tr>
</tbody>
</table>

**QoL/wellbeing informal caregivers**

<p>| | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>RCT</td>
</tr>
</tbody>
</table>

**QoL/wellbeing people with ILD**

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</thead>
<tbody>
<tr>
<td>3</td>
<td>RCT</td>
</tr>
</tbody>
</table>

**Breathlessness people with ILD**

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</thead>
<tbody>
<tr>
<td>3</td>
<td>RCT</td>
</tr>
</tbody>
</table>

**No studies report on outcomes:**

- Communication with family and/or healthcare professional
- Grief/bereavement caregiver

---

1 – The three studies are judged at high risk of bias for blinding and attrition
2 – Did not downgrade for inconsistency even if results were different between studies, as outcomes were measured with different instruments
3 – Likely underpowered trials and large uncertainty around point estimates
References for Evidence summary table for question 4


Evidence to decision framework for question 4

**Should (intervention) vs. (control) be used for?**

In people with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used?

<table>
<thead>
<tr>
<th>POPULATION:</th>
<th>People with ILD and their informal caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTERVENTION:</td>
<td>Palliative care involving informal caregivers</td>
</tr>
<tr>
<td>COMPARISON:</td>
<td>Palliative care not involving informal caregivers or no palliative care intervention</td>
</tr>
</tbody>
</table>
| MAIN OUTCOMES: | 1. Communication within the family and/or with healthcare professionals  
2. Anxiety of informal caregivers  
3. Anxiety of people with ILD  
4. Burden / stress for informal caregivers  
5. Depression of the informal caregivers  
6. Depression of people with ILD  
7. Quality of life / well-being of the informal caregivers  
8. Quality of life / well-being of people with ILD  
9. Grief/ bereavement/loss experienced by the informal caregivers  
10. Breathlessness of people with ILD |
| SETTING: | No restriction |
| PERSPECTIVE: | Population |
| BACKGROUND: | Interstitial lung disease (ILD) imposes tremendous daily challenges not just to people with ILD but also to informal caregivers [1, 2]. As the disease advances, the need for support often increases exponentially³. Most of this support is provided by informal caregivers. Palliative care could have a key role to improve the quality of life of those with ILD and support their informal caregivers however, this dyad, i.e., person with ILD-informal caregiver, is not often seen as a target group for palliative care [3, 4]. |
| CONFLICT OF INTERESTS: | All panelists declared no conflicts of interest. |

**ASSESSMENT**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Is the problem a priority?</th>
</tr>
</thead>
<tbody>
<tr>
<td>JUDGEMENT</td>
<td>RESEARCH EVIDENCE</td>
</tr>
<tr>
<td>○ No</td>
<td>○ Probably no</td>
</tr>
</tbody>
</table>
### Desirable Effects

**How substantial are the desirable anticipated effects?**

<table>
<thead>
<tr>
<th><strong>JUDGEMENT</strong></th>
<th><strong>RESEARCH EVIDENCE</strong></th>
<th><strong>ADDITIONAL CONSIDERATIONS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Anxiety of informal caregivers: Marginal reduction of anxiety in the intervention group [5].</td>
<td>Evidence was found also in non-RCT studies, and qualitative studies exploring the effects of palliative care interventions in people with ILD and their informal caregivers.</td>
</tr>
<tr>
<td></td>
<td>Anxiety of people with ILD: A significant improvement of symptoms of anxiety experienced by people with ILD has been found [5]. Nevertheless, no significant differences were observed in other studies [6, 7].</td>
<td>Significant improvements in communication and discussions between people with ILD, informal caregivers and health care professionals have been observed after palliative care interventions in ILD [8-11]. Significant effect on informal caregivers’ knowledge, disease preparedness, and confidence in caring for the person with ILD was observed [7]. Such improvements enabled people with ILD feeling less isolated [6], with better symptom management [8, 12], informal caregivers engagement [8] and death out of the hospital [8, 11].</td>
</tr>
<tr>
<td></td>
<td>Burden / stress for informal caregivers: One study found a significant improvement in the burden experienced by informal caregivers [6], while other not [5].</td>
<td>Conflicting evidence seems to be explained by the variability in disease progression of participants and the rapid progression of the illness [6]. Satisfaction with care was generally high in the narrative synthesis [5, 6] and wishes to have access to the intervention earlier were expressed. Acceptability was also high for people with ILD and informal caregivers [7].</td>
</tr>
<tr>
<td></td>
<td>Depression of informal caregiver: A significant improvement in symptoms of depression experienced by the informal caregiver after the intervention was found in one study [5]. No significant differences were also observed in other study [6].</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Depression of people with ILD: Improvements in depressive symptoms were observed in people with ILD after the intervention [5]. But in two other studies, no significant differences were observed [6, 7].</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quality of life / well-being of informal caregivers: no effect of the intervention was found on measurements of quality of life [5-7].</td>
<td></td>
</tr>
</tbody>
</table>
were found. Nevertheless, no significant differences were also observed [7].

Breathlessness of people with ILD: One study showed better overall symptom control including breathlessness [5], while two other studies did not found significant differences [6, 7].

No data was found on the following outcomes: Communication within the family and/or with healthcare professionals; and Grief/ bereavement/Loss experienced by the informal caregiver.

<table>
<thead>
<tr>
<th>Undesirable Effects</th>
<th>How substantial are the undesirable anticipated effects?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>JUDGEMENT</strong></td>
<td><strong>RESEARCH EVIDENCE</strong></td>
</tr>
<tr>
<td>○ Large</td>
<td>No harmful or adverse events were reported for neither of the interventions.</td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
</tr>
<tr>
<td>○ Small</td>
<td></td>
</tr>
<tr>
<td>○ <strong>Trivial</strong></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
</tr>
<tr>
<td>○ Don't know</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Certainty of evidence</th>
<th>What is the overall certainty of the evidence of effects?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>JUDGEMENT</strong></td>
<td><strong>RESEARCH EVIDENCE</strong></td>
</tr>
<tr>
<td>○ Very low</td>
<td>Based on GRADE assessment.</td>
</tr>
<tr>
<td>○ Low</td>
<td></td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
</tr>
<tr>
<td>○ High</td>
<td></td>
</tr>
<tr>
<td>○ No included studies</td>
<td></td>
</tr>
</tbody>
</table>
Values
Is there important uncertainty about or variability in how much people value the main outcomes?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
</table>
| ● Important uncertainty or variability  
   ● Possibly important uncertainty or variability  
   ● Probably no important uncertainty or variability  
   ● No important uncertainty or variability | No evidence found in the included studies. | Palliative care is a holistic and multidisciplinary person-centered approach highly valued by people with ILD and by their informal caregivers for the optimal management of the disease (symptoms, psychosocial, communication) [4, 7, 10-12]. Views of representatives of people with COPD or ILD and informal caregivers: The integration of informal caregivers is much relevant as they see informal caregivers as the main person communicating with the palliative care team. |

Balance of effects
Does the balance between desirable and undesirable effects favor the intervention or the comparison?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
</table>
| ● Favors the comparison  
   ● Probably favors the comparison  
   ● Does not favor either the intervention or the comparison  
   ● Probably favors the intervention  
   ● Favors the intervention  
   ● Varies  
   ● Don’t know | Palliative care interventions involving informal caregivers seem to favor symptom management (anxiety) and quality of life and well-being of people with ILD and may impact burden/stress and depression of informal caregivers. No harmful or adverse events were reported with any of the interventions. | Additional evidence from non-RCT and qualitative studies exploring the effects of palliative care interventions involving informal caregivers have shown: The intervention seemed to improve identification of needs of people with ILD.[3, 5, 6, 9] Odds of achieving home or hospice deaths (favored by the people with ILD) improved and caregiver involvement increased.[3, 8, 14] Informal caregivers felt better informed, more prepared and better supported.[11, 12] |

Resources required
How large are the resource requirements (costs)?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
</table>
| ● Large costs  
   ● Moderate costs  
   ● Negligible costs and savings  
   ● Moderate | No evidence found in the included studies. | None of the studies explicitly addressed health care costs. Probably costs will be associated with the local situation, content and design of the palliative care intervention. One study showed that people with ILD in the intervention were 24 times less likely to have respiratory-related emergency room visits and 2.3 times less likely to have respiratory-related hospitalization [14]. |
<table>
<thead>
<tr>
<th>Savings</th>
<th>Large savings</th>
<th>Varies</th>
<th>Don’t know</th>
</tr>
</thead>
</table>

Certainty of evidence of required resources
What is the certainty of the evidence of resource requirements (costs)?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Very low</td>
<td>No evidence was sought or found.</td>
<td></td>
</tr>
<tr>
<td>• Low</td>
<td>Modest</td>
<td></td>
</tr>
<tr>
<td>• Moderate</td>
<td>High</td>
<td></td>
</tr>
<tr>
<td>• No included studies</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost effectiveness
Does the cost-effectiveness of the intervention favor the intervention or the comparison?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Favors the comparison</td>
<td>No evidence was sought or found.</td>
<td>Results were few and ambiguous. Nevertheless, in a non-RCT study, the use of palliative care interventions involving informal caregivers was associated with a 24% reduced health care usage in the last year of life [14].</td>
</tr>
<tr>
<td>• Probably favors the comparison</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Does not favor either the intervention or the comparison</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Probably favors the intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Favors the intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• No included studies</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Equity
What would be the impact on health equity?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Reduced</td>
<td>No evidence found in the included studies.</td>
<td>There is inequity access of people with ILD to palliative care interventions [1, 5, 6, 9, 15, 16].</td>
</tr>
<tr>
<td>• Probably reduced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Probably no impact</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acceptability</td>
<td>Is the intervention acceptable to key stakeholders?</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>---------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>JUDGEMENT</td>
<td>RESEARCH EVIDENCE</td>
<td>ADDITIONAL CONSIDERATIONS</td>
</tr>
<tr>
<td>○ No</td>
<td>No evidence found in the included studies.</td>
<td>The recognition of the need to involve informal caregivers in palliative care interventions as well as provide access to this fundamental treatment to people with ILD has been widely recognized [4, 8, 9, 11, 12, 14]. Views of representatives of people with COPD or ILD and informal caregivers: For people with ILD and informal caregivers, palliative care continues to be associated with end of life and cancer and sometimes they associate it with assisted dying/euthanasia. Some may need support to reframe their understanding of palliative care and to know when palliative care is suitable.</td>
</tr>
<tr>
<td>○ Probably no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feasibility</th>
<th>Is the intervention feasible to implement?</th>
</tr>
</thead>
<tbody>
<tr>
<td>JUDGEMENT</td>
<td>RESEARCH EVIDENCE</td>
</tr>
<tr>
<td>○ No</td>
<td>No evidence found in the included studies.</td>
</tr>
<tr>
<td>○ Probably no</td>
<td></td>
</tr>
<tr>
<td>○ Probably yes</td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
</tr>
<tr>
<td>○ Don’t know</td>
<td></td>
</tr>
</tbody>
</table>
palliative care interventions of people with ILD and their informal caregivers [6].

Please see question 7 for further details.
### SUMMARY OF JUDGEMENTS

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>PROBLEM</th>
<th>DESIRABLE EFFECTS</th>
<th>UNDESIRABLE EFFECTS</th>
<th>CERTAINTY OF EVIDENCE</th>
<th>VALUES</th>
<th>BALANCE OF EFFECTS</th>
<th>RESOURCES REQUIRED</th>
<th>CERTAINTY OF EVIDENCE OF REQUIRED RESOURCES</th>
<th>COST EFFECTIVENESS</th>
<th>EQUITY</th>
<th>ACCEPTABILITY</th>
<th>FEASIBILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Probably no</td>
<td>Probably yes</td>
<td>Yes</td>
<td>Varies</td>
<td>Don’t know</td>
<td></td>
<td>Varies</td>
<td>No included studies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DESIRABLE EFFECTS</td>
<td>Trivial</td>
<td>Small</td>
<td>Moderate</td>
<td>Large</td>
<td>Varies</td>
<td>Don’t know</td>
<td></td>
<td>Varies</td>
<td>No included studies</td>
<td></td>
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<tr>
<td>UNDESIRABLE EFFECTS</td>
<td>Large</td>
<td>Moderate</td>
<td>Small</td>
<td>Trivial</td>
<td>Varies</td>
<td>Don’t know</td>
<td></td>
<td>Varies</td>
<td>No included studies</td>
<td></td>
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</tr>
<tr>
<td>CERTAINTY OF EVIDENCE</td>
<td>Very low</td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
<td></td>
<td></td>
<td></td>
<td>Varies</td>
<td>No included studies</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>VALUES</td>
<td>Important uncertainty or variability</td>
<td>Possibly important uncertainty or variability</td>
<td>Probably no important uncertainty or variability</td>
<td>No important uncertainty or variability</td>
<td></td>
<td></td>
<td></td>
<td>Varies</td>
<td>No included studies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BALANCE OF EFFECTS</td>
<td>Favors the comparison</td>
<td>Probably favors the comparison</td>
<td>Does not favor either the intervention or the comparison</td>
<td>Probably favors the intervention</td>
<td>Favors the intervention</td>
<td>Varies</td>
<td>Don’t know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RESOURCES REQUIRED</td>
<td>Large costs</td>
<td>Moderate costs</td>
<td>Negligible costs and savings</td>
<td>Moderate savings</td>
<td>Large savings</td>
<td>Varies</td>
<td>Don’t know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CERTAINTY OF EVIDENCE OF REQUIRED RESOURCES</td>
<td>Very low</td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
<td></td>
<td></td>
<td></td>
<td>Varies</td>
<td>No included studies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>COST EFFECTIVENESS</td>
<td>Favors the comparison</td>
<td>Probably favors the comparison</td>
<td>Does not favor either the intervention or the comparison</td>
<td>Probably favors the intervention</td>
<td>Favors the intervention</td>
<td>Varies</td>
<td>No included studies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EQUITY</td>
<td>Reduced</td>
<td>Probably reduced</td>
<td>Probably no impact</td>
<td>Probably increased</td>
<td>Increased</td>
<td>Varies</td>
<td>Don’t know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACCEPTABILITY</td>
<td>No</td>
<td>Probably no</td>
<td>Probably yes</td>
<td>Yes</td>
<td>Varies</td>
<td>Don’t know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FEASIBILITY</td>
<td>No</td>
<td>Probably no</td>
<td>Probably yes</td>
<td>Yes</td>
<td>Varies</td>
<td>Don’t know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### TYPE OF RECOMMENDATION

<table>
<thead>
<tr>
<th>Strong recommendation</th>
<th>Conditional recommendation</th>
<th>Conditional recommendation for either the</th>
<th>Conditional recommendation for the intervention</th>
<th>Strong recommendation for the intervention</th>
</tr>
</thead>
</table>
CONCLUSIONS

Recommendation

In people with ILD, we suggest palliative care interventions including support for informal caregivers should be offered. (conditional recommendation - very low quality of evidence).

Justification

Palliative care interventions found were few and very heterogeneous, often applied to a mixture of populations (not exclusively composed of people with ILD) and support to informal caregivers varied. Nevertheless, anxiety and quality of life of people with ILD and stress and depression of informal caregivers was shown to improve after a palliative care intervention, but not in all studies. Moreover, outcomes of informal caregivers were often not assessed but they reported the need to be involved in palliative care interventions. Nevertheless, number of available studies is very low, some outcomes of interest were never reported and different instruments have been used to assess the outcomes of interests, leading to very low evidence of the literature regarding the use of palliative care interventions involving informal caregivers among people with ILD. Hence, our recommendation is conditional.

Subgroup considerations

Not applicable.

Implementation considerations

We suggest to involve informal caregivers as early as possible in palliative care interventions implemented in different settings (community, hospitals, home) according to people with ILD and informal caregivers’ needs and preferences. Strategies such as promoting more involvement of healthcare professionals on identifying eligible candidates for palliative care interventions, availability of assessment tools, awareness sessions, initiatives with patients’ associations, educational programs, and additional information via technology and peer support, might be needed to facilitate the involvement of informal caregivers during the implementation of these interventions in real-world settings, according to the available resources.

Please see questions 7 and 8 for more implementation details.

Monitoring and evaluation

We suggest monitoring the involvement of informal caregivers in the palliative care interventions offered to people with ILD and measure the impact of interventions on outcomes for informal caregivers.

Research priorities

1. Establish the effects (short- and long-term) of palliative care interventions involving informal caregivers on multiple outcomes, namely on those considered “critical” by the panel members:

Communication within the family and/or with healthcare professionals; Anxiety of informal caregivers; Anxiety of people with ILD; Burden / stress for informal caregivers; Depression of informal caregivers; Depression of people with ILD; Quality of life / well-being of informal caregiver; Quality of life / well-being of
people with ILD; Grief/ bereavement/Loss experienced by informal caregivers; Breathlessness of people with ILD.

2. Study effective components of palliative care interventions for people with ILD and their informal caregivers.

3. Establish the feasibility and effectiveness of implementing palliative care interventions involving informal caregivers of people with ILD across different settings (e.g., hospital, long-term-facility, homes).

4. Define strategies to promote equity of access to palliative care interventions involving informal caregivers of people with ILD.

5. Establish the cost-effectiveness of palliative care interventions involving informal caregivers of people with ILD.

References for Evidence to decision framework for question 4

Evidence summary table for question 5

Question: 5. Advance Care Planning (ACP) interventions compared to no or unstructured forms of advance care planning for people with COPD

Setting: Specialist care


<table>
<thead>
<tr>
<th>Certainty assessment</th>
<th>Ne of people</th>
<th>Effect</th>
<th>Certainty</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ne of studies</td>
<td>Study design</td>
<td>Risk of bias</td>
<td>Inconsistency</td>
<td>Indirectness</td>
</tr>
<tr>
<td>1 randomised trials</td>
<td>not serious</td>
<td>not serious</td>
<td>very serious²</td>
<td>none</td>
</tr>
</tbody>
</table>

Quality of communication between people with COPD and healthcare professionals (follow-up: range 6 months to 24 months; assessed with: QOC end-of-life care communication score; Scale from: 0 to 10)

Prevalence of ACP discussions with physician after 6 months (follow-up: range 6 months to 24 months; assessed with: Proportion)
<table>
<thead>
<tr>
<th>№ of studies</th>
<th>Study design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Advance Care Planning (ACP) interventions</th>
<th>Relative (95% CI)</th>
<th>Absolute (95% CI)</th>
<th>Certainty</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>not serious</td>
<td>not serious</td>
<td>not serious</td>
<td>very serious &lt;sup&gt;b&lt;/sup&gt;</td>
<td>none</td>
<td>52.1% of intervention group had a subsequent ACP discussion with a physician versus 29.7% of controls, p=0.003</td>
<td>☮️◯◯◯ Low</td>
<td>Critical</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Experience of end-of-life care (follow-up: range 6 months to 24 months; assessed with: Quality of Death and Dying questionnaire; Scale from 0 to 100)**

<table>
<thead>
<tr>
<th>№ of studies</th>
<th>Study design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Advance Care Planning (ACP) interventions</th>
<th>Relative (95% CI)</th>
<th>Absolute (95% CI)</th>
<th>Certainty</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>not serious</td>
<td>not serious</td>
<td>not serious</td>
<td>Very serious &lt;sup&gt;b&lt;/sup&gt;</td>
<td>none</td>
<td>“The mean QODD-score in the intervention group was 80.01 (SD 8.57) and ranged from 61.25 to 91.11. In the control group, the mean QODD-score was 74.71 (SD 11.51) with a range from 41.76 to 91.33. Independent-samples t-test revealed no significant difference between both groups (p=0.17).”</td>
<td>☮️◯◯◯ Low</td>
<td>Critical</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CI: confidence interval; MD: mean difference

**Explanations**

a. Single study, confidence interval encompasses both marginal benefit and large effect

b. Downgraded due to the absence of confidence intervals and relatively small sample size.
### Evidence to decision framework for question 5

<table>
<thead>
<tr>
<th>Should (intervention) vs. (control) be used for?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>POPULATION:</strong> People with COPD</td>
</tr>
<tr>
<td><strong>INTERVENTION:</strong> Advance care planning (ACP)</td>
</tr>
<tr>
<td><strong>COMPARISON:</strong> No or unstructured forms of ACP</td>
</tr>
<tr>
<td><strong>MAIN OUTCOMES:</strong></td>
</tr>
<tr>
<td>1. Quality of communication between people with COPD and healthcare professionals</td>
</tr>
<tr>
<td>2. Concordance between the wishes of the person with COPD and received care at the end of life</td>
</tr>
<tr>
<td>3. Documented discussions between informal caregivers and health professional about goals of care / advance care planning</td>
</tr>
<tr>
<td>4. Symptom control at the end of life</td>
</tr>
<tr>
<td>5. Experience of end of life care</td>
</tr>
<tr>
<td>6. Avoidable hospital visits near end of life, measured by emergency department attendance without admission</td>
</tr>
<tr>
<td>7. Informal caregivers’ satisfaction with end of life care</td>
</tr>
<tr>
<td><strong>SETTING:</strong> No restriction</td>
</tr>
<tr>
<td><strong>PERSPECTIVE:</strong> Population</td>
</tr>
<tr>
<td><strong>BACKGROUND:</strong> COPD is one of the leading causes of morbidity and mortality worldwide. The disease has a variable and often unpredictable course, marked by periods (short or prolonged) of stability as well as exacerbations, deterioration, respiratory failure and premature death. The disease is associated with high health care utilization, but people with COPD, as compared with people with lung cancer, are less likely to be referred to specialised palliative care and are more likely to die in hospital, suggesting a potential role for ACP in the management of people with COPD.</td>
</tr>
<tr>
<td><strong>CONFLICT OF INTERESTS:</strong> No conflicts of interest.</td>
</tr>
</tbody>
</table>

### ASSESSMENT

#### Problem
Is the problem a priority?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ No</td>
<td>COPD is the third leading cause of death worldwide according to WHO 2019 data. People with COPD often experience an unpredictable clinical trajectory with increasing burden of debilitating symptoms (breathlessness, anxiety, etc.) as well as acute exacerbations, hospitalization and uncertain prognosis. The unpredictable clinical course may increase the risk of people with COPD receiving suboptimal care at the end of life, in relation to their wishes and values. This also underlines the need for timely ACP and raises the importance of early patient-health care</td>
<td>The evidence from studies of people with cancer and non-cancer chronic serious illnesses indicated that ACP may improve several outcomes, including satisfaction of people with COPD, advance directive documentation, competence of people with COPD to undertake end-of-life discussions, autonomous motivation of people with COPD, and shared decision making in a trustful relationship.</td>
</tr>
<tr>
<td>○ Probably no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
professional communication regarding prognosis, treatments and end-of-life care preferences.\(^1\)

<table>
<thead>
<tr>
<th>Desirable Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How substantial are the desirable anticipated effects?</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>○ Trivial</td>
</tr>
<tr>
<td></td>
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<td></td>
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<tr>
<td></td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Undesirable Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How substantial are the undesirable anticipated effects?</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>○ Large</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
Caveats on evidence: There is increasing recognition that ACP is essential to ensure that the care received is consistent with preferences and values of people with COPD, at a time when they may be unable to communicate their wishes. However, there is limited evidence about how and when it should be implemented.

<table>
<thead>
<tr>
<th>Certainty of evidence</th>
<th>What is the overall certainty of the evidence of effects?</th>
</tr>
</thead>
<tbody>
<tr>
<td>JUDGEMENT</td>
<td>RESEARCH EVIDENCE</td>
</tr>
<tr>
<td>○ Very low</td>
<td>Based on GRADE assessment</td>
</tr>
<tr>
<td>○ Low</td>
<td></td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
</tr>
<tr>
<td>○ High</td>
<td></td>
</tr>
<tr>
<td>○ No included studies</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Values</th>
<th>Is there important uncertainty about or variability in how much people value the main outcomes?</th>
</tr>
</thead>
<tbody>
<tr>
<td>JUDGEMENT</td>
<td>RESEARCH EVIDENCE</td>
</tr>
<tr>
<td>○ Important uncertainty or variability</td>
<td>No information.</td>
</tr>
<tr>
<td>○ Possibly important uncertainty or variability</td>
<td></td>
</tr>
<tr>
<td>○ Probably no important uncertainty or variability</td>
<td></td>
</tr>
<tr>
<td>○ No important uncertainty or variability</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Balance of effects</th>
<th>Does the balance between desirable and undesirable effects favor the intervention or the comparison?</th>
</tr>
</thead>
<tbody>
<tr>
<td>JUDGEMENT</td>
<td>RESEARCH EVIDENCE</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ACP provided low evidence for desirable effects; no undesirable effects were reported.

There is also evidence that people change their minds or wish to revise their opinions. Therefore, if ACP discussions are not a recurrent event it is uncertain whether ACP reflects the current wishes and beliefs. ACP should be discussed and revised as needed as part of routine care.

Resources required
How large are the resource requirements (costs)?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
</table>
| ○ Large costs  
○ Moderate costs  
Negligible costs and savings  
○ Moderate savings  
○ Large savings  
○ Varies  
○ Don’t know | No information. | Studies of resources required were not specifically sought in this review. Requirements and cost of introducing ACP for all people with COPD were thought to include staff, time and training, and were thought to probably be small to negligible in most settings. Savings could occur by avoiding unwanted intensive care unit (ICU) and hospital admissions, and are likely to vary by country. |

Certainty of evidence of required resources
What is the certainty of the evidence of resource requirements (costs)?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
</table>
| ○ Very low  
○ Low  
○ Moderate  
○ High  
○ No included studies | No information. | We did not conduct a systematic review on costs or calculate specific cost savings. |

Cost effectiveness
Does the cost-effectiveness of the intervention favor the intervention or the comparison?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
</table>
| ○ Favors the comparison  
○ Probably favors the comparison | No information. | The cost of the intervention is low whereas the cost of the hospital admissions could be high. |
<table>
<thead>
<tr>
<th>Does not favor either the intervention or the comparison</th>
<th>Probably favors the intervention</th>
<th>Favors the intervention</th>
<th>Varies</th>
<th>No included studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Another study regarding ACP interventions on nursing home residents found that ACP decreased hospitalization rates by 9%-26% and decrease in hospitalization was not associated with increased mortality. In addition, it increased the number of residents dying in their nursing home by 29%-40%.⁹</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**Equity**

What would be the impact on health equity?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced</td>
<td>No information.</td>
<td>ACP would need to be offered in a sensitive way, considering different cultural and personal attitudes toward death and dying. There could be an improvement in health equity if everyone had access to flexible ACP programs. In addition, ACP was thought to potentially increase healthcare equity.</td>
</tr>
<tr>
<td>Probably reduced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Probably no impact</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Probably increased</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Acceptability**

Is the intervention acceptable to key stakeholders?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No information.</td>
<td>Probably varies for people with COPD and informal caregivers. We think most people would find it acceptable to be offered ACP.</td>
</tr>
<tr>
<td>Probably no</td>
<td></td>
<td>Acceptability for HCP varies across cultures and may be affected by religious factors. In some countries, ACP has no legal status, reflecting varied acceptability among stakeholders in society.</td>
</tr>
<tr>
<td>Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Feasibility**

Is the intervention feasible to implement?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No information.</td>
<td>Specialist training may be required in some settings. It depends on nature and complexity of ACP intervention.⁷</td>
</tr>
<tr>
<td>Probably no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Varies</td>
<td>Don't know</td>
<td></td>
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<tr>
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<td>------------</td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SUMMARY OF JUDGEMENTS</td>
<td></td>
<td></td>
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<tr>
<td>-----------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>JUDGEMENT</td>
<td></td>
</tr>
<tr>
<td>PROBLEM</td>
<td>No</td>
<td>Probably no</td>
</tr>
<tr>
<td>DESIRABLE EFFECTS</td>
<td>Trivial</td>
<td>Small</td>
</tr>
<tr>
<td>UNDESIRABLE EFFECTS</td>
<td>Large</td>
<td>Moderate</td>
</tr>
<tr>
<td>CERTAINTY OF EVIDENCE</td>
<td>Very low</td>
<td>Low</td>
</tr>
<tr>
<td>VALUES</td>
<td>Important uncertainty or variability</td>
<td>Possibly important uncertainty or variability</td>
</tr>
<tr>
<td>BALANCE OF EFFECTS</td>
<td>Favors the comparison</td>
<td><strong>Probably favors the comparison</strong></td>
</tr>
<tr>
<td>RESOURCES REQUIRED</td>
<td>Large costs</td>
<td>Moderate costs</td>
</tr>
<tr>
<td>CERTAINTY OF EVIDENCE OF REQUIRED RESOURCES</td>
<td>Very low</td>
<td>Low</td>
</tr>
<tr>
<td>COST EFFECTIVENESS</td>
<td>Favors the comparison</td>
<td><strong>Probably favors the comparison</strong></td>
</tr>
<tr>
<td>EQUITY</td>
<td>Reduced</td>
<td>Probably reduced</td>
</tr>
<tr>
<td>ACCEPTABILITY</td>
<td>No</td>
<td>Probably no</td>
</tr>
<tr>
<td>FEASIBILITY</td>
<td>No</td>
<td>Probably no</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TYPE OF RECOMMENDATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong recommendation</td>
</tr>
</tbody>
</table>
CONCLUSIONS

Recommendation

We suggest that ACP should be offered to people with COPD (conditional recommendation; low quality of evidence).

Remark: ACP should be periodically revised, respecting individual needs and values of people with COPD and their informal caregivers.

Justification

Evidence was limited, but it demonstrated beneficial effects of ACP to people with COPD as improving quality of communication with healthcare professional, increasing follow-up ACP discussions, and decreasing anxiety in informal caregivers. Undesirable effects have not been systematically investigated, but they were considered small and mostly associated to unprepared healthcare professionals to develop ACP discussions.

Subgroup considerations

None.

Implementation considerations

How and when ACP should be implemented for people with COPD is uncertain due to the unpredictable trajectory of the disease. Standardized ACP programs (e.g. guidelines and standardized documentation) may facilitate the initiation and continuous assessment of the plan, but they should also allow some flexibility to respect preferences of people with COPD and informal caregivers. Sociocultural and individual factors may play a role on how and when the ACP discussions should be conducted and implemented. Healthcare professional should be trained to develop ACP discussions. The timing to initiate the ACP discussions should include the perception of the clinically relevant moment from the different angles including person with COPD, informal caregivers, and health care professional.

Monitoring and evaluation

ACP should be re-visited regularly as peoples’ preferences may change over time.

Research priorities

1. Determine the effects of ACP in people with COPD and their informal caregivers.
2. Explore the perspective of COPD people and their informal caregivers regarding acceptability and feasibility of (how/when to initiate) ACP.
3. Identify successful components of ACP for people with COPD and informal caregivers.
4. Identify barriers to ACP implementation for people with COPD.
5. Explore changes in care preferences and values of people with COPD over time.
6. Assess the cost-effectiveness of ACP for people with COPD.

References for Evidence to decision framework for question 5
1. World health Organization. WHO global health estimates. Available at: https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death (accessed on 10 April 2022)


Evidence summary table for question 6

**Question:** 6. Advance Care Planning (ACP) interventions compared to no or unstructured forms of advance care planning for people with ILD

**Setting:** Specialist care


<table>
<thead>
<tr>
<th>№ of studies</th>
<th>Study design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Impact</th>
<th>Certainty</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>observational studies</td>
<td>serious(^a)</td>
<td>not serious</td>
<td>serious(^b)</td>
<td>not serious</td>
<td>none</td>
<td>A greater percentage of people who died at home or hospice received ACP (96% vs 83%, (P = .02)). 92 people were included in the study.</td>
<td>⬤⬤⬤⬤</td>
<td>Critical</td>
</tr>
</tbody>
</table>

\(^{a}\) Retrospective study, downgraded for serious confounding and information bias: unclear if ACP discussion occurred before eventual location of death was established; cohorts were defined by outcome (location of death); data for preferred location of death available but not used in analysis.

\(^{b}\) Outcome of location of death is proxy for patient experience (indirect outcome).

CI: confidence interval

*Explanations*

- a. Retrospective study, downgraded for serious confounding and information bias: unclear if ACP discussion occurred before eventual location of death was established; cohorts were defined by outcome (location of death); data for preferred location of death available but not used in analysis.

- b. Outcome of location of death is proxy for patient experience (indirect outcome).
**Evidence to decision framework for question 6**

**Should (intervention) vs. (control) be used for?**

<table>
<thead>
<tr>
<th><strong>POPULATION:</strong></th>
<th>People with ILD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INTERVENTION:</strong></td>
<td>Advance care planning (ACP)</td>
</tr>
<tr>
<td><strong>COMPARISON:</strong></td>
<td>No or unstructured forms of ACP</td>
</tr>
</tbody>
</table>

**MAIN OUTCOMES:**

1. Quality of communication between person with ILD and healthcare professionals
2. Concordance between the wishes of the person with ILD and received care at the end of life
3. Documented discussions between informal caregivers and health professional about goals of care / advance care planning
4. Symptom control at the end of life
5. Experience of end of life care
6. Avoidable hospital visits near end of life, measured by emergency department attendance without admission
7. Informal caregivers’ satisfaction with end of life care

**SETTING:**

No restriction

**PERSPECTIVE:**

Population

**BACKGROUND:**

ILD is often irreversible and worsens over time. Disease progression can be varied. It is frequently associated with high health care utilization and people with ILD are less likely to be referred to specialised palliative care and more likely to die in hospital, suggesting a potential role for ACP in the management of people with ILD.

**CONFLICT OF INTERESTS:**

No conflicts of interest

**ASSESSMENT**

**Problem**

Is the problem a priority?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
<td>People with ILD have expressed that being able to plan for future care and discussing end of life preferences is important to them. [1]</td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Desirable Effects**

How substantial are the desirable anticipated effects?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Trivial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Small</td>
<td></td>
<td>Quantitative date showed improvements in palliative care concerns, symptom control, quality of life in those who received the mixed palliative care intervention earlier than those whose who received it later. Qualitative data: people with ILD and their informal caregivers wanted to</td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Large</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Varies of people (n=92) who received ACP died at home or hospice compared to those who did not receive ACP (96% vs 83%, p=.02). [2]

People with ILD and informal caregivers willingness to partake in ACP changed over time. [3]

Death in hospital is common for people with ILD. In the UK, death in hospital is most common for these people (70%). Reduction in hospital deaths would be a desirable outcome in this group. [4]

Undesirable Effects
How substantial are the undesirable anticipated effects?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Large</td>
<td>No harmful or adverse events were reported for any intervention.</td>
<td>Qualitative data showed not all people with ILD wanted to talk about advance care planning decisions such as preferred place of care and preferred place of death.[3] Decreased health related quality of life and increased anxiety of people and families. Qualitative data however suggested that people felt less isolated after a disease management program.[5] There is increasing recognition in ILD that ACP is essential to ensure that the care received is consistent with preferences and values of people with ILD, at a time when they may be unable to communicate their wishes. However, there is limited evidence about how and when it should be implemented and any undesirable effects.</td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Small</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Trivial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Don't know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Certainty of evidence
What is the overall certainty of the evidence of effects?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Very low</td>
<td>Based on GRADE assessment</td>
<td>Observational study with evidence of bias and imprecision. [2]</td>
</tr>
<tr>
<td>○ Low</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ High</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ No included studies</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Values
Is there important uncertainty about or variability in how much people value the main outcomes?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Important uncertainty or variability</td>
<td>People with ILD and informal caregivers value the quality of communication between people with ILD and healthcare professionals. [1, 3, 6]</td>
<td></td>
</tr>
</tbody>
</table>
### People with ILD value documented discussions between about goals of care and advance care planning.\[3\]

People with ILD and informal caregivers value improved symptom control at the end of life.\[3\]

**Views of representatives of people with COPD or ILD and informal caregivers:**
Conversations about end of life need to come at a time before a person is too tired/distressed to be able to talk about it – but also not at diagnosis stage, later than this. Goal of ACP is that end of life will be managed with compassion. Each person is different. Some people want information about their disease and access to support. Some people don’t want to know about progression of their disease.
### Certainty of evidence of required resources

**What is the certainty of the evidence of resource requirements (costs)?**

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
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<tbody>
<tr>
<td>○ Very low</td>
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<td></td>
</tr>
<tr>
<td>○ Low</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Moderate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ High</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ No included studies</td>
<td></td>
<td>We did not conduct a systematic review or calculate cost savings as the data was not available.</td>
</tr>
</tbody>
</table>

### Cost effectiveness

**Does the cost-effectiveness of the intervention favor the intervention or the comparison?**

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Favors the comparison</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably favors the comparison</td>
<td></td>
<td>Studies in other populations have suggested mixed evidence for cost-effectiveness of ACP.</td>
</tr>
<tr>
<td>○ Does not favor either the intervention or the comparison</td>
<td></td>
<td>Hospital costs and outcomes of a nurse-led ACP intervention compared with usual care in the last 12 months of life for older people with end-stage kidney disease managed with haemodialysis in Australia were examined. The mean cost of ACP was AUD$519 per person. The mean hospital costs of care in last 12 months of life were $100,579 for those who received ACP versus $87,282 for those who did not, suggesting nurse-led ACP leads to receipt of patient preferences for end-of-life care, but at an increased cost. [8]</td>
</tr>
<tr>
<td>○ Probably favors the intervention</td>
<td></td>
<td>A decision analytic model was developed to identify the costs and outcomes of an ACP program for people aged 65+ years in Australia who were at risk of developing dementia. The results showed that, compared to usual care, a nationwide ACP program for people aged 65+ years who were at risk of dementia would be cost-effective. [9]</td>
</tr>
<tr>
<td>○ Favors the intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ No included studies</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Equity

**What would be the impact on health equity?**

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Reduced</td>
<td></td>
<td>There could be an improvement in health care equity if everyone had the same access to ACP. However, no direct effect on health equity is unlikely to occur.</td>
</tr>
<tr>
<td>○ Probably reduced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably no impact</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably increased</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Increased</td>
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<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Acceptability
Is the intervention acceptable to key stakeholders?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td>Acceptability probably varies for people with ILD and informal caregivers and across different cultures and religions. We consider that most people would find it acceptable to be offered ACP in a sensitive way. In some countries, ACP has no legal status, reflecting varied acceptability among stakeholders in society.</td>
</tr>
<tr>
<td>○ Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Feasibility
Is the intervention feasible to implement?

<table>
<thead>
<tr>
<th>JUDGEMENT</th>
<th>RESEARCH EVIDENCE</th>
<th>ADDITIONAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Probably yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Varies</td>
<td></td>
<td>Specialist training may be required in some settings. Depends on nature and complexity of ACP intervention. [10]</td>
</tr>
<tr>
<td>○ Don’t know</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>PROBLEM</td>
<td>DESIRABLE EFFECTS</td>
</tr>
<tr>
<td>-------------------------</td>
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<td>-------------------</td>
</tr>
<tr>
<td>JUDGEMENT</td>
<td>No</td>
<td>Probably no</td>
</tr>
<tr>
<td>Probable no</td>
<td>Small</td>
<td>Moderate</td>
</tr>
<tr>
<td>Large</td>
<td>Moderate</td>
<td>Small</td>
</tr>
<tr>
<td>Probable yes</td>
<td>Yes</td>
<td>Varies</td>
</tr>
<tr>
<td>Varies</td>
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<td>Don't know</td>
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</tbody>
</table>

**TYPE OF RECOMMENDATION**

<table>
<thead>
<tr>
<th>Strong recommendation</th>
<th>Conditional recommendation</th>
<th>Conditional recommendation for either the</th>
<th>Conditional recommendation for the intervention</th>
<th>Strong recommendation for the intervention</th>
</tr>
</thead>
</table>
CONCLUSIONS

Recommendation

We suggest that ACP should be offered to people with ILD (conditional recommendation; very low quality of evidence).

Remark: ACP should be periodically revised, respecting individual needs and values of people with ILD and their informal caregivers.

Justification

There is limited evidence that ACP may reduce hospital deaths. In other disease groups, for example COPD, it has been shown to improve quality of communication with healthcare professional, and decrease anxiety in relatives. The undesirable effects of ACP have not been systematically investigated, but it is considered they are small.

Subgroup considerations

Sociocultural factors may play an important role on how and when the ACP discussions should be conducted.

Implementation considerations

How and when ACP should be implemented for people with ILD is uncertain due to the unpredictable trajectory of the disease. Standardised ACP programs (e.g.: guidelines and standardised documentation) may facilitate the initiation and continuous assessment of a plan, but some flexibility should be allowed to respect preferences of people with ILD and informal caregivers. Healthcare professionals should be trained to develop their skills to offer ACP discussions. The timing to initiate the ACP discussions should include the perception of the clinically relevant moment from the different angles including person with ILD, relative/carer, and health care professional. ACP should also be revisited regularly as preferences may change over time.

Monitoring and evaluation

Preferences may change over time. ACP should be revisited regularly.

Research priorities

There is a paucity of research examining the effects of ACP as a separate intervention. We would recommend that future research examines ACP separately and reports outcomes appropriately. Where possible mixed methods should be used.

Specific research areas:

1. Determine the effects of ACP in people with ILD and informal caregivers.
2. Explore the perspective of people with ILD, informal caregivers and health professionals regarding acceptability and feasibility (how/when initiate) of ACP- including across different cultures.
3. Identify successful components of ACP
4. Identify barriers to ACP implementation
5. Explore changes in preferences of people with ILD over time.
6. Assess the health economics, including resource requirements, cost savings and cost-effectiveness, of ACP for people with ILD.

References for Evidence to decision framework for question 6


### Evidence to decision framework for question 7

**How to implement palliative care with routine clinical care for people with COPD and ILD and their informal caregivers?**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Judgement</th>
<th>Research evidence</th>
<th>Additional considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Priority</strong></td>
<td>Is the problem a priority?</td>
<td>COPD 1-3,5,8,37,39,42,47,53,56</td>
<td>Policy, organizational, institutional, professional and health service configurations differ between countries. These need to be understood as well as individual persons with serious illness, informal caregiver and clinician barriers to effective implementation of palliative care for people with COPD and ILD.</td>
</tr>
</tbody>
</table>
| | | COPD 1,2,39,42,45,47,56 | Observational studies demonstrate a serious inequity for people with COPD and ILD and their informal caregivers with regard to accessing palliative care compared with people with cancer despite equivalent palliative care needs.  

i. Addressing this deficit in care has become a global imperative, vi. fundamental to universal health coverage, vii. enshrined in EU policy, viii. a priority for professional organisations and ix. a concern for patient organisations.  

|  | COPD 1-3,5,8,37,39,42,47,53,56 | |  |
|  | COPD 1,2,39,42,45,47,56 | |  |
|  | This is compounded as people with COPD or ILD may be reluctant to accept a referral to ‘palliative’ care because of a perceived association with cancer and end-of-life, COPD 3,19,26,46,54 though once referred acceptability was high, COPD 1. There is limited evidence about optimal timing of referral, COPD 3 but ‘early’ referral has been recommended, COPD 2,5,35,46 defined by people with COPD or ILD and informal caregivers in one study as when the COPD is classed as ‘moderate’, COPD 26. Lack of awareness amongst respiratory and generalist colleagues of the availability of palliative care has been highlighted, COPD 3,19,39,49 and some studies have proactively initiated screening, for example during a hospital admission, COPD 1,15,46,51 or searching for prognostic indicators in primary care records. COPD 1,25,52 | |  |
|  | ILD 1-3,5,12 | |  |
|  | ILD 1,5,6,9,11 | |  |
|  | ILD 1,5,6,11 | |  |

#### COPD

Although a number of indicators (commonly hospitalisation, long-term oxygen therapy, symptom burden) are cited to prompt referral of people with COPD to palliative care services, COPD 1-3,5,8,37,39,42,47,53,56 the uncertain disease trajectory, COPD 1-3,5,8,37,39,42,47,53,56 lack of a clear transition to ‘end-of-life’ COPD 2,17 and normalisation of living with COPD COPD 3 can lead to hesitancy on the part of healthcare professionals to consider a palliative care approach. COPD 1,2,39,42,45,47,56 This is compounded as people with COPD or ILD may be reluctant to accept a referral to ‘palliative’ care because of a perceived association with cancer and end-of-life, COPD 3,19,26,46,54 though once referred acceptability was high. COPD 1. There is limited evidence about optimal timing of referral, COPD 3 but ‘early’ referral has been recommended, COPD 2,5,35,46 defined by people with COPD or ILD and informal caregivers in one study as when the COPD is classed as ‘moderate’, COPD 26. Lack of awareness amongst respiratory and generalist colleagues of the availability of palliative care has been highlighted, COPD 3,19,39,49 and some studies have proactively initiated screening, for example during a hospital admission, COPD 1,15,46,51 or searching for prognostic indicators in primary care records. COPD 1,25,52

#### ILD

People with ILD are often not referred to palliative care services, or referred too late to address the high levels of unmet need (e.g., 71% within the last month of life ILD 2). Suggested triggers for palliative care referral are oxygen therapy, ventilatory support, uncontrolled symptoms, functional decline, and opioid consideration ILD 1-3,5,12 as well as unmet holistic needs (anxiety and depression, loneliness and isolation, and increasing caregiver dependence/burden). ILD 1,5,6,9,11 The poor prognosis and downward trajectory over time, albeit still seen as uncertain, ILD 1,12 underpin calls for a palliative care approach to be incorporated within usual care from soon after diagnosis. ILD 1,5,6,11

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Summary: Despite the different trajectory, there are similar challenges in identifying the optimal moment for referral to specialist palliative care services with the result that for many people referral is delayed.

<table>
<thead>
<tr>
<th>Certainty of evidence</th>
<th>The evidence-base for COPD represents data from 225 original studies (13 systematic reviews reporting 175 original papers, plus 46 primary studies not included in the systematic reviews). The evidence-base for ILD is considerably smaller representing data from 56 original studies (4 systematic reviews reporting 46 original papers, plus 10 primary studies not included in the systematic reviews).</th>
</tr>
</thead>
</table>

**COPD**

The SRs reported a few RCTs:

- Broese 2021\(^{COPD1}\) (1 RCT of a palliative care service in generic ‘advanced disease’; 2 RCTs specifically of a breathlessness service; and 4 pilot RCTs)
- Disler 2012\(^{COPD2}\) (1 RCT that showed ACP improved adherence to EoL wishes)
- Fusi-Schmidhauser 2019\(^{COPD3}\) (1 RCT of a palliative care service in generic ‘advanced disease’; 1 RCT specifically of a breathlessness service and 1 pilot RCT)
- Meehan 2020\(^{COPD6}\) (4 RCTs specifically of ACP that showed improved use of ACP)
- Ora 2019\(^{COPD10}\) (2 RCTs of nurse-led care improved use of ACP; 2 pilot trials);
- Singer 2016\(^{COPD11}\) (19 highly heterogenous RCTs, 11 showed benefit on ‘one or more patient reported outcome’. Very little data presented in the SR, but the conclusion is: ‘Strongest evidence is for the roles of nurses and social workers and home-based multidisciplinary approaches in improving use of ACP, psychosocial health with weaker evidence for health outcome’)

The other studies are observational, qualitative, mixed methods before and after studies, cohort and cross-sectional studies. Whilst not high-quality evidence, what is striking is the consistency of the findings across multiple studies with a broad range of methodologies.

**ILD**

None of the SRs or primary studies reported any RCTs of palliative care interventions (as opposed to trials of specific components such as breathlessness interventions).

Currently there are no studies which formally test implementation strategies or models of integration.

Informative work exists for breathlessness intervention services in multiple conditions,\(^{i,ii}\) and ACP for people with non-malignant lung disease (as distinct from full palliative care services),\(^{iii}\) and validating assessment tools\(^{iv}\) (but no trials of their clinical effectiveness). Descriptive studies of existing integrated palliative care services demonstrate before-after benefits.

The GOLD Global COPD Guidelines\(^{v}\) is cautiously supportive of specialist palliative care (and more specifically ACP) in theory, but does not support any evidence to support effectiveness.

A Cochrane review of hospital based palliative care for any ‘advanced disease’,\(^{vi}\) only included one study (out of 42 RCTs) in people with COPD\(^{vii}\) and one in ILD.\(^{viii}\) Both are small pilot trials.

- Farquhar et al. *Trials* 2016; 17: 185
- Detering et al. *BMJ* 2010;340:c1345
Current practice

Models of COPD palliative care

Three of the systematic reviews explicitly considered implementation of palliative care in terms of ‘patients, professionals and organisations’, COPD 1-3 and this approach was implicit in other reviews and original research papers. COPD 19,20,42

- **People with COPD or ILD and their informal caregivers.** Key priorities for people with COPD or ILD and their informal caregivers was accessing information about COPD and support services, COPD 1,2,14,30,40,41,45,47 optimising treatment to reduce physical symptoms, COPD 1,2,5,19,26 coping with psychosocial challenges and maintaining activities they enjoy, COPD 2,19,25 and ‘being listened to’ so that their care is appropriately tailored. COPD 1,5,56 Empathy, 14 feeling ‘cared for’, COPD 32 establishing, maintaining, and in due course closing, COPD 15 a relationship were valued, COPD 15,35 and led to increased confidence in ability to cope. COPD 1 Informal caregivers echoed the need for information, and valued practical support (e.g. respite care; resources) for their caring role. COPD 5,14,17,47

- **Skilled professionals.** Studies stressed the need for knowledgeable professionals, trained in respiratory and palliative care and with access to multidisciplinary generalist and specialist expertise. COPD 1,3,20,35,36,39,42,49,52-54,56,57 Specific skills required included ability to optimise treatment, COPD 2,5,17 provide holistic care, COPD 2,5,17,19,20 and discuss prognosis and ACP, COPD 2,3,9,19,20,23,26,39,45,47,52,56 in advance of critical events. COPD 23 Lead/co-ordinating professionals could be from specialist respiratory or palliative care disciplines, general practitioners or community nurses, COPD 1,3,8,9 but continuity of care was described as crucial enabling a trusted relationship to form. COPD 2,3,14,29,35,50

- **Flexible, multidisciplinary organisation.** Models of care delivery varied, but key considerations are a service that is accessible (often community-based), COPD 1,2,45 flexible (to respond to individual needs and a fluctuating clinical condition). COPD 2,17

A whole systems approach is widely applied to improving the quality of healthcare, i and was adopted (or modified) by three of the SRs and several other studies in this review. This framework identifies levels that need to be addressed to effect change. Initiatives in both COPD and ILD fitted within this approach offering a framework for synthesising the findings:

- Individual (person with COPD or ILD) level
- Professional level
- Local organization of healthcare system level
- National policy and context

i. Ferlie et al. The Milbank Quarterly 2001; 79: 281-315
and adequately resourced to be able to provide sufficient professional time,\textsuperscript{COPD 1,8,35,39,42,45,52,56} and links to the range of services required to meet physical, psychological, social and spiritual care needs of people with COPD.\textsuperscript{COPD 1,2,5,14,30,36,49,51}

Multidisciplinary teams need to be collaborative, co-ordinated with good communication and defined referral channels for specialist support as required.\textsuperscript{COPD 2,3,8,17,18,29,36,37,39,45,46,49,53-55}

Fostering relationships with one - or a very few - trusted professionals was widely emphasised, enabling a sense of continuity within the wider multidisciplinary team.\textsuperscript{COPD 1,3,14,29,32,33,38,43,49,50,52}

**Models of ILD palliative care**

A needs-based, not prognosis-based, approach was recommended,\textsuperscript{ILD 1,3,5,9} with care co-ordinated across primary, respiratory (including pulmonary rehabilitation) and specialist palliative care settings, with adequate allied health support to enable care at home (if preferred).\textsuperscript{ILD 1,3,5,6,11} Palliation should be part of multidisciplinary case discussion and a palliative approach triggered by unmet needs, and not seen as a “near-death” intervention.\textsuperscript{ILD 1,3,5,6,9,11} Unmet needs should be identified systematically, using an assessment tool and clinical conversation,\textsuperscript{ILD 6,9,13} preferably in the ambulatory care setting and not during an acute admission.\textsuperscript{ILD 6,9,13} Holistic needs assessments should also include consideration of informal caregivers.\textsuperscript{ILD 1,3,5,9}

- **People with COPD or ILD and family caregivers.** Access to information, supportive and palliative care services to address symptom control, psycho-social needs, provision of practical help in the home and support for informal caregivers are important.\textsuperscript{ILD 1,3,5,9} The need for clarity about prognosis was highlighted along with continuity of care from trusted professionals. Informal caregivers’ needs should be assessed alongside the needs of people with COPD or ILD (e.g. the validated NAT:ILD includes two caregiver domains (ability to care; caregiver wellbeing) though is not yet evaluated in clinical practice.\textsuperscript{ILD 9}

- **Skilled professionals.** The need to upskill ILD specialists and primary care clinicians in holistic assessment, symptom management, planning current and future goals of care was a consistent finding.\textsuperscript{ILD 1,2,13} Access to, and support from, specialist palliative care teams were important components of successful provision of palliative care. Embedding the use of a needs assessment tool into routine care, or multidisciplinary respiratory/palliative integration with case conferences and
referral checklists/decision aids were suggested, \(^{1,3,5,9,11}\) but challenging in practice. \(^{13}\)

- **Flexible, multidisciplinary organisation.** Implementation needed to prioritise: i) service reconfiguration to allow time for holistic assessment and management, and multidisciplinary team discussions, ii) communication skills training for by clinicians, managers and institutions, iii) adequate flexible resources, especially psychological and social support services. Models ranged from linking respiratory/generalists with specialist palliative care teams for mutual education, training and referral, \(^{1,3,5,9,11}\) to a fully integrated collaborative ILD-palliative care service encompassing medication, oxygen, nutritional advice, self-management education and psychological support. \(^{1,3,5,11}\) Initial evaluation of the full collaborative model showed promising benefit, \(^{1,3,5,11}\) but lacked a health economic evaluation. Ongoing case specialist palliative care for every person with ILD is unnecessary and unsustainable: most issues can be addressed by the ILD team or primary care with support and training. \(^{1,3,5,11}\)

**Values**

<table>
<thead>
<tr>
<th>Importance</th>
<th>COPD</th>
<th>ILD</th>
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<tbody>
<tr>
<td>Is there important uncertainty about or variability in how much people value the main outcomes?</td>
<td>Holistic needs assessment: COPD</td>
<td>Holistic needs assessment: ILD</td>
</tr>
<tr>
<td>o Important uncertainty or variability</td>
<td>Holistic assessment of physical, psychological, social and spiritual needs (of people with COPD or ILD and informal caregivers), (^{1,3,5,9,11}) is widely described as a crucial first step, (^{1,3,5,9,11}) with practical advice that arrangements should be comprehensive, (^{1,3,5,9,11}) accessible (potentially involving home-visits), (^{1,3,5,9,11}) interdisciplinary, (^{1,3,5,9,11}) with needs shared between support agencies to avoid duplication. (^{1,3,5,9,11}) A multidimensional needs assessment should not only consider the needs of the person with COPD, but also the needs of informal caregivers, as well as the timing of support provision. (^{1,3,5,9,11}) The Support Needs Approach for Patients (SNAP) tool asks people with advanced COPD to identify their support needs in 15 domains using questions that have been validated with people with COPD, informal caregivers and healthcare professionals, (^{1,3,5,9,11}) but is not yet evaluated in a clinical context.</td>
<td>Multidisciplinary, holistic needs assessment is preferable to a prognosis-based approach, (^{1,3,5,9,11}) with care plans and goals discussed whilst ambulatory rather than during an acute crisis. (^{1,3,5,9,11}) Three systematic approaches are described in the literature: a validated needs assessment tool to guide consultations (NAT-ILD) (^{1,3,5,9,11}) a bespoke</td>
</tr>
<tr>
<td>o Possibly important uncertainty or variability</td>
<td>o Probably no important</td>
<td>o Probably no important</td>
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The data were synthesised initially by disease, on the assumption that two respiratory diseases with such different trajectories might require different approaches. In the event, the themes that emerged were similar so that overarching conclusions can be drawn.

- In both diseases the need for a structured needs assessment at diagnosis (in the typically rapidly progressive ILD) or onset of troublesome symptoms (in the slowly progressive COPD) and reviewed as the disease deteriorates.
- Communication is pivotal people with COPD or ILD/caregivers and their healthcare professionals, but also between professionals within the team. It follows that communication-skills training is a prerequisite of introducing a palliative care service.
uncertainty or variability
● Not important uncertainty or variability
○ No known undesirable outcomes

clinician supportive care decision aid (SCDAT) \( ^{ILD\ 6} \) and a multidisciplinary collaborative ILD-palliative care bundle. \( ^{ILD\ 5} \)

Communication: COPD
Communication emerged as a key theme not only between people with COPD or ILD/informal caregivers and their healthcare professionals, but also between professionals within the team. Strategies to overcome the potential of services to appear fragmented and uncoordinated, \( ^{COPD\ 17,37,40,47,49} \) included allocating a named professional who is accessible and able to signpost resources, \( ^{COPD\ 1,14,18,29,43} \) regular multidisciplinary team meetings, \( ^{COPD\ 20,29,51,53} \) joint consultations, \( ^{COPD\ 25} \) and case management. \( ^{COPD\ 5} \) People with COPD often know very little about COPD and want information on coping with their condition, and open and honest communication about their prognosis. \( ^{COPD\ 2,3,14,18,23,32,35,40,47} \) Some studies have suggested that digital communication may be useful including phone calls to check progress, \( ^{COPD\ 11} \) telemonitoring of status, \( ^{COPD\ 1} \) teleconsultations, \( ^{COPD\ 34} \) web-based counselling or support for ACP. \( ^{COPD\ 5} \)

Communication: ILD
Good communication was emphasised as crucial across all settings. “Silo” working, \( ^{ILD\ 3} \) with poor communication between sectors and teams was seen as major obstacle. \( ^{ILD\ 2,3,12} \) Inappropriate optimism, perpetuated by poor communication skills and/or confidence was a problem as clinicians avoided talking about goals of care for fear of “taking away hope”. \( ^{ILD\ 2,3,8} \) The concept of palliative care providing a layer of care alongside active treatment was not commonly understood by any stakeholder, \( ^{ILD\ 1-3} \) and often referrals were seen as a covert message that death was very near - with accompanying stigma. \( ^{ILD\ 1,3} \)

Summary: There is marked consensus on the important issues relevant to both COPD and ILD:
• The need for structured holistic assessment that identifies needs of people with COPD or ILD and informal caregivers and facilitates appropriate care from a multidisciplinary team with easy access to specialist palliative care
• Communication emerges as a key theme which underpins much of the palliative care approach. Appropriate skilling of healthcare professionals is an essential pre-requisite whatever the model of care

Views of representatives of people with COPD or ILD and informal caregivers:
Palliative care should be part of routine clinical care. So an integrated service, but individualized. There is a need for healthcare professionals to ‘plant a seed’ early on so that people know that such support is available when they need it.
<table>
<thead>
<tr>
<th>Benefits and harms</th>
<th>How substantial are the benefits of the intervention compared to harms?</th>
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<tbody>
<tr>
<td></td>
<td><strong>Limited quantitative evidence</strong></td>
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<tr>
<td></td>
<td>The SRs in the review, COPD 1-3,6,9,11 included a number of RCTs, but only seven specifically recruited people with COPD. Of these:</td>
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<td>- four were pilot/under-powered trials, COPD 87, 125, 168, 215</td>
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<td>- one was a controlled clinical trial, COPD 110, which showed an increase in provision of ACP with hospital-based palliative care</td>
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<td>- one was a cluster RCT, COPD 76, which showed that sending people with COPD a survey of preferences for end-of-life care improved the occurrence and quality of communication</td>
</tr>
<tr>
<td></td>
<td>- one was cluster-randomised trial in which HCPs were trained to deliver ACP, COPD 163. The trial concluded that the intervention increased provision of ACP; improved quality of EoL communication (p&lt;0.001); reduced anxiety in caregivers, reduced anxiety and depression, and increased the ‘Quality of Death and Dying score’</td>
</tr>
<tr>
<td></td>
<td>In addition a trial of providing ACP for people with severe respiratory conditions (including COPD), COPD 225 improved improved quality of EoL communication (p&lt;0.001); reduced anxiety in caregivers, reduced anxiety and depression for people with COPD and improved ‘Quality of Death and Dying score’</td>
</tr>
<tr>
<td></td>
<td>More specifically, two trials of a Breathlessness Intervention Service reduced breathlessness and improved survival at 6 months (including in the sub-group with people with COPD or ILD).</td>
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</tbody>
</table>

**Qualitative synthesis**

There are some key themes related to how to implement palliative care with routine clinical care that emerge consistently from the broad range of included studies in both COPD and ILD:

- Palliative care and routine COPD and ILD disease management are complementary.
- Models of integrated care vary according to the healthcare context, but a key feature is flexible responsive working within an extended multidisciplinary team.

Although there is a lack of data in people with COPD or ILD, there are data from RCTs in people with other advanced illnesses:

- A Cochrane review of hospital-based specialist palliative care for people with advanced illness showed ‘small benefits for several person-centred outcomes including HRQoL, symptom burden and satisfaction with care of people with advanced illness, while also increasing the chances of people dying in their preferred place’. There was no evidence of serious harms.
- The review included studies in people with cancers and non-malignant disease (most commonly heart failure)

A fifth theme is related to ACP (see Q8):

- Initiating ACP conversations is challenging, and is too often delayed the because the uncertain disease trajectory (especially in COPD) can lead to hesitancy on the part of healthcare professionals to consider a palliative care approach. Services should prioritise training for professionals, and clarify who within the multi-disciplinary team is responsible for (and has the allocated time to deliver) offering timely ACP, and checking preferences as circumstances change.
where people with persistent/unmet palliative care needs have access to specialist palliative care support.

- Accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual needs (of people with COPD or ILD and informal caregivers) is a crucial first step in providing supportive and palliative care. In COPD increasing disability, or events such as admissions, or commencing LTOT should trigger an assessment; in more the rapidly progressive ILDs assessments should be considered early after the diagnosis is made.
- The need for continuity of care is a recurring theme, and the opportunity to develop a trusting relationship with one - or a very few - trusted professionals is highly valued by people with COPD or ILD and informal caregivers.

### Equity

**What would be the impact on health equity?**

- Reduced
- Probably reduced
- Probably no impact
- Probably increased
- Increased
- Varies
- Don't know

None of the studies explicitly addressed the issue of equity, though there is widespread concern that people with life-limiting non-malignant disease (such as COPD and ILD) do not have access to the palliative care services available for people with cancer. In addition, COPD is strongly associated with deprivation which will further exacerbate inequities.

**Integrating palliative care with respiratory management: COPD.**

In a condition in which a fluctuating but slowly progressive trajectory makes prognosis uncertain and clinicians struggle to identify the point at which to involve palliative care, several studies addressed service models in which palliative care was seamlessly integrated into the routine care of COPD, whether that be with respiratory specialists, primary care generalists, or community respiratory teams. A key advantage was facilitating early provision of holistic care, specifically including early discussions of prognosis and ACP. One study exploring perceptions of people with COPD and their informal caregivers suggested that a palliative care approach should be considered when the COPD was of moderate severity, recognising that active disease management and palliation are complementary in a lifelong condition.

There is limited evidence for the best approach to integrating the multiple domains of palliative care with active management, but strategies described include joint respiratory/palliative care clinics, providing respiratory clinicians with palliative care.

Palliative care is explicitly recognised by the World Health Organisation within the Human Rights to Health.

Systematic needs assessment to identify unmet palliative care needs for people with COPD and ILD would trigger the necessary referral to both general and specialist palliative care. This would redress the current major inequity in access to palliative care experienced by people with COPD and ILD irrespective of socio-economic status. Further, systematic identification and referral (needs-based) may also help address the known inequities of accessing palliative care for older people, more deprived, and ethnic minorities.

i. WHO: Human Rights to Health.

care skills, COPD 19,39,42  regular inter-professional communication, COPD 2,29,52  and involvement of a key professional who could coordinate interdisciplinary working and transfer of information between disciplines and sectors, COPD 9,17,18,52  General raising of awareness amongst professionals was considered important as well as a role for lay communication with the general public, COPD 3,5,39  The intention was that involvement of a palliative care approach should be regarded as “usual” care by people with COPD and clinicians alike, COPD 30  Underpinning these initiatives was the support of healthcare policy for organisational change and re-alignment of services, COPD 3,21,23,42

Summary: Initiatives that integrate a palliative care approach with routine clinical care of COPD or ILD, has the potential to improve equity by facilitating early referral and improving access to supportive care throughout the disease trajectory.

<table>
<thead>
<tr>
<th>Acceptability</th>
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<tbody>
<tr>
<td>Is the intervention acceptable to key stakeholders?</td>
<td>○ No ○ Probably no ○ Probably yes ● Yes ○ Varies ○ Don’t know</td>
</tr>
<tr>
<td>The evidence base in COPD and ILD includes multiple qualitative studies which suggest that early and integrated approach to providing a palliative care approach is acceptable to people with COPD, informal caregivers, and professionals (for example, Broese 2021 COPD 1). Other specific examples in COPD include: ‘Continuity of care, high quality communication and feeling cared for were greatly valued’, COPD 32  ‘People with COPD and informal caregivers valued continuity of care, integrated working and a relationship with a skilled named professional’, COPD 28  ‘Participants most appreciated the information learned and the openness and opportunity to share’, COPD 24  In the context of ILD: ‘Practical care planning was appreciated by people with ILD, as well as discussing existential topics’, ILD 8  ‘Web-based ACP was acceptable and useful’, ILD 7</td>
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</tbody>
</table>
How to implement palliative care with routine clinical care for people with COPD and ILD and their informal caregivers?

<table>
<thead>
<tr>
<th>TYPE OF RECOMMENDATION</th>
<th>Strong recommendation against the intervention</th>
<th>Conditional recommendation against the intervention</th>
<th>Conditional recommendation for either the intervention or the alternative</th>
<th>Conditional recommendation for the intervention</th>
<th>Strong recommendation for the intervention</th>
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**Recommendation**

We suggest, with regard to people with COPD or ILD and their informal caregivers, services should:
- integrate palliative care into routine care, explicitly recognising active disease management and palliation as complementary;
- provide accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual/existential needs;
- embed a system within an extended multidisciplinary team where people with COPD or ILD and persistent, unmet palliative care needs have access to specialist palliative care support;
- foster relationships with trusted healthcare professionals enabling continuity of care;
- recognise that initiating ACP conversations is challenging, and multi-disciplinary services should prioritise training, clarify responsibilities, and ensure capacity to offer timely ACP, with preferences checked as circumstances change.

**Justification**

Whilst the lack of rigorous RCTs mean that the certainty of evidence is graded as ‘low’, the consistency of the findings across multiple studies with a broad range of methodologies is striking. Our recommendations build on the key emerging themes from this narrative synthesis.

**Subgroup considerations**

Our assumption was that COPD and ILD had very different trajectories and might require different palliative care approaches; we therefore synthesised the studies in these two areas separately. In the event, the key themes were consistent across the two disease areas and we have combined the summary schema and recommendations. There is, however, a much larger evidence base for COPD than ILD, and it may be that as new evidence emerges on ILD some differences may appear. One specific area in which ILD literature is stronger is in structured approaches to needs assessment and provision of integrated care.

**Implementation consideration**

A multi-level, systematic approach is required, where challenges affecting all stakeholders can be addressed. Our recommendations resonate with a whole systems approach to implementation of palliative care integrated with, and complementary to, the routine care of people with COPD or ILD. The recommendations include strategies to meet the needs of people with COPD or ILD, provide professionals with the necessary skills and expertise, and to prioritise organisational arrangements that can provide the time, resources and clinical pathways that are pre-requisites of a multidisciplinary integrated service.

**Monitoring and evaluation**

There is a very broad evidence base, especially in COPD, but there is an urgent need for rigorously designed evaluation - ideally RCTs for highest quality evidence - though other approaches may be needed for practical or ethical reasons.

**Research priorities**

Recommen_dations for research
- Research is needed to inform service delivery, specifically implementation of models that integrate palliative care approach into routine care of people with COPD or ILD
- Holistic needs assessment tools have been validated, but need evaluation in clinical practice
Initiating discussions about prognosis and ACP remain a major barrier to provision of palliative care and interventions need to be developed and evaluated.

References for Evidence to decision framework for question 7 - COPD


33. Tavares N, Hunt KJ, Jarrett N, Wilkinson TM. The preferences of patients with chronic obstructive pulmonary disease are to discuss palliative care plans with familiar respiratory clinicians, but to delay conversations until their condition deteriorates: A study guided by interpretative phenomenological analysis. *Palliat Med* 2020;34:1361-73


39. Fairlamb HJ, Murtagh FE. Health professionals’ perceptions of palliative care for end-stage cardiac and respiratory conditions: a qualitative interview study. *BMC Palliat Care* 2021;20:1-10


41. Gardener AC, Ewing G, Farquhar M. Enabling patients with advanced chronic obstructive pulmonary disease to identify and express their support needs to health care professionals: a qualitative study to develop a tool. *Palliat Med* 2019;33:663-75


43. Green E, Shaw SE, Harris T. ‘They shouldn't be coming to the ED, should they?’ A qualitative study of why patients with palliative care needs present to the emergency department. *BMJ Support Palliat Care* 2019;9:e29


45. Hyde KF, Coats HL, Meek PM. Home-Based Palliative Care: Perspectives of Chronic Obstructive Pulmonary Disease Patients and Their Caregivers. Chronic Obstructive Pulmonary Diseases: *J COPD Foundation* 2020;7:327


References for Evidence to decision framework for question 7 - ILD

1. Igai Y. A narrative literature review of palliative care regarding patients with idiopathic pulmonary fibrosis. Nursing Open 2018;5:536-45


Evidence to decision framework for question 8
How do we implement ACP in routine clinical care for people with COPD and ILD?

<table>
<thead>
<tr>
<th>Domain</th>
<th>Judgement</th>
<th>Research evidence</th>
<th>Additional considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Priority</td>
<td>Is the problem a priority?</td>
<td>ACP COPD HCPs were described as having a 'dilemma'. Almost all the papers highlight that HCPs acknowledge the importance of ACP discussions but are unsure when, and how, to start the conversation. HCPs are aware that some people with COPD do not want to discuss prognosis, and are afraid of destroying hope by opening a discussion. As a result, ACP conversations are rarely initiated by HCPs with many professionals stating that they prefer people with COPD to initiate the discussion, which also rarely happens. Overcoming this block is arguably the biggest challenge for providing people with COPD with the benefits of a palliative care approach. Summary: Aligned with the difficulty identifying the optimal moment for referral to specialist palliative care services, clinicians find it difficult to find the ‘right’ moment to initiate ACP conversations. The result is that for many people the conversations are delayed until a crisis intervenes.</td>
<td>ACP is recognised as an integral part of palliative care and end-of-life discussions about goals of care are encouraged. However, difficulties initiating ACP conversations mean that too often ACP happens late, or not at all. i. Selecky et al. Chest 2005;128:3599–610 ii. Jabbarian et al. Thorax 2018;73:222-30</td>
</tr>
<tr>
<td>Certainty of evidence</td>
<td>What is the overall certainty of the evidence of effects?</td>
<td>The evidence-base for COPD represents data from 225 original studies (13 systematic reviews reporting 175 original papers, plus 46 primary studies not included in the systematic reviews). The evidence-base for ILD is considerably smaller representing data from 56 original studies (4 systematic reviews reporting 46 original papers, plus 10 primary studies not included in the systematic reviews). COPD</td>
<td>In contrast to the lack of RCTs of implementation strategies or models of integrated palliative care, there are trials of ACP for people with non-malignant lung disease (as distinct from full palliative care services), reported in our included SRs. The GOLD Global COPD Guidelines is cautiously supportive of specialist palliative care (and more specifically ACP) in theory, but does not support any evidence to support effectiveness.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>COPD The SRs reported a few RCTs: • Broese 2021 (1 RCT of a palliative care service in generic ‘advanced disease’; 2 RCTs specifically of a breathlessness service; and 4 pilot RCTs) • Disler 2012 (1 RCT that showed ACP improved adherence to EoL wishes) • Fusi-Schmidhauser 2019 (1 RCT of a palliative care service in generic ‘advanced disease’; and 1 RCT of specifically of a breathlessness service) • Meehan 2020 (4 RCTs specifically of ACP that showed improved use of ACP)</td>
<td></td>
</tr>
</tbody>
</table>

COPD: Clinical Outcomes of Preventive Drugs
ILD: Interstitial Lung Disease
• Ora 2019\textsuperscript{COPD 10} (2 RCTs of nurse-led care improved use of ACP; 2 pilot trials);
• Singer 2016\textsuperscript{COPD 11} (19 highly heterogenous RCTs, 11 showed benefit on 'one or more patient reported outcome'. Very little data presented in the SR, but the conclusion is: ‘Strongest evidence is for the roles of nurses and social workers and home-based multidisciplinary approaches in improving use of ACP, psychosocial health with weaker evidence for health outcome’)

The other studies are observational, qualitative, mixed methods before and after studies, cohort and cross-sectional studies. Whilst not high-quality evidence, what is striking is the consistency of the findings across multiple studies with a broad range of methodologies.

ILD
None of the SRs or primary studies reported any RCTs of palliative care interventions (as opposed to trials of specific components such as breathlessness interventions).

### Current practice

**Advance Care Planning: COPD**

ACP was described by all the papers as central to a palliative care approach whether incorporated by the people with COPD\textsuperscript{'} usual respiratory/general healthcare professional or following referral to specialist palliative care.\textsuperscript{COPD 3,5,36,39,45,53} Decisions regarding wishes of people with COPD for end-of-life management (e.g. ventilation, resuscitation) balanced the individual’s prognostic awareness, illness burden, and existential concerns.\textsuperscript{COPD 28} Systematic provision of ACP improved involvement in the treatment decisions made,\textsuperscript{COPD 1,2} and recording wishes of people with COPD,\textsuperscript{COPD 1} though with the caveat that pre-stated wishes could change in the acute situation,\textsuperscript{COPD 10,58} and were not always respected.\textsuperscript{COPD 28} Benefits of ACP included a positive impact on perceived control,\textsuperscript{COPD 1,2} and confidence in self-managing symptoms,\textsuperscript{COPD 1} though health outcomes such as unscheduled care and quality of life showed variable outcomes.\textsuperscript{COPD 1,31}

ACP should be started early,\textsuperscript{COPD 2,13,39} and incorporated into routine COPD care.\textsuperscript{COPD 6,30,55} Organisational barriers to delivering ACP include lack of time and capacity,\textsuperscript{COPD 4,12,13,33,39} and lack of clarity on who is responsible for initiating ACP conversations.\textsuperscript{COPD 4,6,7,12} A significant minority of people with COPD avoid discussion about prognosis,\textsuperscript{COPD 2,4,5,7} and even if they

The US National Academy of Medicine define advance care planning (ACP) as: ‘the whole process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders. This process can start at any time and be revisited periodically, but it becomes more focused as health status changes. Ideally, these conversations (1) occur with a person’s healthcare agent and primary clinician, along with other members of the clinical team; (2) are recorded and updated as needed; and (3) allow for flexible decision making in the context of the current medical situation’.\textsuperscript{i}
want information rarely initiate the conversation.\textsuperscript{COPD 12,50} Group sessions (e.g. within a pulmonary rehabilitation course \textsuperscript{COPD 10,24}) may have some advantages for broaching discussions as they were often perceived as less threatening than individual discussions.\textsuperscript{COPD 10,24,56} The identification of triggers (such as repeated need for acute care) that might indicate appropriate timing,\textsuperscript{COPD 4,6,33} and repeating offers of ACP discussions as preferences may change after such events.\textsuperscript{COPD 7,10,12} Use of technology (e.g. a Web-based ACP tool for lung disease) was potentially useful and acceptable.\textsuperscript{COPD 5,58}

**Advance Care Planning: ILD**

The findings from the studies in COPD (see main text and on-line Supplement 4) were mirrored in the ILD literature.\textsuperscript{ILD 1-3,11} Planning for palliation at an early stage of the disease, with a systematic approach to conversations about disease progression, improving communication about end-of-life needs help people with COPD or ILD and caregivers manage the uncertainty of illness.

Systematic provision of ACP enabled practical planning for future needs and palliation,\textsuperscript{ILD 1,8,11} as well as discussions about existential topics.\textsuperscript{ILD 8,12} Use of technology (e.g. an interactive web-based ACP tool for lung disease which included videos of clinical scenarios and narratives of people with ILD \textsuperscript{ILD 7}) was potentially useful and acceptable, in part because it could be completed at home with loved ones.\textsuperscript{ILD 7}

ACP should be started early,\textsuperscript{ILD 1,3,10} and not restricted to those nearing the end of life.\textsuperscript{ILD 3} Although most people with ILD wanted an honest discussion about prognosis,\textsuperscript{ILD 1,4} HCPs often had concerns about the starting of ACP discussion,\textsuperscript{ILD 3,8} expressing fears about destroying hope.\textsuperscript{ILD 8} Studies adopted different approaches to facilitating ACP: for example, embedded with a structured process of needs assessment\textsuperscript{ILD 9,11,12} or triggered by a specific event such an admission,\textsuperscript{ILD 5} the need for specific treatment,\textsuperscript{ILD 2,3} or following a multidisciplinary team discussion.\textsuperscript{ILD 6} Pulmonary rehabilitation was perceived by people with ILD as an ‘ideal’ context for broaching discussions they were clinically stable at the time and felt more able to understand and take decisions compared to when they were acutely unwell.\textsuperscript{ILD 4} Almost all the studies explicitly stated the need for training in ACP for professionals within the multidisciplinary team,\textsuperscript{ILD 1,3,13} or highlighted a lack of professional skills and confidence as a barrier.\textsuperscript{ILD 8}
<table>
<thead>
<tr>
<th>Values</th>
<th>Communication – COPD</th>
<th>Communication - ILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there important uncertainty about or variability in how much people value the main outcomes?</td>
<td>In the context of a condition with poor public understanding, people with COPD often lacked insight into the likely prognosis of their disease, and informal caregivers were unprepared for the death. A core function of ACP is to meet information needs, recognising that needs of people with ILD and their informal caregivers may be different, and careful discussion may be needed to identify preferences.</td>
<td>Perceived benefits of ACP included improved communication and involvement in the treatment decisions made, which reduced uncertainty for people with ILD and their informal caregivers. A multidisciplinary initiative that increased provision of ACP discussions reduced anxiety as medical and financial plans place were in place. Preferences for place of death were more likely to be recorded, with some evidence that concordance with these wishes increased. A core function of ACP is to meet information needs, recognising that needs of people with ILD and informal caregivers and coping strategies may be different.</td>
</tr>
<tr>
<td>• Important uncertainty or variability</td>
<td>Echoing the call for continuity of care, a recurring theme was that ACP discussions were best delivered in the context of a good relationship with a trusted professional. Almost all the studies emphasised the need for training in ACP for respiratory specialists and primary care professionals, specifically including recognising (and responding to) appropriate timing for ACP, and developing advanced communication skills. The legal context and place of advance directives was highlighted in one paper.</td>
<td>The data were synthesised initially by disease, on the assumption that two respiratory diseases with such different trajectories might require different approaches. In the event, the themes that emerged were similar so that overarching conclusions can be drawn.</td>
</tr>
<tr>
<td>• Possibly no important uncertainty or variability</td>
<td>• Communication is pivotal for people with COP or ILD/ informal caregivers (including ACP) and their healthcare professionals, but also between professionals within the team. It follows that communication-skills training is a pre-requisite of introducing a palliative care service.</td>
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</tr>
<tr>
<td>• Not important uncertainty or variability</td>
<td>In both diseases the need for a structured needs assessment at diagnosis (in the typically rapidly progressive ILD) or onset of troublesome symptoms (in the slowly progressive COPD) and reviewed as the disease deteriorates.</td>
<td>In both diseases the need for a structured needs assessment at diagnosis (in the typically rapidly progressive ILD) or onset of troublesome symptoms (in the slowly progressive COPD) and reviewed as the disease deteriorates.</td>
</tr>
<tr>
<td>• No known undesirable outcomes</td>
<td>Views of representatives of people with COPD or ILD and informal caregivers: Need for individualized ACP, both in regard to when to talk and what to talk about. But important to discuss these topics before someone gets too ill to talk about these things. But not at diagnosis stage – this is too early.</td>
<td>Views of representatives of people with COPD or ILD and informal caregivers: Need for individualized ACP, both in regard to when to talk and what to talk about. But important to discuss these topics before someone gets too ill to talk about these things. But not at diagnosis stage – this is too early.</td>
</tr>
<tr>
<td>Benefits and harms</td>
<td>Limited quantitative evidence</td>
<td></td>
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<tr>
<td>-------------------</td>
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</tr>
<tr>
<td>How substantial are the benefits of the intervention compared to harms?</td>
<td>Although there is limited RCT evidence specifically for ACP in COPD, there is some relevant evidence in populations that included people with COPD.</td>
<td></td>
</tr>
<tr>
<td>○ Trivial</td>
<td><strong>Houben 2019; COPD 163</strong> <em>Cluster RCT of delivering ACP in COPD.</em> (Cluster=29 HCPs; people with COPD n=165+196 caregivers). The intervention improved occurrence of ACP; improved quality of EoL communication (p&lt;0.001); and reduced anxiety in informal caregivers.</td>
<td>Delivery of palliative care is inextricably linked to provision of ACP. Additional themes related to palliative care (see Q7) are:</td>
</tr>
<tr>
<td>○ Small</td>
<td><strong>Detering 2010; COPD 106</strong> <em>RCT of ACP in elderly.</em> (n=309; 97 of whom had respiratory disease. 56 of the participants died during the trial). EoL wishes were more likely to be known and followed in the intervention group (25/29, 86%) compared with control group (8/27, 30%; P&lt;0.001). ACP reduced caregivers’ stress, anxiety and depression, and improved satisfaction.</td>
<td>• Palliative care and routine COPD and ILD disease management are complementary.</td>
</tr>
<tr>
<td>○ Moderate</td>
<td><strong>Sinclair 2017; COPD 31, 224</strong> <em>RCT of ACP in severe respiratory disease</em> (n=149 of which 40 had COPD and 4 had ILD). The intervention increased uptake of ACP, and communication with ACPs, but had no effect on health-related quality of life, 12-month mortality or satisfaction with health care, though clinic attendances (but not admissions or home nursing) were reduced.</td>
<td>• Models of integrated care vary according to the healthcare context, but a key feature is flexible responsive working within an extended multidisciplinary team where people with persistent/unmet palliative care needs have access to specialist palliative care support.</td>
</tr>
<tr>
<td>○ Large</td>
<td><strong>Thoonsen 2015; COPD 238</strong> <em>Cluster RCT of training GPs to deliver ACP in severe disease</em> (Cluster = 159 GPs; people with illness n=487 of whom 46 had COPD). The intervention had no impact on out of hours or other health service use.</td>
<td>• Accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual needs is a crucial first step in providing supportive and palliative care. In COPD increasing disability, or events such as admissions, or commencing LTOT should trigger an</td>
</tr>
<tr>
<td>○ Varies</td>
<td><em>Qualitative synthesis</em> There are some key themes that emerge consistently from the broad range of included studies in both COPD and ILD:</td>
<td></td>
</tr>
<tr>
<td>● Don’t know</td>
<td>• Initiating ACP conversations is challenging, and is too often delayed the because the uncertain disease trajectory (especially in COPD) can lead to hesitancy on the part of healthcare professionals to consider a palliative care approach. Services should prioritise training for professionals, and clarify who within the multi-disciplinary team is responsible for (and has the allocated time to deliver) offering timely ACP, and checking preferences as circumstances change.</td>
<td></td>
</tr>
</tbody>
</table>

Detering 2010: COPD 106

RCT of ACP in elderly. (n=309; 97 of whom had respiratory disease. 56 of the participants died during the trial). EoL wishes were more likely to be known and followed in the intervention group (25/29, 86%) compared with control group (8/27, 30%; P<0.001). ACP reduced caregivers’ stress, anxiety and depression, and improved satisfaction.

Sinclair 2017; COPD 31, 224

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Thoonsen 2015; COPD 238

Cluster RCT of training GPs to deliver ACP in severe disease (Cluster = 159 GPs; people with illness n=487 of whom 46 had COPD). The intervention had no impact on out of hours or other health service use.
<table>
<thead>
<tr>
<th><strong>Equity</strong></th>
<th><strong>What would be the impact on health equity?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reduced</strong></td>
<td>None of the studies explicitly addressed the issue of equity, though there is widespread concern that people with life-limiting non-malignant disease (such as COPD and ILD) do not have access to the palliative care services available for people with cancer. In addition, COPD is strongly associated with deprivation which will further exacerbate inequities. Provision of ACP is typically embedded with a palliative care approach, so reducing inequities for access to ACP requires consideration of models of care for palliative care.</td>
</tr>
<tr>
<td><strong>Increased</strong></td>
<td>Integrating palliative care with respiratory management: COPD. In a condition in which a fluctuating but slowly progressive trajectory makes prognosis uncertain and clinicians struggle to identify the point at which to involve palliative care,(^1) several studies addressed service models in which palliative care was seamlessly integrated into the routine care of COPD, whether that be with respiratory specialists, primary care generalists, or community respiratory teams.(^2) A key advantage was facilitating early provision of holistic care, specifically including early discussions of prognosis and ACP.(^3) One study exploring perceptions of people with COPD and their informal caregivers suggested that a palliative care approach should be considered when the COPD was of moderate severity,(^4) recognising that active disease management and palliation are complementary in a lifelong condition.(^5) <strong>Summary:</strong> Initiatives that integrate a palliative care approach with routine clinical care of COPD or ILD, have the potential to improve equity by facilitating early referral and assessment; in more the rapidly progressive ILDs assessments should be considered early after the diagnosis is made.</td>
</tr>
<tr>
<td><strong>Variates</strong></td>
<td>Palliative care is explicitly recognised by the World Health Organisation within the Human Rights to Health.(^6) Systematic needs assessment to identify unmet palliative care needs for people with COPD and ILD would trigger the necessary referral to both general and specialist palliative care. This would redress the current major inequity in access to palliative care experienced by people with COPD and ILD irrespective of socio-economic status. Further, systematic identification and referral (needs-based) may also help address the known inequities of accessing palliative care for older people, more deprived, and ethnic minorities.</td>
</tr>
<tr>
<td><strong>Don't know</strong></td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Is the intervention acceptable to key stakeholders? | The evidence base in COPD and ILD includes multiple qualitative studies which suggest that early and integrated approach to providing a palliative care approach (including ACP) is acceptable to people with COPD, informal caregivers, and professionals (for example, Broese 2021 [COPD 1]). Other specific examples in COPD include: ‘Continuity of care, high quality communication and feeling cared for were greatly valued’. [COPD 28] ‘People with COPD and informal caregivers valued continuity of care, integrated working and a relationship with a skilled named professional’. [COPD 28] ‘Participants most appreciated the information learned and the openness and opportunity to share’. [COPD 24] In the context of ILD: ‘Practical care planning was appreciated by people with ILD, as well as discussing existential topics’. [ILD 8] ‘Web-based ACP was acceptable and useful’. [ILD 7] | An overview of ACP in multiple disease areas' that synthesised the findings of 80 SRs (n=1660 original articles) concluded that:  
- Legislations, institutional policies, and cultural factors influence ACP development.  
- Many factors related to attitudes of people with illness and providers, and perceptions toward life and mortality influence ACP implementation, decision making, and completion.  
- Limited, low-quality evidence points to several ACP benefits, such as improved end-of-life communication, documentation of care preferences, dying in preferred place, and health care savings.  
- Recurring features that make ACP programs effective include repeated and interactive discussion sessions, decision aids, and interventions targeting multiple stakeholders.  

How do we implement ACP in routine clinical care for people with COPD and ILD?

<table>
<thead>
<tr>
<th>TYPE OF RECOMMENDATION</th>
<th>Strong recommendation against the intervention</th>
<th>Conditional recommendation against the intervention</th>
<th>Conditional recommendation for either the intervention or the alternative</th>
<th>Conditional recommendation for the intervention</th>
<th>Strong recommendation for the intervention</th>
</tr>
</thead>
</table>

**Recommendation**

We suggest, with regard to people with COPD or ILD and their informal caregivers, services should:

- Integrate palliative care into routine care, explicitly recognising active disease management and palliation as complementary;
- Provide accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual/existential needs;
- Embed a system within an extended multidisciplinary team where people with COPD or ILD and persistent, unmet palliative care needs have access to specialist palliative care support;
- Foster relationships with trusted healthcare professionals enabling continuity of care;
- Recognise that initiating ACP conversations is challenging, and multi-disciplinary services should prioritise training, clarify responsibilities, and ensure capacity to offer timely ACP, with preferences checked as circumstances change.

**Justification**

Whilst the paucity of rigorous RCTs mean that the certainty of evidence is graded as ‘low’, the consistency of the findings across multiple studies with a broad range of methodologies is striking. Our recommendations build on the key emerging themes from this narrative synthesis and, because ACP is not delivered in isolation; we have embedded the recommendation about ACP in the recommendations from Q7.

**Subgroup considerations**

Our assumption was that COPD and ILD had very different trajectories and might require different palliative care approaches; we therefore synthesised the studies in these two areas separately. In the event, the key themes were consistent across the two disease areas and are likely to need ACP as part of a general palliative approach from soon after, if not from, diagnosis.

**Implementation consideration**

A multi-level, systematic approach is required, where challenges affecting all stakeholders can be addressed. Our recommendations resonate with a whole systems approach to implementation of palliative care complementary to the routine care of people with COPD or ILD. The recommendations include strategies to meet the needs of people with COPD or ILD, provide professionals with the necessary skills and expertise, and to prioritise organisational arrangements that can provide the time, resources and clinical pathways that are pre-requisites of a multidisciplinary integrated service.

**Monitoring and evaluation**

The following should be evaluated and monitored regarding ACP: i) process outcomes such as proportion of people with COPD or ILD with ACP documentation communicated and available across health care settings, proportion of staff trained in ACP delivery/communication skills training, referrals to specialist palliative care; ii) clinical outcomes such as place of care/death and proportion with inappropriate interventions such as CPR; iii) experience of people with COPD or ILD and family.

**Research priorities**

*Recommendations for research*

- Research is needed to inform service delivery, specifically implementation of models that integrate palliative care approach into routine care of people with COPD or ILD
- Holistic needs assessment tools have been validated, but need evaluation in clinical practice
Initiating discussions about prognosis and ACP remain a major barrier to provision of palliative care and interventions need to be developed and evaluated.
References for Evidence to decision framework for question 8 - COPD


33. Tavares N, Hunt KJ, Jarrett N, Wilkinson TM. The preferences of patients with chronic obstructive pulmonary disease are to discuss palliative care plans with familiar respiratory clinicians, but to delay conversations until their condition deteriorates: A study guided by interpretative phenomenological analysis. *Palliat Med* 2020;34:1361-73


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References for Evidence to decision framework for question 8 - ILD
1. Igai Y. A narrative literature review of palliative care regarding patients with idiopathic pulmonary fibrosis. Nursing Open 2018;5:536-45


Online supplement 4

European Respiratory Society clinical practice guideline:
Palliative care for people with chronic obstructive pulmonary disease or interstitial lung disease

Methods and findings for Q7 and 8 (COPD)

<table>
<thead>
<tr>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q7</td>
</tr>
<tr>
<td>Q8</td>
</tr>
</tbody>
</table>

Methods

The same methods were used for Q7 and 8 (COPD) and Q7 and 8 (ILD). Although the searches were undertaken separately, it was clear that there was considerable overlap in the papers identified, the themes described and the conclusions reached. Most papers about palliative care included ACP as a core component, and most papers investigating ACP commented on the palliative care context in which discussions occurred. We therefore opted to combine the data extracted from questions 7 and 8 into a single table, PRISMA diagram and summary text. (e-Figure 8. PRISMA diagram)

Search strategy, selection of papers for inclusion and data extraction.

From the list of 108 titles and abstracts, we initially identified 27 systematic reviews that had comparable aims and objectives to our questions. Fourteen were not relevant on full text screening; see Additional Table COPD-A1 (Additional tables are below summary text) for reasons for exclusion. We extracted the key themes from the remaining 13 papers (Table COPD-1) to answer the questions about implementation including referral processes, models of care and components (Q7) and specifically Advance Care Planning (ACP) (Q8). We then developed a preliminary schema which summarised the themes using a whole systems approach, illustrating person with COPD, professional and organisational features that were identified as ‘needed’ by any of the person with COPD, informal caregiver or professional stakeholders.

We assessed the overlap of the papers included in the 13 systematic reviews (See Additional Table COPD-A2) which include 175 unique papers. From title and abstract screening of our searches, plus three additional papers suggested by the study team, we identified 161 potentially relevant primary papers, of which 98 were not included in the systematic reviews. The full text of these were read and classified as:

- Adding novel insights not identified in the systematic reviews: data extracted and studies added to Table COPD-2 (n=21)
- Corroborating existing themes: themes summarised in Table COPD-3 (n=25)
- Not relevant to our questions: paper excluded (Additional Table COPD-A3 lists reasons for exclusion) (n=52)
The new themes were used to refine the schema. (Figure 1)

*Update searches*

The search was updated in April 2022. Of 22 systematic reviews identified in the update search, none were included in the COPD synthesis. These are listed in Additional Table COPD-A34.

*Framework for synthesis*

We used a whole systems approach as a framework for analysis, relating the findings of included papers to the needs of people with COPD, professional requirements and service organisation. In addition, we looked for evidence on timing of palliative care involvement, referral criteria and processes of assessment as a specific component of the patient journey. Finally, to address Q8, we specifically synthesised data on ACP and the related theme of communication.

*Structure of reporting synthesis*

In the report below we first provide the summary tables of included systematic reviews, and original papers (Tables COPD-1, COPD-2, and COPD-3), then provide a synthesis of the findings in text. Figure COPD-2 summarises the key themes in a schema.

Excluded papers with reasons for exclusion are in Additional Tables COPD-A1, A2, A3, A4.
### Table COPD-1: Themes from COPD systematic reviews

<table>
<thead>
<tr>
<th>Systematic review (listed alphabetically)</th>
<th>Triggers that initiate palliative care involvement</th>
<th>Barriers to referral</th>
<th>Needs assessment</th>
<th>PATIENTS Perceptions and goals of care</th>
<th>PROFESSIONAL Staff training and composition</th>
<th>ORGANISATION Place/sector and model of care</th>
<th>Barriers to provision of palliative care</th>
<th>Communication</th>
<th>Q8: Advance care planning (ACP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broese 20211</td>
<td>• Hospitalisation for acute exacerbation</td>
<td>Barriers: Relies on</td>
<td>For this vulnerable</td>
<td>Acceptability of the palliative care</td>
<td>Multidisciplinary interventions</td>
<td>Multicomponent interventions</td>
<td>Most frequently named barriers</td>
<td>Components of the interventions that were highly valued</td>
<td>Positive effects were found on outcomes related to ACP and perceived symptom control and self-management, but not on health outcomes</td>
</tr>
<tr>
<td>Mixed methods narrative review</td>
<td>• Severe reduction in lung function</td>
<td>being referred by HCPs.</td>
<td>patient group care needs to be easily accessible (e.g. assessments during home visits and monitoring needs by phone).</td>
<td>but often led by a specialist nurse.</td>
<td>(short or long-term) typically community-based</td>
<td>with palliative care specialists involved when needed.</td>
<td>were uncertainty about the timing of referral due to the unpredictable disease trajectory (referrers), time availability (providers) and accessibility (patients).</td>
<td>should be ACP choices for patients who are nearing the final stages of life, and need for greater communication around disease trajectory, prognosis and what to expect when nearing the final stages of life.</td>
<td>ACP engages patients in decision making, improves sense of control in preparation for end-of-life, and prepares family for final stages of the disease. Providers acknowledge the need for timely ACP, however few initiate such discussions</td>
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<tr>
<td>31 papers (20 interventions) including 4 RCTs</td>
<td>• Functional limitation</td>
<td></td>
<td>Proactively identified by screening during hospitalization for acute exacerbation or by using a computerized screening program based on diagnosis + hospitalizations or measures of disease severity.</td>
<td>Multidisciplinary approach was high among patients, informal caregivers and healthcare professionals. Quant/qual data suggest positive effects related to symptom control, self-management and self-confidence.</td>
<td>One study used telemonitoring</td>
<td>Components are COPD-specific and with sufficient training could be integrated into regular COPD-care</td>
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<tr>
<td>To review multi-component palliative care interventions targeting patients with advanced COPD and their informal caregivers. [Framework ‘referrers, providers and patients’]</td>
<td>• Oxygen therapy</td>
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<td>Disler 20122</td>
<td>• Depression</td>
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<td>Multidisciplinary in order to offer both pharmacological and non-pharmacological treatment.</td>
<td>The fluctuating COPD trajectory can make the application of a palliative model difficult.</td>
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<tr>
<td>Integrative review 118 papers, 25 RCTs, 19 qual, 21 reviews</td>
<td>• Poor nutrition</td>
<td></td>
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<td>Relationships with HCPs with specialist knowledge provide emotional support and a source of reliable information</td>
<td>Difficulty in estimating the terminal phase of COPD and lack of communication around end-of-life planning has been a well-documented barrier</td>
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<tr>
<td>Aim: To review interventions to support a palliative care approach in patients with end-stage COPD [Framework: ‘personal, provider and system’]</td>
<td>• Comorbidities</td>
<td></td>
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<td>Community nurses are skills based</td>
<td>Lack of research</td>
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<td></td>
<td>• Surprise question</td>
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<td>A flexible system allows active management to be combined with planning for the final stages of life and encourages collaboration across health services and specialties</td>
<td>Timely ACP engages patients in decision making, improves sense of control in preparation for end-of-life, and prepares family for final stages of the disease. Providers acknowledge the need for timely ACP, however few initiate such discussions</td>
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<td></td>
<td>The progressive deterioration, punctuated with potentially fatal deteriorations</td>
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<td>Evidence exists for discrete elements of palliative management in COPD, but there is limited evidence</td>
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<td></td>
<td>Patients have a variety of needs (symptom management, psychological and social issues, communication) which would be appropriate for a palliative care approach</td>
<td></td>
<td>A comprehensive approach is required to address the complex and varied needs of individuals with end-stage COPD and their families.</td>
<td>A collaborative palliative care approach would assist patients in utilising supports and interventions that enable them to balance the demands of their disease while</td>
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<td></td>
<td>Advance care planning should be commenced early to ensure care is commensurate with individuals’ needs</td>
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**Notes:**
- RCTs: Randomized Controlled Trials
- ACP: Advance Care Planning
<table>
<thead>
<tr>
<th>Systematic review (listed alphabetically)</th>
<th>Needs assessment</th>
<th>PATIENTS Perceptions and goals of care</th>
<th>PROFESSIONAL Staff training and composition</th>
<th>ORGANISATION Place/sector and model of care Outcomes</th>
<th>Barriers to provision of palliative care</th>
<th>Communication</th>
<th>Q8: Advance care planning (ACP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>elements’ to achieve healthcare reform]</td>
<td>decreases providers’ confidence in the appropriate timing of referral of patients to palliative care</td>
<td>maximising involvement and enjoyment in pursuits that give them pleasure</td>
<td>Training is required to support providers in commencing ACP discussions.</td>
<td>for models that integrate the multiple domains of palliative care with active management.</td>
<td>Some patients and HCPs actively avoid discussions around death</td>
<td>Improving providers’ confidence in initiating end-of-life discussions, would assist in implementing ACP</td>
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<tr>
<td>Fusi-Schmidhauser 2019³</td>
<td>Holistic assessment of needs.</td>
<td>Four aspects: patients’ and caregivers’ needs, awareness of palliative care provision in COPD, importance of continuity of care and need for an organisational change for care integration. Patient organisations need to increase awareness about right to palliative care for advanced COPD.</td>
<td>Trained multidisciplinary palliative care team. Skilled primary care teams can deliver high-quality palliative care; with specialist consultations as needed. Focused education and training on communication skills for HCPs who are involved with advanced COPD.</td>
<td>Solo practice: GP/specialist provides all care</td>
<td>Disease unpredictability Misconception about palliative care being only for cancer and only relevant in the last days of life</td>
<td>Advance care planning is a core component of integrated care</td>
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<tr>
<td>Jabbarian 2018⁴</td>
<td>Providing patients with information about their disease can help meet their needs.</td>
<td>Training and professional experience of end-of-life in CRD</td>
<td>Identification of trigger points, and clarity on whose responsibility it is to initiate discussions could facilitate ACP</td>
<td>Complex disease course of CRD and ambivalence of both patients and HCPs to engage in ACP</td>
<td>Lack of time Lack of continuity</td>
<td>ACP is uncommon in CRD.</td>
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<tr>
<td>Mathews 2017⁵</td>
<td>The fluctuating and unpredictable nature of CRD suggests the benefits of ongoing</td>
<td>Care interventions need to be based on patient preferences rather</td>
<td>Treatment optimisation (drug and rehabilitation)</td>
<td>Holistic care across physical, psychological and spiritual domains</td>
<td>Uncertain disease trajectory and timing of intervention.</td>
<td>Positive (lay) communication improve patient understanding</td>
<td>Key conversations to establish personal preferences and</td>
</tr>
<tr>
<td>Systematic review (listed alphabetically)</td>
<td>Triggers that initiate palliative care involvement Barriers to referral</td>
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<tr>
<td>To explore patient and family/carer perspectives on key issues for ensuring quality of end of life care for people with COPD.</td>
<td>holistic assessment commenced at an earlier stage in the disease trajectory entry points for conducting holistic needs assessment</td>
<td>than professionally driven Regular attention to the particular needs of family caregivers improves clinical outcomes</td>
<td>Better case management to help families prepare for uncertainty</td>
<td>Patients avoid discussing prognosis Lack of congruence between patient/carers perspectives and HCPs left areas of unmet need Lack of research</td>
<td>Use of technology (e.g. a Web-based ACP tool for lung disease) was potentially useful and acceptable.</td>
<td>timely information on COPD was a recurrent theme</td>
<td></td>
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<tr>
<td>Meehan 2020⁶</td>
<td>Repeated episodes of acute care was identified as a key transition point for identifying the time for palliative care and ACP.</td>
<td>Facilitators included an increased focus on ACP in professional education.</td>
<td>ACP should be incorporated into routine COPD management. Lack of protocols for who is responsible for initiating ACP is a barrier</td>
<td>Barriers included prognostic uncertainty, insufficient time.</td>
<td>ACP does not occur in everyday practice, with conversations focusing on day-to-day symptom management.</td>
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<td>Momen 2012⁷</td>
<td>Although a substantial minority of people with COPD do not want ACP conversations with their HCP, most do but are not being given the opportunity to have such a discussion</td>
<td>Adequate training and experience and specialist knowledge were seen as important. A good rapport with the patient facilitates discussion.</td>
<td>Barriers: uncertain prognosis; poor patient/public understanding of COPD; unclear who is responsible for ACP.</td>
<td>HCPs described as having a ‘dilemma’ – recognise the importance of ACP discussions but unsure when/how to start the conversation. Many prefer patients to initiate them.</td>
<td>HCPs need to respect the wishes of the substantial minority not wanting to discuss end-of-life care whilst providing multiple opportunities for those who do wish to have these discussions</td>
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<tr>
<td>Oishi 2014⁸</td>
<td>Barriers include unpredictable illness trajectory Patients and carers expect GPs to provide compassionate care, have appropriate knowledge and play central roles in providing care.</td>
<td>The roles of professionals are unclear to patients, carers and professionals themselves.</td>
<td>Continuity of care and willingness to spend time</td>
<td>Uncertainty of illness trajectory and lack of collaboration between HCPs were barriers to effective care.</td>
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<td>Systematic review (listed alphabetically)</td>
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<td>Ora 2019&lt;sup&gt;9&lt;/sup&gt;</td>
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<td>6 papers (4RCTs + 2 unpublished)</td>
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<td>Aim: To describe nurse-led models of integrated COPD palliative care</td>
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<tr>
<td>Nurse-led holistic assessment</td>
<td>Holistic care delivered more routinely throughout the life-long course of COPD was recommended</td>
<td>Two main types of nurse-led palliative care. Led by: • Specialist palliative care nurses • Palliative care trained specialist respiratory nurses</td>
<td>Nurse-led ACP intervention improved quality of patient–physician end-of-life care communication</td>
<td>ACP was main focus of nurse-led interventions – often with a trained respiratory specialist nurse increasing uptake of ACP</td>
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<td>Ora 2021&lt;sup&gt;10&lt;/sup&gt;</td>
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<td>7 papers</td>
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<tr>
<td>Aim: to understand COPD patients’ experiences of ACP</td>
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<td>Right timing varies for each individual, and views change over time</td>
<td>Patient readiness and willingness for ACP discussions (including after PR sessions)</td>
<td>For ACP to be practical it could be integrated into routine care so that patients’ personal values, life goals and preferences can be revisited as COPD progresses.</td>
<td>Patients needed rapport and open communication with a trusted health professional who knew them and had a good understanding of their illness.</td>
<td>Patients want HCPs to discuss their concerns for the future, and revisit previously stated preferences as they change over time.</td>
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<td>Singer 2016&lt;sup&gt;11&lt;/sup&gt;</td>
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<td>124 RCTs (19 in COPD)</td>
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<td>Aim: To inform payors/providers on identifying and managing advanced disease</td>
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<td>Determine patient preferences</td>
<td>Most services were home based. Strongest evidence for benefit was in cancer, CHF, and COPD.</td>
<td>Advanced nurse practitioners provided case management, treatment of symptoms and counselling</td>
<td>Nurse-led services, 26% including multidisciplinary teams</td>
<td>48% involved technology (e.g. telephone, and a few used video consulting). Reinforces a focus on improving communication and psychosocial support</td>
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<td>Stephen 2013&lt;sup&gt;12&lt;/sup&gt;</td>
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<td>14 papers (CRD but all included COPD)</td>
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<tr>
<td>Aim: highlight key challenges for conducting ACP in nonmalignant CRD</td>
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<td>Typically triggered by admission, provision of LTOT</td>
<td>Facilitators included trusting</td>
<td>Uncertain prognosis; unclear</td>
<td>Frequency and quality of palliative care</td>
<td>Patients and physicians identified many barriers and</td>
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<tr>
<td>Tavares 2017&lt;sup&gt;13&lt;/sup&gt;</td>
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<td>37 papers (14 quantitative; 11</td>
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<tr>
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<td>qualitative; 12 other)</td>
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<td>Q8: Advance care planning (ACP)</td>
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<tr>
<td>Aim: to explore palliative care conversations between clinicians and COPD patients.</td>
<td></td>
<td>patient/clinician relationship</td>
<td></td>
<td>point for starting discussion</td>
<td>care conversations is generally poor.</td>
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<td>Q8: Advance care planning (ACP)</td>
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<td>or deterioration in condition. Barriers included perception of palliative care as end of life</td>
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<td>Lack of time</td>
<td>When discussions did happen, they</td>
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<td>Q8: Advance care planning (ACP)</td>
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<td></td>
<td>Limited capacity of palliative care services</td>
<td>occurred at an advanced stage of illness and in acute wards and ICUs</td>
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<td>Q8: Advance care planning (ACP)</td>
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<td>important topics were not discussed.</td>
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<td>Q8: Advance care planning (ACP)</td>
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<td>Patients and clinicians reported tension between remaining hopeful and the reality of the condition.</td>
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<td>Q8: Advance care planning (ACP)</td>
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</table>

Abbreviations: ACP= Advance care planning; CRD=Chronic Respiratory Disease; GP= General Practitioner; HCP= healthcare professional; ICU= Intensive Care Unit.
<table>
<thead>
<tr>
<th>Original paper (listed alphabetically)</th>
<th>Themes or insights from original research not included in the systematic reviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ates 201814</td>
<td>survey and qualitative interviews with carers (31% COPD: 6 European countries)</td>
</tr>
<tr>
<td>Back 200915</td>
<td>serial qualitative interviews with 31 HCPs and 55 patients (half with COPD; US)</td>
</tr>
<tr>
<td>Carlucci 201616</td>
<td>prospective study of 43 patients’ preferences and outcomes</td>
</tr>
<tr>
<td>Crawford 201317</td>
<td>qualitative interviews with patients/carers + expert panel + focus groups. (COPD: Australia).</td>
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<td></td>
<td>Care was perceived as fragmented, episodic and reactive. The role of carers was poorly recognised.</td>
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<td></td>
<td>Multidisciplinary approach to disease management Recognition that active disease management and palliation are complementary, not mutually exclusive,</td>
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<td></td>
<td>Absence of a coordinated pathway for support</td>
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<td></td>
<td>Absence of ACP conversations.</td>
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<tr>
<td>Original paper (listed alphabetically)</td>
<td>• Triggers that initiate palliative care involvement</td>
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<tr>
<td>den Herder-van der Eerden 2017&lt;sup&gt;18&lt;/sup&gt; Longitudinal qualitative study with 152 patients and carers (24% COPD); 5 European countries</td>
<td></td>
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<tr>
<td>Fu 2021&lt;sup&gt;19&lt;/sup&gt; Qualitative interviews with 20 COPD patients, 6 carers, 25 HCPs</td>
<td>A standardized screening and needs assessment tool is required to improve timely palliative care</td>
</tr>
<tr>
<td>Fusi-Schmidhauser 2021&lt;sup&gt;20&lt;/sup&gt; COPD Participatory action research with key professional stakeholders</td>
<td>Focus on patients: Multidimensional needs’ assessment should consider: • patients’ needs • palliative care timing • identification of palliative care recipients</td>
</tr>
<tr>
<td>Gadoud 2020&lt;sup&gt;21&lt;/sup&gt; Sequential cross-sectional study of deceased adults (including COPD)</td>
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<tr>
<td>Gardener 2019&lt;sup&gt;a&lt;/sup&gt;&lt;sup&gt;22&lt;/sup&gt; Validation of a needs assessment for COPD</td>
<td>The SNAP tool is a concise evidence-based tool to help patients with COPD identify and express their support needs.</td>
</tr>
</tbody>
</table>

<sup>1</sup> Longitudinal qualitative study with 152 patients and carers (24% COPD); 5 European countries.
<sup>2</sup> COPD Participatory action research with key professional stakeholders.
<sup>a</sup> Validation of a needs assessment for COPD.
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<tr>
<td>Goodridge 2008&lt;sup&gt;23&lt;/sup&gt; Qualitative study of ICU nurse and therapist views</td>
<td>A sense of futility, and questions about the patient/family's understanding of treatment pervaded much of the discourse about caring for people with advanced COPD in the ICU.</td>
<td>Difficulties in palliating dyspnoea and anxiety were associated with caregiver feelings of helplessness, and fears about 'killing the patient'.</td>
<td>The need to prioritise care to the most unstable ICU patients meant that patients with COPD did not always receive the attention clinicians felt they should ideally have.</td>
<td>Organizational support must be made available for critical care clinicians to effectively deal with these issues.</td>
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<td>Appropriate ACP would have pre-empted the admission to the ICU.</td>
</tr>
<tr>
<td>Grossman 2019&lt;sup&gt;24&lt;/sup&gt; Mixed methods evaluation of ACP sessions in pulmonary rehabilitation</td>
<td>Participants most appreciated the information learned and the openness and opportunity to share</td>
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<td>Bringing individuals together as a group allows this difficult discussion, to be shifted from the individual towards a group.</td>
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<tr>
<td>Huntley 2020&lt;sup&gt;25&lt;/sup&gt; Quantitative and qualitative evaluation of 107 users of combined respiratory (COPD 71%) and palliative care service</td>
<td>Identified from primary care records as meeting Gold Standard Framework prognostic indicators.</td>
<td>Joint consultations with respiratory and palliative care specialists – supported by a community nurse</td>
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<td>Hosting the clinic at the hospice helped break the stigma attached to hospice settings</td>
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<tr>
<td>Iyer 2019&lt;sup&gt;26&lt;/sup&gt; Qualitative evaluation of 10 COPD patient/carer dyads exploring early palliative care</td>
<td>Moderate COPD (mild COPD is 'too early')</td>
<td>Coping with COPD and emotional symptoms were highest priority</td>
<td>Misconception that palliative care was synonymous with end-of-life care</td>
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<td>Need for illness understanding and prognostic awareness</td>
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<tr>
<td>Kelleher 2020&lt;sup&gt;27&lt;/sup&gt; E-Delphi 38 HCPs to achieve</td>
<td>Professional training in ACP should include legal issues</td>
<td></td>
<td></td>
<td>Need information on the best timing and content of ACP</td>
<td></td>
<td></td>
<td>Training to enable HCPs to incorporate ACP</td>
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<tr>
<td>Pang 200428</td>
<td>consensus on training requirements</td>
<td>Information sharing about patients’ needs and tailored care</td>
<td>Patients and carers valued continuity of care, integrated working and a relationship with a skilled named professional</td>
<td>Specialist nurses and hospice teams appeared to work closely together but this may leave GPs feeling deskilled</td>
<td>Hospices supported and supplemented other local services; some supplanted other services by providing inpatient facilities.</td>
<td>discussions with patients with COPD.</td>
<td>Prognostic awareness, illness burden, and existential concerns delineated how patients made decisions about resuscitation</td>
<td></td>
</tr>
<tr>
<td>Payne 201829</td>
<td>Case studies with patients (n=34: 10 with COPD) and family carers</td>
<td>Information sharing about patients’ needs allowed continuity and tailored care</td>
<td>Patients and carers valued continuity of care, integrated working and a relationship with a skilled named professional</td>
<td>Specialist nurses and hospice teams appeared to work closely together but this may leave GPs feeling deskilled</td>
<td>Hospices supported and supplemented other local services; some supplanted other services by providing inpatient facilities.</td>
<td>Joint patient information systems and multidisciplinary meetings facilitated integration.</td>
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<tr>
<td>Philip 200730</td>
<td>Development of a conceptual model of care</td>
<td>Tasks include screening for physical and psychological symptoms, social and community support.</td>
<td>Tasks include provision of information, and discussions around goals and preferences for care</td>
<td>Transition to palliative care services is facilitated as the patient nears death</td>
<td>Care is embedded in routine ambulatory respiratory care, ensuring that it is regarded as “usual” care by patients and clinicians alike</td>
<td>Joint patient information systems and multidisciplinary meetings facilitated integration.</td>
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<tr>
<td>Sinclair 202031</td>
<td>Preference trial of nurse-led ACP (n=149: 95 had COPD)</td>
<td>Entry to palliative care occurs routinely triggered by clinical transitions in care</td>
<td>Tasks include screening for physical and psychological symptoms, social and community support.</td>
<td>Tasks include provision of information, and discussions around goals and preferences for care</td>
<td>Transition to palliative care services is facilitated as the patient nears death</td>
<td>Care is embedded in routine ambulatory respiratory care, ensuring that it is regarded as “usual” care by patients and clinicians alike</td>
<td>An ACP intervention for patients with severe respiratory disease did not affect satisfaction, health-related quality of life, or 12-month mortality rate</td>
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<tr>
<td>Smallwood 201932</td>
<td>Continuity of care, high quality</td>
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<tr>
<td>Original paper (listed alphabetically)</td>
<td>• Triggers that initiate palliative care involvement</td>
<td>Needs assessment</td>
<td>PATIENTS Perceptions and goals of care</td>
<td>PROFESSIONAL Staff training and composition</td>
<td>ORGANISATION Place/sector and model of care</td>
<td>Outcomes</td>
<td>Barriers to provision of palliative care</td>
<td>Communication</td>
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<tr>
<td>Survey of 64 users of an integrated respiratory and palliative care service (60 COPD)</td>
<td>A sudden deterioration in the patient’s condition may be a suitable trigger</td>
<td>communication and feeling cared for were greatly valued.</td>
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<tr>
<td>Tavares 202033 Interviews with 33 UK COPD patients</td>
<td>Preferred timing for discussions was ‘in the future’ – as they were not ‘that bad yet’</td>
<td>Need to provide large amounts of information</td>
<td>Patients valued COPD-expert clinicians and continuity of care</td>
<td>Integration of palliative care conversations into the COPD disease trajectory ‘annual reviews’</td>
<td>Lack of time, no established relationship and belief that appointments were for disease management were barriers</td>
<td>Clinicians need to initiate ACP conversations</td>
<td>Different perceptions, competing priorities and service rationing inhibit patients from initiating early discussions</td>
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<tr>
<td>Van Gurp 201634 Observation of teleconsultations (n=18 patients: 2 with COPD)</td>
<td>Teleconsultations improved interprofessional understanding</td>
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</table>

Abbreviations: ACP= Advance care planning; CRD=Chronic Respiratory Disease; GP= General Practitioner; HCP= healthcare professional; ICU= Intensive Care Unit.
### Table COPD-3: Corroborative themes from original papers not included in the systematic reviews

<table>
<thead>
<tr>
<th>Original paper (listed alphabetically)</th>
<th>Needs assessment</th>
<th>PATIENTS Perceptions and goals of care</th>
<th>PROFESSIONAL Staff training and composition</th>
<th>ORGANISATION Place/sector and model of care Outcomes</th>
<th>Barriers to provision of palliative care</th>
<th>Communication</th>
<th>Q8: Advance care planning (ACP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beernaert 2014&lt;sup&gt;35&lt;/sup&gt; (HCP: Generic)</td>
<td>Assessment scales</td>
<td>Trusting relationship</td>
<td>Knowledge of care options</td>
<td>Continuity of care</td>
<td>Making time</td>
<td>Communication</td>
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<tr>
<td>Boland J 2014&lt;sup&gt;36&lt;/sup&gt; (HCP: COPD)</td>
<td>Holistic assessment</td>
<td>Multidisciplinary team</td>
<td>Coordinated care</td>
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<td>ACP</td>
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<tr>
<td>Broese 2021&lt;sup&gt;37&lt;/sup&gt; (HCP: COPD)</td>
<td>Uncertain timing of referral</td>
<td>Relationship with professionals</td>
<td>One lead professional</td>
<td>Continuity of care</td>
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<tr>
<td>den Herder 2018&lt;sup&gt;38&lt;/sup&gt; (Patient: COPD 25%)</td>
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<tr>
<td>Fairlamb 2021&lt;sup&gt;39&lt;/sup&gt; (HCP: COPD 50%)</td>
<td>Early integration</td>
<td>Uncertain prognosis</td>
<td>Lack of disease insight</td>
<td>Need to improve palliative care skills</td>
<td>Fragmented and variable</td>
<td>Synonymous with end-of-life</td>
<td>Communication across services</td>
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<tr>
<td>Fuseya 2019&lt;sup&gt;40&lt;/sup&gt; (Patient: COPD)</td>
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<td></td>
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<td></td>
<td>Patients/physician communication gap</td>
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<td>Gardner 2019b&lt;sup&gt;41&lt;/sup&gt; (Patient: COPD)</td>
<td>Needs assessment tool</td>
<td>Information and practical needs</td>
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<tr>
<td>Goodridge 2019&lt;sup&gt;42&lt;/sup&gt; (HCP: respiratory)</td>
<td>Uncertain prognosis</td>
<td>Need to improve palliative care skills</td>
<td>Alignment of services</td>
<td>Lack of time; need training</td>
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<td>Green 2019&lt;sup&gt;43&lt;/sup&gt; (patient: COPD)</td>
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<td>Communication across services</td>
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<tr>
<td>Hirakawa 2021&lt;sup&gt;44&lt;/sup&gt; (HCP: COPD)</td>
<td>Information sharing</td>
<td>Professional training</td>
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<td>Communication advanced skills</td>
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<tr>
<td>Hyden 2020&lt;sup&gt;45&lt;/sup&gt; (Patient: resp)</td>
<td>Uncertain timing of referral</td>
<td>Information and practical needs</td>
<td>Community/home-based care</td>
<td>Lack of time</td>
<td>Care co-ordination, spiritual needs</td>
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<td>ACP</td>
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<tr>
<td>Iyer 2020&lt;sup&gt;46&lt;/sup&gt; (HCP: COPD)</td>
<td>Frequent hospitalisations</td>
<td>Clearly defined roles</td>
<td>Consensus referral criteria</td>
<td>Synonymous with end-of-life</td>
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<tr>
<td>McVeigh 2018&lt;sup&gt;47&lt;/sup&gt; (Carer: respiratory)</td>
<td>Uncertain prognosis</td>
<td>Carer: Information/practical needs</td>
<td>Fragmented and variable</td>
<td>Lack of information from HCPs</td>
<td>Unprepared for death.</td>
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<tr>
<td>Original paper (listed alphabetically)</td>
<td>Triggers that initiate palliative care involvement</td>
<td>Needs assessment</td>
<td>PATIENTS Perceptions and goals of care</td>
<td>PROFESSIONAL Staff training and composition</td>
<td>ORGANISATION Place/sector and model of care</td>
<td>Outcomes</td>
<td>Barriers to provision of palliative care</td>
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<tr>
<td>Meehan 2019 (HCP: COPD)</td>
<td>Increase public awareness of ACP</td>
<td>Professional training</td>
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<tr>
<td>Mousing 2018a (Carer: COPD)</td>
<td>Poor awareness</td>
<td>Difficulties identifying needs</td>
<td>Need for education, training</td>
<td>Lack of continuity in patient care</td>
<td>Lack of time, home care is fragmented</td>
<td>Lack of team communication</td>
<td>Reluctance to start conversations</td>
</tr>
<tr>
<td>Mousing 2018b (patient: COPD)</td>
<td>Anxieties about future</td>
<td>Value of continuity of care</td>
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<tr>
<td>Roberts 2008 (HCP: COPD)</td>
<td>Episode of respiratory failure</td>
<td>Multidisciplinary teams</td>
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<tr>
<td>Rosenfeld 2003 (Service: generic)</td>
<td>Case finding for poor prognosis</td>
<td>Interdisciplinary assessment</td>
<td>Based on patient values and goals</td>
<td>Nurse-led case management</td>
<td>Continuity of holistic care</td>
<td>Resource limitations</td>
<td>ACP</td>
</tr>
<tr>
<td>Scheerens 2018 (HCP: COPD)</td>
<td>Admission, starting oxygen therapy</td>
<td>Lack of disease insight</td>
<td>Professional training</td>
<td>Improving care integration</td>
<td>Uncertain prognosis</td>
<td>Interprofessional communication</td>
<td>ACP</td>
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<tr>
<td>Siouta 2018 (HCP: COPD)</td>
<td></td>
<td>Professional training</td>
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<td>Synonymous with end-of-life</td>
<td>Interprofessional communication</td>
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<tr>
<td>Smallwood 2018 (HCP: COPD)</td>
<td>Patient and carer support</td>
<td>Multidisciplinary organisation</td>
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<tr>
<td>Sorensen 2020 (HCP: respiratory)</td>
<td>Uncertain prognosis</td>
<td>Need awareness of cultural context</td>
<td>Awareness of ACP, but rarely conduct</td>
<td>Need multi-disciplinary setting</td>
<td>Lack of time; barriers to ACP</td>
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<tr>
<td>Thoonsen 2016 (HCP: generic)</td>
<td>Uncertain timing of ACP challenging</td>
<td>Professional training</td>
<td>ACP discussions ‘difficult’</td>
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<td>Training to deliver ACP</td>
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<tr>
<td>Van Scyon 2016 (patient: COPD)</td>
<td></td>
<td>On-line ACP aid is feasible/acceptable</td>
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<tr>
<td>Wichman 2018 (HCP: generic)</td>
<td>Uncertain timing of ACP challenging</td>
<td>ACP needs to be individually tailored</td>
<td></td>
<td>Need to allow for changing views</td>
<td>ACP is a ‘hot topic’</td>
<td></td>
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</tr>
</tbody>
</table>

Abbreviations: ACP= Advance care planning; CRD=Chronic Respiratory Disease; GP= General Practitioner; HCP= healthcare professional; ICU= Intensive Care Unit.
Summary of main findings

Evidence base

Our evidence-base represents data from 221 original studies (13 systematic reviews reporting 175 original papers, plus 46 primary studies not included in the systematic reviews).

Initiating a palliative care approach, or referral for palliative care services

Although a number of indicators (commonly hospitalisation, long-term oxygen therapy, symptom burden) are cited to prompt referral of people with COPD to palliative care services, the uncertain disease trajectory, lack of a clear transition to ‘end-of-life’ and normalisation of living with COPD can lead to hesitancy on the part of the healthcare professionals to consider a palliative care approach. This is compounded as people with COPD may be reluctant to accept a referral to ‘palliative’ care because of a perceived association with cancer and end-of-life, though once referred acceptability was high. There is limited evidence about optimal timing of referral, but ‘early’ referral has been recommended, defined by people with COPD and informal caregivers in one study as when the COPD is classed as ‘moderate’. Lack of awareness amongst respiratory and generalist colleagues of the availability of palliative care has been highlighted, and some studies have proactively initiated screening, for example during a hospital admission, searching for prognostic indicators in primary care records.

Holistic needs assessment

Holistic assessment of physical, psychological, social and spiritual needs (of people with COPD and informal caregivers), is widely described as a crucial first step, with practical advice that arrangements should be comprehensive, accessible (potentially involving home-visits), interdisciplinary, with needs shared between support agencies to avoid duplication. A multidimensional needs assessment should not only consider the needs of the person with COPD, but also the needs of informal caregivers and family, as well as the timing of support provision. The Support Needs Approach for Patients (SNAP) tool asks people with advanced COPD to identify their support needs in 15 domains using questions that have been validated with people with COPD, informal caregivers and healthcare professionals but is not yet evaluated in a clinical context.

Models of palliative care

Three of the systematic reviews explicitly considered implementation of palliative care in terms of ‘patients, professionals and organisations’, and this approach was implicit in other reviews and original research papers.

- People with COPD and their informal caregivers. Key priorities for people with COPD and their informal caregivers was accessing information about COPD and support services, optimising treatment to reduce physical symptoms, coping with psychosocial challenges and maintaining activities they enjoy, and ‘being listened to’ so that their care is appropriately tailored. Empathy, feeling ‘cared for’, establishing, maintaining, and in due course closing, a relationship were valued, and led to increased confidence in ability to cope. Informal caregivers echoed the need for information, and valued practical support (e.g. respite care; resources) for their caring role.
• **Skilled healthcare professionals.** Studies stressed the need for knowledgeable professionals, trained in respiratory and palliative care and with access to multidisciplinary generalist and specialist expertise. Specific skills required included ability to optimise treatment, provide holistic care, and discuss prognosis and ACP in advance of critical events. Lead/co-ordinating professionals could be from specialist respiratory or palliative care disciplines, general practitioners or community nurses, but continuity of care was described as crucial enabling a trusted relationship to form.

• **Flexible, multidisciplinary organisation.** Models of care delivery varied, but key considerations are a service that is accessible (often community-based), flexible (to respond to individual needs and a fluctuating clinical condition), and adequately resourced to be able to provide sufficient professional time and links to the range of services required to meet physical, psychological, social and spiritual care needs of people with COPD. Multidisciplinary teams need to be collaborative, co-ordinated with good communication and defined referral channels for specialist support as required. Fostering relationships with one - or a very few - trusted professionals was widely emphasised, enabling a sense of continuity within the wider multidisciplinary team.

**Communication**

Communication emerged as a key theme not only between people with COPD/informal caregivers and their healthcare professionals, but also between professionals within the team. Strategies to overcome the potential of services to appear fragmented and uncoordinated included allocating a named professional who is accessible and able to signpost resources, regular multidisciplinary team meetings, joint consultations, and case management. People with COPD often know very little about COPD and want information on coping with their condition, and open and honest communication about their prognosis. Some studies have suggested that digital communication may be useful including phone calls to check progress, telemonitoring of status, teleconsultations, and web-based counselling or support for ACP.

**Integrating palliative care with respiratory management COPD.**

In a condition in which a fluctuating but slowly progressive trajectory makes prognosis uncertain and clinicians struggle to identify the point at which to involve palliative care, several studies addressed service models in which palliative care was seamlessly integrated into the routine care of COPD, whether that be with respiratory specialists, primary care generalists, or community respiratory teams. A key advantage was facilitating early provision of holistic care, specifically including early discussions of prognosis and ACP. One study exploring perceptions of people with COPD and their informal caregivers suggested that a palliative care approach should be considered when the COPD was of moderate severity, recognising that active disease management and palliation are complementary in a lifelong condition. There is limited evidence for the best approach to integrating the multiple domains of palliative care with active management, but strategies described include joint respiratory/palliative care clinics, providing respiratory clinicians with palliative care skills, regular inter-professional communication, and involvement of a key professional who could coordinate interdisciplinary working and transfer of information between disciplines and sectors. General raising of awareness amongst professionals
was considered important as well as a role for lay communication with the general public.\textsuperscript{3,5,39} The intention was that involvement of a palliative care approach should be regarded as “usual” care by people with COPD and clinicians alike.\textsuperscript{30} Underpinning these initiatives was the support of healthcare policy for organisational change and re-alignment of services.\textsuperscript{3,21,23,42}

\textit{Advance Care Planning}

ACP was described by all the papers as central to a palliative care approach whether incorporated by the usual respiratory/general professional of the person with COPD or following referral to specialist palliative care.\textsuperscript{3,5,36,40,45,53} Decisions regarding wishes of people with COPD for end-of-life management (e.g. ventilation, resuscitation) balanced the individual’s prognostic awareness, illness burden, and existential concerns.\textsuperscript{28} Systematic provision of ACP improved involvement in the treatment decisions made,\textsuperscript{1,2} and recording of wishes of the person with COPD,\textsuperscript{1} though with the caveat that pre-stated wishes could change in the acute situation,\textsuperscript{10,59} and were not always respected.\textsuperscript{28} Benefits of ACP included a positive impact on perceived control,\textsuperscript{1,2} and confidence in self-managing symptoms,\textsuperscript{1} but not necessarily health outcomes such as unscheduled care and quality of life which showed variable outcomes.\textsuperscript{1,31}

In the context of a condition with poor public understanding,\textsuperscript{7,48} people with COPD often lacked insight into the likely prognosis of their disease,\textsuperscript{53} and informal caregivers were unprepared for the death.\textsuperscript{23,47} A core function of ACP is to meet information needs,\textsuperscript{4,5,12,33,44} recognising that needs of the person with COPD and informal caregiver may be different,\textsuperscript{2,5,14,23} and careful discussion may be needed to identify preferences. A significant minority of people with COPD avoid discussion about prognosis,\textsuperscript{2,4,5,7} and even if they want information rarely initiate the conversation.\textsuperscript{12,50} Group sessions (e.g. within a pulmonary rehabilitation course\textsuperscript{10,24}) may have some advantages for broaching discussions as they were often perceived as less threatening than individual discussions,\textsuperscript{10,24,56} though a few found them ‘depressing’.\textsuperscript{24}

HCPs were described as having a ‘dilemma’. Almost all the papers highlight that HCPs acknowledge the importance of ACP discussions but are unsure when, and how, to start the conversation. HCPs are aware that some people with COPD do not want to discuss prognosis, and are afraid of destroying hope by opening a discussion.\textsuperscript{13,39} As a result, ACP conversations are rarely initiated by HCPs,\textsuperscript{2,6,13,17,26,39,40,49,56} with many professionals stating that they prefer people with COPD to initiate the discussion,\textsuperscript{7} which also rarely happens.\textsuperscript{12} Overcoming this block is arguably the biggest challenge for providing people with COPD with the benefits of a palliative care approach. Echoing the call for continuity of care, a recurring theme was that ACP discussions were best delivered in the context of a good relationship with a trusted professional.\textsuperscript{7,10,12,13,33} Almost all the studies emphasised the need for training in ACP for respiratory specialists and primary care professionals,\textsuperscript{2,4,6,7,9,12,20,27,39,44,48,57} specifically including recognising (and responding to) appropriate timing for ACP,\textsuperscript{4,7,10,13,27,57} and developing advanced communication skills.\textsuperscript{2,3,19,44}

The legal context and place of advance directives was highlighted in one paper.\textsuperscript{27} ACP should be started early,\textsuperscript{2,13,39} and incorporated into routine COPD care.\textsuperscript{6,30,55} Organisational barriers to delivering ACP include lack of time and capacity,\textsuperscript{4,12,13,33,39} and lack of clarity on who is responsible for initiating ACP conversations.\textsuperscript{4,6,7,12} The identification of triggers (such as repeated need for acute care) that might indicate appropriate timing,\textsuperscript{4,6,33} and repeating offers of ACP discussions as preferences may change after such events.\textsuperscript{7,10,12} Use of technology (e.g. a Web-based ACP tool for lung disease) was potentially useful and acceptable.\textsuperscript{5,58}

\textbf{Summary and recommendations (applicable to both COPD and ILD)}
The key themes are summarised in Figure 1 in the main text

**Recommendations for clinical practice and delivery of care**

- Integrate palliative care into routine COPD and ILD care, explicitly recognising active disease management and palliation as complementary
- Provide accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual needs (of people with COPD and informal caregivers) as a crucial first step.
- Embed a system within an extended (multidisciplinary team where people with persistent/unmet palliative care needs have access to specialist palliative care support.
- Foster relationships with one - or a very few - trusted professionals enabling continuity of care
- Recognise that initiating ACP conversations is challenging, and multi-disciplinary services should prioritise training, clarify responsibilities, and ensure capacity to offer timely ACP, with preferences checked as circumstances change.

**Recommendations for research**

- Research is needed to inform service delivery, specifically implementation of models that integrate palliative care approach into routine care of people with COPD or ILD
- Holistic needs assessment tools have been validated, but need evaluation in clinical practice
- Initiating discussions about prognosis and ACP remain a major barrier to provision of palliative care and interventions need to be developed and evaluated.

**Additional COPD tables**

**Additional Table COPD-A1. Table of excluded systematic reviews:**

<table>
<thead>
<tr>
<th>Systematic review</th>
<th>Reason for exclusion</th>
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<tbody>
<tr>
<td>Barnes 2012⁶⁰</td>
<td>Generic systematic review, no COPD-specific data</td>
</tr>
<tr>
<td>Beraza 2015⁶¹</td>
<td>Highlights needs but no insights into improved care</td>
</tr>
<tr>
<td>Bigger 2019⁶²</td>
<td>Generic systematic review, no COPD-specific data</td>
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<tr>
<td>Clari 2018⁶³</td>
<td>Highlights needs but no insights into improved care</td>
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<tr>
<td>Dalgaard 2014⁶⁴</td>
<td>Generic systematic review, limited COPD-specific data</td>
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<tr>
<td>Habrazen 2007⁶⁵</td>
<td>Highlights needs but no insights into improved care</td>
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<tr>
<td>Janssen 2012⁶⁶</td>
<td>Not a systematic review (Clinical review)</td>
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<tr>
<td>Oczkowski 2016⁶⁷</td>
<td>Generic systematic review, no COPD-specific data</td>
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<tr>
<td>Patel 2012⁶⁸</td>
<td>Not a systematic review (Clinical review)</td>
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<tr>
<td>Phongtankuel 2016⁶⁹</td>
<td>Generic review of current status; minimal COPD data</td>
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<tr>
<td>Rajnoveanu 2920⁷⁰</td>
<td>Meta review, and not done to SR methodology</td>
</tr>
<tr>
<td>Siouta 2016⁷¹</td>
<td>Overview of existing guidelines</td>
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<tr>
<td>Smith 2020⁷²</td>
<td>Not palliative care (about components of PR)</td>
</tr>
<tr>
<td>Williams 2020⁷³</td>
<td>Generic systematic review, no COPD-specific data</td>
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## Additional Table COPD-A2  Papers included in the COPD systematic reviews

Included papers are shaded in green

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<td>Aiken 2006(^4)</td>
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### Additional Table COPD-A3. Table of excluded original studies:

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<th>Publication</th>
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<tr>
<td>Bausewein 2012249</td>
<td>Conference abstract</td>
</tr>
<tr>
<td>Brown 2016250</td>
<td>Clinical review/perspective</td>
</tr>
<tr>
<td>Brozek 2019251</td>
<td>Highlights shortcomings but no insights into improved care</td>
</tr>
<tr>
<td>Bushor 2009252</td>
<td>Generic LTCs, no insights relevant to COPD services</td>
</tr>
<tr>
<td>Chandramouli 2011253</td>
<td>Clinical review/perspective</td>
</tr>
<tr>
<td>Chou 2017254</td>
<td>Highlights needs but no insights into improved care</td>
</tr>
<tr>
<td>Cohen 2009255</td>
<td>Review of Back 2009 (included)</td>
</tr>
<tr>
<td>Connor DA256</td>
<td>Trial registration (inpatients; not respiratory)</td>
</tr>
<tr>
<td>David 2020257</td>
<td>Survey of shortcomings but no insights into improved care</td>
</tr>
<tr>
<td>Detering 2016258</td>
<td>Clinical review/perspective</td>
</tr>
<tr>
<td>Duenk 2017259</td>
<td>Prediction of mortality post-admission</td>
</tr>
<tr>
<td>Ek 2008260</td>
<td>Description of living with COPD, no insights into care provision</td>
</tr>
<tr>
<td>Enguidanos 2018261</td>
<td>Conference abstract</td>
</tr>
<tr>
<td>Fleuren 2014262</td>
<td>Framework for describing interventions</td>
</tr>
<tr>
<td>Freeland 2019263</td>
<td>Clinical review/perspective</td>
</tr>
<tr>
<td>Fried 2016264</td>
<td>Generic, no COPD outcomes</td>
</tr>
</tbody>
</table>
Gainza-Miranda 2019<sup>265</sup>  Highlights needs but no insights into improved care  
Griffiths 2021<sup>266</sup>  Letter; ACP claims data  
Grudzen 2019<sup>267</sup>  Protocol (no report identified); generic ‘non-malignant disease’  
Hajizadeh 2010<sup>268</sup>  Modelling outcomes  
Hajizadeh 2012<sup>269</sup>  Modelling outcomes  
Hardin 2008<sup>270</sup>  Clinical review/perspective  
Hjorth 2020<sup>271</sup>  Generic; majority cancer  
Hung 2013<sup>272</sup>  Survey of shortcomings but no insights into improved care  
Hyden 2019<sup>273</sup>  Conference abstract (published as Hyden 2020)  
Janssen 2010<sup>274</sup>  Clinical review/perspective  
Janssen 2011<sup>275</sup>  Conference abstract  
Jerpseth 2017<sup>276</sup>  Nursing roles. Not ACP  
Kendall 2015<sup>277</sup>  Generic, overview of qualitative studies  
Leiter 2018<sup>278</sup>  Generic; only three participants had COPD  
Loomer 2021<sup>279</sup>  Generic, no COPD data  
Lunder 2017<sup>280</sup>  Clinical review/perspective  
McVeigh 2014<sup>281</sup>  Protocol (published as McVeigh 2018)  
Mechler 2019<sup>282</sup>  Clinical review/perspective  
Michaud-Young 2009<sup>283</sup>  Clinical review/perspective  
Monteiro 2018<sup>284</sup>  Survey of decisions (CRD), but no insights into improved care  
Nava 2007<sup>285</sup>  Survey of decisions (CRD), but no insights into improved care  
Pesut 2017<sup>286</sup>  Generic; only one participant had COPD  
Reinke 2010<sup>287</sup>  Highlights shortcomings but no insights into improved care  
Rosenwax 2016<sup>288</sup>  Routine data, but no insights into improved care  
Rush 2017<sup>289</sup>  Routine data, but no insights into improved care  
Seamark 2010<sup>290</sup>  Clinical review/perspective  
Seamark 2014<sup>291</sup>  Generic; unclear how many were COPD  
Shangher 2017<sup>292</sup>  Conference abstract  
Siouta 2021<sup>293</sup>  Survey of shortcomings but no insights into improved care  
Smallwood 2018<sup>294</sup>  Routine data, but no insights into improved care  
Soto-Rubio 2020<sup>295</sup>  Survey of shortcomings but no insights into improved care  
Traveline 1995<sup>296</sup>  Highlights needs but no insights into improved care  
Van der Eerden 2016<sup>297</sup>  Conference abstract  
White 2011<sup>298</sup>  Highlights needs but no insights into improved care  
Wilson 2008<sup>299</sup>  Highlights needs but no insights into improved care  
Winthereik 2018<sup>300</sup>  Generic palliative care training; no mention of COPD

<table>
<thead>
<tr>
<th>Systematic review</th>
<th>Reason for exclusion</th>
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<tbody>
<tr>
<td>Cerulus 2022&lt;sup&gt;301&lt;/sup&gt;</td>
<td>Generic systematic review, no COPD-specific data</td>
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<tr>
<td>Chyr 2022&lt;sup&gt;302&lt;/sup&gt;</td>
<td>Generic systematic review, no COPD-specific data</td>
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<tr>
<td>Fusi Schmidhauser 2021&lt;sup&gt;303&lt;/sup&gt;</td>
<td>Not a systematic review (Clinical review)</td>
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<tr>
<td>Rose 2022&lt;sup&gt;304&lt;/sup&gt;</td>
<td>Not a systematic review (Clinical review)</td>
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</table>
References


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Rajnoheau RM, Rajnoheau AG, Fildan AP, Todega DA, Man MA, Motoc NS, Mossoiu D. Palliative Care Initiation in Chronic Obstructive Pulmonary Disease: Prognosis-Based, Symptoms-Based or Needs-Based? Int J COPD 2020;15:1591


Williams MT, Kozachik SL, Karlkear M, Wright R. Advance Care Planning in Chronically Ill Persons Diagnosed With Heart Failure or Chronic Obstructive Pulmonary Disease: An Integrative Review. Am J Hospice Palliative Med 2020;37:950-6


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Au DH, Udris EM, Engelberg RA, Diehr PH, Bryson CL, Reinke LF, Curtis JR. A randomized trial to improve communication about end-of-life care among patients with COPD. Chest 2012;141:736–735


Bove DG, Lavesen M, Jelligton MO, Marsaa KB, Herling SF. First year experiences with a palliative out-patients structure for patients with COPD: a qualitative study of health professionals’ expectations and experiences. BMC Palliat Care 2018;17:1-0


Crawford A. Respiratory practitioners’ experience of end-of-life discussions in COPD. Br J Nurs 2010;19:1164–11


Curtis JR. Communicating with patients and their families about advance care planning and end-of-life care. Respir Care 2000;45:1385–139


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Detering KM, Sutton EA, McDonald CF. Recognising advanced disease, advance care planning and recognition of dying for people with COPD. *ERS Monograph Palliative care in respiratory disease. Switzerland: European Respiratory Society*. 2016 Sep 1;204-20


Fried TR, Byers AL, Gallo WT, Van Ness PH, Towlle VR, O’Leary JR, Dubin JA. Prospective study of health status preferences and changes in preferences over time in older adults. *Arch Int Med* 2006;166:890-5


Hajizadeh N, Crothers K, Braithwaite RS. A theoretical decision model to help inform advance directive discussions for patients with COPD. *BMC Med Inform Decision making* 2010;10:1-8


Hjorth NE, Schaufeli WR, Sigurdardottir KR, Haugen DR. Feasibility and acceptability of introducing advance care planning on a thoracic medicine inpatient ward: an exploratory mixed method study. *BMJ Open Respir Res* 2020;7:e000485


Hyden K, Coo F, Meek PM. Facilitators and Barriers of High-Quality Community Based Palliative Care (CBPC): Perspectives of Chronic Obstructive Pulmonary Disease (COPD) Patients and Their Caregivers. *Am Thorac Soc* 2019:A22


Mechler K, Lianmone J. Palliative care approach to chronic diseases: end stages of heart failure, chronic obstructive pulmonary disease, liver failure, and renal failure. *Primary Care: Clinics in Office Practice* 2019;46:415-32


Monteiro JF. Life-sustaining treatments in end-stage chronic respiratory failure: A single-centre study. *Clinical Ethics* 2018;13:26-33


288. Rosenwax L, Spilsbury K, McNamara BA, Semmens JB. A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? BMC Palliat Care 2016;15:46


293. Siouta N, Heylen A, Aertgeerts B, Clement P, Janssens W, Van Cleemput J, Menten J. Quality of Life and Quality of Care in patients with advanced Chronic Heart Failure (CHF) and advanced Chronic Obstructive Pulmonary Disease (COPD): Implication for Palliative Care from a prospective observational study. Progr Palliat Care 2021;29:11-19


300. Winthereik AK, Neergaard MA, Jensen AB, Vedsted P. Development, modelling, and pilot testing of a complex intervention to support end-of-life care provided by Danish general practitioners. BMC Fam Pract 2018;19:1-1


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Online supplement 5

European Respiratory Society Clinical Practice Guideline:

Palliative care for people with chronic obstructive pulmonary disease or interstitial lung disease

Methods and findings for Q7 and 8 (ILD)

Note: Methods and findings for Q7 and 8 (COPD) are in Online supplement 4

Questions

Q7 How do we implement palliative care with routine clinical care for people with ILD and their informal caregivers?

Q8 How do we implement ACP in routine clinical care for people with ILD?

Methods

Comparable methods were used for Q7 and 8 (COPD) and Q7 and 8 (ILD). Although the searches were undertaken separately, it was clear that there was considerable overlap in the papers identified, the themes described and the conclusions reached. Most papers about palliative care included ACP as a core component, and most papers investigating ACP commented on the palliative care context in which discussions occurred. We therefore opted to combine the data extracted from questions 7 and 8 into combined tables and summary text. (e-Figure 8. PRISMA diagram)

Search strategy, selection of papers for inclusion and data extraction.

From the list of 108 titles and abstracts, we initially identified 12 systematic reviews that had comparable aims and objectives to our questions. Eight were not relevant on full text screening; see Additional Table COPD-A1 (Additional tables are below summary text) for reasons for exclusion. We extracted the key themes from the remaining four papers (Table ILD-1) to answer the questions about implementation including referral processes, models of care and components (Q7) and specifically Advance Care Planning (ACP) (Q8). We had developed preliminary schema which summarised the themes using a whole systems approach, illustrating patient, professional and organisational features that were identified as ‘needed’ by any of the patient, caregiver or professional stakeholders.

We assessed the overlap of the papers included in the four systematic reviews (See Additional Table COPD-A2). Overall, the systematic reviews drew data from 45 unique primary studies. From title and abstract screening of our searches for primary studies, we identified 39 papers that were potentially relevant but not included in the systematic reviews. The full text of these were read and classified as:

- Adding novel insights not identified in the systematic reviews: data extracted and studies added to Table ILD-2 (n=10)
- Corroborating existing themes: themes summarised in Table ILD-3 (n=0)
- Not relevant to our questions: paper excluded (Additional Table ILD-A3 lists reasons for exclusion) (n=29)

The new themes were used to refine the schema (Figure ILD-2)
Update searches

The search was updated for systematic reviews in April 2022. No further relevant publications were identified.

Framework for synthesis

Data were extracted under the headings of goals of care, staff training and composition, place or setting for delivering palliative care, barriers to and pre-requisites for delivery of palliative care. We used a whole systems approach as a framework for analysis, relating the findings of included papers to the needs of people with ILD, professional requirements and service organisation. In addition, we looked for evidence on timing of palliative care involvement, referral criteria and processes of assessment as a specific component of the patient journey. Finally, to address Q8, we specifically synthesised data on ACP and the related theme of communication.

Structure of reporting synthesis

In the report below we first provide the summary tables of included systematic reviews, and original papers (Tables ILD-1, and ILD-2), then provide a synthesis of the findings in text. Figure 1 summarizes the key themes in a schema.

Excluded papers with reasons for exclusion are in Additional Tables ILD-A1, A2, A3, A4.
To summarise 10 studies Mixed methods SR Kim 2018

ILD-relevant systematic reviews

<table>
<thead>
<tr>
<th>Systematic review (listed alphabetically)</th>
<th>Triggers that initiate palliative care involvement</th>
<th>Needs assessment</th>
<th>PATIENT Goals of care</th>
<th>PROFESSIONAL Staff training and composition</th>
<th>ORGANISATION Place/sector and model of care Outcomes</th>
<th>Barriers to provision of palliative care</th>
<th>Pre-requisites</th>
<th>QB: Advance care planning (ACP)</th>
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<tbody>
<tr>
<td>Igai 2018¹ 19 studies To examine the characteristics of palliative care for patients with IPF.</td>
<td>• Persistent symptoms • Unmet needs (including caregiver needs) • Initiation of ventilation Patients and families should be informed about palliative care early following the diagnosis of IPF.</td>
<td>Deterioration in condition prior to “terminal phase” by timely identification of changes in health status, functional activity and understanding of symptoms Decision making whilst ambulatory not in the acute situation</td>
<td>Appropriate use of hospital services (preventing avoidable admissions and futile treatments) Control symptoms Reduce psychological, social and spiritual distress Address education/information needs Early discussions about disease progression and honesty re disease progression</td>
<td>Multidisciplinary teams (care conference) Integrated care Collaborative care HCPs need support and training on symptom management and communication skills A HCP, well-trained in ACP, would know how to begin the discussion even in the early stages of the disease</td>
<td>Co-ordinated care across settings and services, including home care (care conference) Place and timing of the end-of-life discussions could begin either during hospitalisation or in OPD Individual care plans</td>
<td>Resource constraints Lack of skills and confidence in communication Poor awareness of palliative care Stigma against hospice and palliative care Predicting the prognosis of IPF is difficult; complex course Some patient resistance to ACP has been reported</td>
<td>Integrated care models Multicomponent programmes combining drug therapy, oxygen therapy, nutritional advice, self-management education and psychological support</td>
<td>ACP including place of care Systematic approach to end-of-life conversations Help patients and care givers manage the uncertainty by early discussions about disease progression, improving communication and planning for palliation at an early stage</td>
</tr>
<tr>
<td>Kim 2018² Mixed methods SR 10 studies To summarise studies addressing barriers to referring patients to specialist palliative care services</td>
<td>• Need for ventilation • Needs for long-term oxygen therapy • Need for antibiotics • ‘Do not resuscitate’ status</td>
<td>More ILD clinic visits → rapport with clinicians facilitating the discussion of palliative care options Use of needs assessment tools to identify needs and trigger</td>
<td>Support for management of symptoms and other concerns Discussion about place of care/death</td>
<td>Training for ILD teams should include: • needs assessment • symptom management • communication skills to facilitate palliative care referral</td>
<td>More clinic visits give more opportunities to establish rapport with HCPs, facilitating the discussion of palliative care options and referral.</td>
<td>Delay in palliative care referrals (71% in last month of life; 74% of decisions made in the last 3 days) Prognostic uncertainty, deterioration not recognised, death unexpected</td>
<td>Palliative services should be provided based on needs not prognosis</td>
<td>The main facilitators were more contact with healthcare professionals, teaching hospital settings, older age and advanced care planning</td>
</tr>
</tbody>
</table>

Table I: Themes from ILD systematic reviews

- Table I: Themes from ILD systematic reviews

**Table I: Themes from ILD systematic reviews**

**Systematic review (listed alphabetically)** | **Triggers that initiate palliative care involvement** | **Needs assessment** | **PATIENT Goals of care** | **PROFESSIONAL Staff training and composition** | **ORGANISATION Place/sector and model of care Outcomes** | **Barriers to provision of palliative care** | **Pre-requisites** | **QB: Advance care planning (ACP)**
---|---|---|---|---|---|---|---|---
**ILD-relevant systematic reviews**

- **Igai 2018¹ 19 studies**
  - To examine the characteristics of palliative care for patients with IPF.
  - Persistent symptoms
  - Unmet needs (including caregiver needs)
  - Initiation of ventilation
  - Patients and families should be informed about palliative care early following the diagnosis of IPF.
  - Deterioration in condition prior to “terminal phase” by timely identification of changes in health status, functional activity and understanding of symptoms
  - Decision making whilst ambulatory not in the acute situation
  - Appropriate use of hospital services (preventing avoidable admissions and futile treatments)
  - Control symptoms
  - Reduce psychological, social and spiritual distress
  - Address education/information needs
  - Early discussions about disease progression and honesty re disease progression
  - Multidisciplinary teams (care conference)
  - Integrated care
  - Collaborative care
  - HCPs need support and training on symptom management and communication skills
  - A HCP, well-trained in ACP, would know how to begin the discussion even in the early stages of the disease
  - Co-ordinated care across settings and services, including home care (care conference)
  - Place and timing of the end-of-life discussions could begin either during hospitalisation or in OPD
  - Individual care plans
  - Resource constraints
  - Lack of skills and confidence in communication
  - Poor awareness of palliative care
  - Stigma against hospice and palliative care
  - Predicting the prognosis of IPF is difficult; complex course
  - Some patient resistance to ACP has been reported
  - Integrated care models
  - Multicomponent programmes combining drug therapy, oxygen therapy, nutritional advice, self-management education and psychological support
  - ACP including place of care
  - Systematic approach to end-of-life conversations
  - Help patients and care givers manage the uncertainty by early discussions about disease progression, improving communication and planning for palliation at an early stage

- **Kim 2018² Mixed methods SR 10 studies**
  - To summarise studies addressing barriers to referring patients to specialist palliative care services
  - Need for ventilation
  - Needs for long-term oxygen therapy
  - Need for antibiotics
  - ‘Do not resuscitate’ status
  - More ILD clinic visits → rapport with clinicians facilitating the discussion of palliative care options
  - Use of needs assessment tools to identify needs and trigger
  - Support for management of symptoms and other concerns
  - Discussion about place of care/death
  - Training for ILD teams should include:
    - needs assessment
    - symptom management
    - communication skills to facilitate palliative care referral
  - More clinic visits give more opportunities to establish rapport with HCPs, facilitating the discussion of palliative care options and referral.
  - Delay in palliative care referrals (71% in last month of life; 74% of decisions made in the last 3 days)
  - Prognostic uncertainty, deterioration not recognised, death unexpected
  - Palliative services should be provided based on needs not prognosis
  - The main facilitators were more contact with healthcare professionals, teaching hospital settings, older age and advanced care planning
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<th>Q8: Advance care planning (ACP)</th>
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<tr>
<td></td>
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<td>generalist action and/or referral to specialist palliative care</td>
<td>Education about the purpose of specialist palliative care is required to inform patients and physicians</td>
<td>There are variations in generalist and specialist palliative provision</td>
<td>Patients’ and HCPs’ fear of talking about the future, Confusion about role of palliative care and variable availability of specialist services</td>
<td>Time constraints and lack of palliative care skills within ILD teams</td>
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<tr>
<td>Lee 2020</td>
<td>35 studies</td>
<td>2621 patients (590 caregivers; 558 professionals)</td>
<td>To identify the supportive care needs reported by people with pulmonary fibrosis and their caregivers</td>
<td>Most frequently reported needs:</td>
<td>Multidisciplinary teams: usual care team and ILD specialist nurses who understand supportive care and work with the specialist palliative care team</td>
<td>Particularly support at home (including option to die at home)</td>
<td>Silo working and poor inter sector communication</td>
<td>Patients like to be prepared and have their ‘affairs in order’. The need for information on end-of-life planning is not restricted to those nearing end-of-life. HCPs have concerns about the timing of ACP discussions; care needed when initiating difficult conversations</td>
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<td></td>
<td>Holistic domains addressed by a multi-disciplinary team</td>
<td>Information</td>
<td>Symptom management</td>
<td>Support to care: peer support, psychological support, specialist centres. Address caregivers support</td>
<td>HCPs need to be knowledgeable, honest and good communicators</td>
<td>Phone support</td>
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<td></td>
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<td></td>
<td></td>
<td>• Starting oxygen therapy</td>
<td>• Uncontrolled symptoms</td>
<td>• Loneliness and isolation (including caregivers)</td>
<td>• ++ Dependence on caregiver for ADLs</td>
<td>• Improve access to care: peer support, psychological support, specialist centres. Address caregivers support</td>
</tr>
</tbody>
</table>

35 studies
2621 patients (590 caregivers; 558 professionals)
<table>
<thead>
<tr>
<th><strong>Systematic review (listed alphabetically)</strong></th>
<th>• Triggers that initiate palliative care involvement</th>
<th>Needs assessment</th>
<th>PATIENT Goals of care</th>
<th>PROFESSIONAL Staff training and composition</th>
<th>ORGANISATION Place/sector and model of care</th>
<th>Barriers to provision of palliative care</th>
<th>Pre-requisites</th>
<th>Q8: Advance care planning (ACP)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Smith 2020</strong></td>
<td>End-of-life care can be incorporated into PR education for both ILD and COPD</td>
<td>A PR programme enables patients to confer with educators and for educators to observe activities, identify individual patient learning issues and support skill development and knowledge</td>
<td>Knowledge about end-of-life care, and raise awareness</td>
<td>Patients were happy to receive this information from a non-medical facilitator</td>
<td>Patients were comfortable discussing information about disease progression in a group setting</td>
<td>Discussions on ACP within PR may be challenging if the participants have different coping methods</td>
<td>Operationalization of education in PR including trained educators in adult learning theory</td>
<td>Patients perceived PR to be an ideal context for a session on ACP, because they were clinically stable at the time facilitating understanding of information compared to when acutely unwell.</td>
</tr>
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</table>

**Abbreviations:** ACP= Advance care planning; HCP= healthcare professional; PR= pulmonary rehabilitation; SR= systematic review
<table>
<thead>
<tr>
<th>Original paper (listed alphabetically)</th>
<th>Themes or insights from original research not included in the systematic reviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Archibald 2021&lt;sup&gt;5&lt;/sup&gt;</td>
<td>Evaluation of the multidisciplinary collaborative ILD – hospital clinic and palliative care bundle (n=92)</td>
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<tr>
<td>Early integration through discussion at an MDT which included SPC. using a supportive care decision aid tool</td>
<td>Integration of the palliative care bundle including ACP, opiate use, AHP home care, use of oxygen, early engagement of caregiver in care</td>
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<tr>
<td>Barratt 2018&lt;sup&gt;6&lt;/sup&gt;</td>
<td>Service improvement evaluation in single site</td>
</tr>
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<td>Use of the (non-validated) supportive care decision aid tool identified patients to be referred to the MDT. SPC referral was a possible outcome</td>
<td>Collaborative, MDT meeting: SPC, psychology, ILD teams</td>
</tr>
<tr>
<td>Chiarchiaro 2015&lt;sup&gt;7&lt;/sup&gt;</td>
<td>Interviews with 21 patients on oxygen; 18 carers; 18 HCPs about an on-line ACP tool.</td>
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<tr>
<td>Clinicians wanted useful and accessible documentation</td>
<td>Recruited from PR, lung and primary care clinics</td>
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<tr>
<td></td>
<td>• Videos of medical scenarios patient narratives</td>
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<tr>
<td></td>
<td>• Interactive content</td>
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<tr>
<td></td>
<td>• User control over how much they complete in one sitting</td>
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<tr>
<td></td>
<td>Web-based ACP was acceptable and useful. Good to complete at home with loved ones</td>
</tr>
<tr>
<td>Original paper (listed alphabetically)</td>
<td>Triggers that initiate palliative care involvement</td>
</tr>
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<tr>
<td>Hjorth 2020⁸ Feasibility and acceptability of ACP on a chest ward Patient interviews (n = 51 clinicians in focus groups)</td>
<td>• Concerns across a wide range of domains (patient and carer) would trigger holistic assessment.</td>
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<tr>
<td>Johnson 2018⁹ Reliability testing and construct validation of the Needs Assessment Tool-ILD</td>
<td>• NAT-ILD includes assessment around future concerns, and could open ACP discussion.</td>
</tr>
<tr>
<td>Kalluri 2018¹⁰ Observation of a multidisciplinary collaborative ILD – hospital clinic (n=32)</td>
<td>• Multidisciplinary collaborative team training not described Staff composition - respiratory doctor, and nurse and rehab staff – not</td>
</tr>
<tr>
<td>Kalluri 2021¹¹ Qualitative interviews with 13 patients and 8 caregivers in a single site clinic</td>
<td>• Integreted early palliative approach – so use from the start</td>
</tr>
<tr>
<td>Original paper (listed alphabetically)</td>
<td>Needs assessment</td>
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<td>---------------------------------------</td>
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<tr>
<td>Kim 202012 Survey about palliative care access for ILD 35 respondents (clinicians mixed disciplines)</td>
<td>Referral for:  • Symptom control  • Psychological/spiritual support,  • General deterioration  • End of Life care</td>
</tr>
<tr>
<td>Reigada 201713 HCP focus group on implementation of the NAT-ILD</td>
<td>Identification of best timing to use (eg. First visit, reassessment following admission, or clinical deterioration)</td>
</tr>
</tbody>
</table>

Abbreviations: ACP= Advance care planning; AHP= Allied Health Professional; HCP= healthcare professional; MDT= Multidisciplinary Team; NAT-ILD=Needs Assessment Tool-ILD; SPC= specialist palliative care
Synthesis of main findings

Evidence base
Our evidence-base represents data from 56 original studies (4 systematic reviews reporting 46 original papers, plus 10 primary studies not included in the systematic reviews).

Summary of main findings

Initiating a palliative care approach, or referral for palliative care services
People with ILD are often not referred to palliative care services, or referred too late to address the high levels of unmet need (e.g., 71% within the last month of life). Suggested triggers for palliative care referral are oxygen therapy, ventilatory support, uncontrolled symptoms, functional decline, and opioid consideration as well as unmet holistic needs (anxiety and depression, loneliness and isolation, and increasing caregiver dependence/burden). The poor prognosis and downward trajectory over time, albeit still seen as uncertain, underpin calls for a palliative care approach to be incorporated within usual care from soon after diagnosis.

Holistic needs assessment
Multidisciplinary, holistic needs assessment is preferable to a prognosis-based approach, with care plans and goals discussed whilst ambulatory rather than during an acute crisis. Three systematic approaches are described in the literature: a validated needs assessment tool to guide consultations (NAT-ILD) a bespoke clinician supportive care decision aid (SCDAT) and a multidisciplinary collaborative ILD-palliative care bundle.

Models of care: integrating palliative care with respiratory management
A needs-based approach was recommended, with care co-ordinated across primary, respiratory (including pulmonary rehabilitation) and specialist palliative care settings, with adequate allied health support to enable care at home (if preferred). Palliation should be part of multidisciplinary case discussion and a palliative approach triggered by unmet needs, and not seen as a “near-death” intervention. Unmet needs should be identified systematically, using an assessment tool and clinical conversation, preferably in the ambulatory care setting and not during an acute admission. Holistic needs assessments should also include consideration of caregivers.

- People with ILD and family caregivers. Access to information, supportive and palliative care services to address symptom control, psycho-social needs, provision of practical help in the home and support for caregivers are important. The need for clarity about prognosis was highlighted along with continuity of care from trusted professionals. Caregivers’ needs should be assessed alongside the needs of the people with ILD (e.g. the validated NAT:ILD includes two caregiver domains (ability to care; caregiver wellbeing) though is not yet evaluated in clinical practice.

- Healthcare professionals. The need to upskill ILD specialists and primary care clinicians in holistic assessment, symptom management, planning current and future goals of care was a consistent findings. Access to, and support from, specialist palliative care teams were important components of successful provision of palliative care. Embedding the use of a needs assessment tool into routine care, or multidisciplinary respiratory/palliative integration with case conferences and referral checklists/decision aids were suggested but challenging in practice.
Flexible, multidisciplinary organisation. Implementation needed to prioritise: i) service reconfiguration to allow time for holistic assessment and management, and multidisciplinary team discussions, ii) communication skills training for by clinicians, managers and institutions, iii) adequate flexible resources, especially psychological and social support services. Models ranged from linking respiratory/generalists with specialist palliative care teams for mutual education, training and referral,13 to a fully integrated collaborative ILD-palliative care service encompassing medication, oxygen, nutritional advice, self-management education and psychological support.5,11 Initial evaluation of the full collaborative model showed promising patient benefit,5,11 but lacked a health economic evaluation. Ongoing case specialist palliative care for every ILD patient is unnecessary and unsustainable: most issues can be addressed by the ILD team or primary care with support and training.6,13

Communication
Good communication was emphasised as crucial across all settings. “Silo” working,3 with poor communication between sectors and teams was seen as major obstacle.2,3,12 Inappropriate optimism, perpetuated by poor communication skills and/or confidence was a problem as clinicians avoided talking about goals of care for fear of “taking away hope”.2,3,8 The concept of palliative care providing a layer of care alongside active treatment was not commonly understood by any stakeholder,1-3 and often referrals were seen as a covert message that death was very near - with accompanying stigma.1,3

Advance Care Planning
The findings from the studies in COPD (see main text and on-line Supplement 4) were mirrored in the ILD literature.1-3,11 Planning for palliation at an early stage of the disease, with a systematic approach to conversations about disease progression, improving communication about end-of-life needs help people with ILD and informal caregivers manage the uncertainty of illness.

Systematic provision of ACP enabled practical planning for future needs and palliation,1,8,11 as well as discussions about existential topics.8,12 Perceived benefits of ACP included improved communication and involvement in the treatment decisions made,4 which reduced uncertainty for people with ILD and their informal caregivers.1 A multidisciplinary initiative that increased provision of ACP discussions,11 reduced anxiety as medical and financial plans place were in place.11 Preferences for place of death were more likely to be recorded,10,11 with some evidence that concordance with these wishes increased.3,5,10 A core function of ACP is to meet information needs,1,3,4 recognising that patient and carer needs and coping strategies may be different.4 Use of technology (e.g. an interactive web-based ACP tool for lung disease which included videos of clinical scenarios and patient narratives7) was potentially useful and acceptable, in part because it could be completed at home with loved ones.7 ACP should be started early,1,3,10 and not restricted to those nearing the end of life.3 Although most people with ILD wanted an honest discussion about prognosis,1,4 HCPs often had concerns about the starting of ACP discussion,3,8 expressing fears about destroying hope.8 Studies adopted different approaches to facilitating ACP: for example, embedded with a structured process of needs assessment8,11,13 or triggered by a specific event such an admission,5 the need for specific treatment,2,3 or following a multidisciplinary team discussion.6 Pulmonary rehabilitation was perceived by people with ILD as an ‘ideal’ context for broaching discussions they were clinically stable at the time and felt more able to understand and take decisions compared to when they were acutely unwell.4 Almost all
the studies explicitly stated the need for training in ACP for professionals within the multidisciplinary team,\textsuperscript{1,3,13} or highlighted a lack of professional skills and confidence as a barrier.\textsuperscript{8}

**Recommendations (applicable to both COPD and ILD)**

**For clinical practice and delivery of care**

- Integrate palliative care into routine COPD and ILD care, explicitly recognising active disease management and palliation as complementary
- Provide accessible, multi-disciplinary holistic assessment of physical, psychological, social and spiritual needs (of people with COPD or ILD and informal caregivers) as a crucial first step.
- Embed a system within an extended (multidisciplinary team where people with persistent/unmet palliative care needs have access to specialist palliative care support.
- Foster relationships with one - or a very few - trusted professionals enabling continuity of care
- Recognise that initiating ACP conversations is challenging, and multi-disciplinary services should prioritise training, clarify responsibilities, and ensure capacity to offer timely ACP, with preferences checked as circumstances change.

**For research**

- Research is needed to inform service delivery, specifically implementation of models that integrate palliative care approach into routine care of people with COPD or ILD
- Holistic needs assessment tools have been validated, but need evaluation in clinical practice
- Initiating discussions about prognosis and ACP remain a major barrier to provision of palliative care and interventions need to be developed and evaluated.

**Additional ILD tables**

**Additional Table ILD-A1. Table of excluded systematic reviews:**

<table>
<thead>
<tr>
<th>Systematic review</th>
<th>Reason for exclusion</th>
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<tbody>
<tr>
<td>Barnes 2012\textsuperscript{14}</td>
<td>Generic LTCs, no insights relevant to ILD services</td>
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<td>Bigger \textsuperscript{15}</td>
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<tr>
<td>Jabbarian 2018\textsuperscript{16}</td>
<td>Generic chronic respiratory disease, no insights specific to ILD services</td>
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<tr>
<td>Lindell 2015\textsuperscript{17}</td>
<td>Survey of shortcomings but no insights into improved care</td>
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<td>Oczkowski 2016\textsuperscript{18}</td>
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<td>Singer 2016\textsuperscript{19}</td>
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<tr>
<td>Zou 2020\textsuperscript{21}</td>
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### Additional Table ILD-A2  Papers included in the ILD systematic reviews

Included papers are shaded in blue

<table>
<thead>
<tr>
<th>ILD Table of Q7 SRs and included papers.</th>
<th>Kim 2018</th>
<th>Igai 2018</th>
<th>Lee 2020</th>
<th>Smith 2020 [ILD studies]</th>
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References


44. Lindell KO, Kavalieratos D, Gibson KF, Tyron L, Rosenzweig M. The palliative care needs of patients with idiopathic pulmonary fibrosis: a qualitative study of patients and family caregivers. *Heart & Lung* 2017;46,24–29


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Goodridge D, Peters J. Palliative care as an emerging role for respiratory health professionals: Findings from a cross-sectional, exploratory Canadian survey. Canadian J Respir Therapy 2019;55:73


Leiter RE, Yusufov M, Hasdienda MA, Fellion LA, Reust AC, Block SD, Tuilsky JA, Ouchi K. Fidelity and feasibility of a brief emergency department intervention to empower adults with serious illness to initiate advance care planning conversations. J Pain Symptom Manage 2018;56:878-85


Monteiro JF. Life-sustaining treatments in end-stage chronic respiratory failure: A single-centre study. Clinical Ethics 2018;13:26-33


Winthereik AK, Neergaard MA, Jensen AB, Vedsted P. Development, modelling, and pilot testing of a complex intervention to support end-of-life care provided by Danish general practitioners. BMC Fam Pract 2018;19:1-1
Legend e-figure 1
Methodology used for development of the Clinical Practice Guideline.
Abbreviation: PICO= Patient, Intervention, Comparison, Outcome.

Legend e-figure 2
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for question 1.

Legend e-figure 3
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for question 2.

Legend e-figure 4
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for question 3.

Legend e-figure 5
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for question 4.

Legend e-figure 6
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for question 5.

Legend e-figure 7
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for question 6.

Legend e-figure 8
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for question 7&8.
Question 1. How do we define palliative care for adults with COPD or ILD?

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

Question 2. When to start a palliative care approach in COPD and ILD?

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

**Identification of studies via databases and registers**
- Medline (n = 903)
- Embase (n = 581)
- Cochrane CDSR (n = 16)
- CENTRAL (n = 77)
- CINAHL (n = 161)
- Scopus (n = 143)
- Web of Science (n = 164)
- Epistemonikos (n = 10)
- Google Scholar (n = 5)
- Caresearch Collection (n = 2)
- Total (n = 2062)

Records removed before screening:
- Duplicate records removed (n = 855)

Records screened (n = 1207)

Reports sought for retrieval (n = 85)

Reports assessed for eligibility (n = 85)

Studies included in review (n = 9)

Reports of included studies (n = 9)

**Identification of studies via other methods**

Records identified from:
- Taskforce members: 1
- Citation searching (n = ) etc.

Reports sought for retrieval (n = 1)

Reports excluded: Reason 1 (n = 0)

Reports not retrieved (n = 0)

**Studies included in review (n = 9)**

Reasons for exclusion:
- Philips review (n = 33)
- Out of topic (n = 24)
- Implementation (n = 8)
- Opinion piece (n = 7)
- Local service audit (n = 3)
- Mortality predictions (n = 2)

Question 3. In adults with COPD and their informal caregivers, should palliative care interventions involving informal caregivers be used?

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

e-figure 4. Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) flow diagram of the literature search (Adapted from Page et al. 2021). Abbreviations: COPD= chronic obstructive pulmonary disease; IC= informal caregivers; PC= palliative care.
Question 4. In adults with ILD and their informal caregivers, should palliative care interventions involving informal caregivers be used?

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

**Identification of studies via databases and registers**

- Records identified from:
  - OVID MEDLINE(R) (n = 200)
  - OVID Embase (n = 209)
  - Cochrane DSR (n = 1)
  - Cochrane CENTRAL (n = 35)
  - Epistemonikos database (n = 14)
  - Web of Science (n = 54)
  - CINAHL via EBSCOhost (n = 33)
  - Scopus (n = 77)
  - Caresearch SR collection (n=2)
  - TOTAL: 625

- Records removed before screening:
  - Duplicate records removed automatically and by human action (n = 318)

- Records screened (n = 307)

- Records excluded based on title, abstract and keywords (n = 293)

- Reports sought for retrieval (n = 14)

- Reports assessed for eligibility (n = 14)

- Reports excluded (n = 7):
  - Conference abstracts (n = 2)
  - Commentary (n = 1)
  - PhD thesis (n = 1)
  - Study protocol (n = 1)
  - Reviews (n = 2)

- Studies included in review (n = 11)

**Identification of studies via other methods**

- Records identified from:
  - Reviews (n = 2)
  - Experts (n = 1)
  - Database alerts (n = 1)

- Reports sought for retrieval (n = 4)

- Reports assessed for eligibility (n = 4)

- Reports excluded (n = 0)

**e-figure 5.** Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) flow diagram of the literature search (Adapted from Page et al. 2021).
**Question 5.** In adults with COPD, should ACP interventions be used?

**PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources**

- **Identification of studies via databases and registers**
  - Medline (n = 798)
  - Embase (n = 1188)
  - Cochrane CDSR (n = 2)
  - CENTRAL (n = 193)
  - CINAHL (n = 426)
  - Scopus (n = 338)
  - Web of Science (n = 235)
  - Epistemonikos (n = 30)
  - Caresearch Collection (n = 0)
  - Total (n = 3210)

- **Records removed before screening**
  - Duplicate records removed (n = 1655)

- **Records screened (n = 1555)**

- **Records excluded (n = 1535)**

- **Reports screened (n = 20)**

- **Reports excluded (n = 15)**

- **Reports assessed for eligibility (n = 5)**

- **Reports excluded:**
  - Observational study (n = 3)
  - No separate effect results for COPD patients (n = 1)

- **Studies included in review (n = 1)**
- **Reports of included studies (n = 0)**

Question 6. In adults with ILD, should ACP interventions be used?

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

Medline (n = 286)
Embase (n = 364)
Cochrane CDSR (n = 5)
CENTRAL (n = 25)
CINAHL (n = 115)
Scopus (n = 73)
Web of Science (n = 188)
Epistemonikos (n = 2)
Caresearch Collection (n = 1)
Total (n = 1059)

Records removed before screening:
Duplicate records removed (n = 438)

Records screened (n = 621)

Records excluded (n = 603)

Reports sought for retrieval (n = 18)

Reports assessed for eligibility (n = 18)

Reports excluded:
Wrong intervention (n = 2)
Wrong outcomes (n = 6)
Wrong study design (n = 6)
Wrong patient population (n = 2)
Abstract only (n = 1)

Reports not retrieved (n = 0)

Studies included in review (n = 1)
Reports of included studies (n = 1)

Records identified from:
Websites (n = 0)
Organisations (n = 0)
Citation searching (n = 0)
etc.

Reports sought for retrieval (n = 0)

Reports assessed for eligibility (n = 0)

SRs for full text screening

COPD N = 27   ILD = 12  
(no overlap)

Excluded N = 85

Combined Q7 and 8 SRs identified after de-duplication N = 124

Studies for full text screening

COPD N = 161   ILD = 44  
(19 in both)

TOTAL N = 975

TOTAL: 1558

TOTAL: N = 161

TOTAL: n = 187

COPD

Systematic reviews N=13
Including 175 unique studies

Already included in the SRs n=63

Included with new themes n = 21

Included as corroborative evidence n = 25

Excluded = 14
6 generic, no COPD data
3 needs analysis
3 not a SR
1 not palliative care
1 overview of guidelines

27 SRs screened for COPD

161 studies screened for COPD

Excluded = 52
17 no insights into service provision
10 clinical reviews
9 generic, no COPD data
6 conference abstracts
3 protocols
3 methodology
1 commentary
1 prediction of death
1 letter to editor
1 Nursing roles

Note: The COPD evidence-base represents data from 221 primary studies: 13 systematic reviews reporting 175 primary papers (blue box), plus 46 primary studies not included in the systematic reviews: 21 adding novel insights not identified in the systematic reviews (green box) and 25 corroborating existing themes (amber box)

Combined Q7 and Q8

Searches for systematic reviews

Q7 Searches

TOTAL: N = 161

SR after de-duplication Q7 N = 72

Combined Q7 and 8 SRs identified after de-duplication N = 124

SRs for full text screening

COPD N = 27   ILD = 12  
(no overlap)

Studies for primary studies

Q7 Searches

TOTAL N = 975

SR after de-duplication Q7 N = 72

Excluded n = 1026

From other sources n = 3

COPD

Systematic reviews N=4
Including 46 unique studies

Already included in the SRs n=5

Included with new themes n = 10

Included as corroborative evidence n = 0

Excluded = 8
6 generic, no ILD data
1 survey of current status
1 not a SR

12 SRs screened for ILD

44 studies screened for ILD

Excluded = 29
18 generic, no ILD data
4 no insights into service provision
2 clinical reviews
2 case studies
1 conference abstract
1 preliminary work
1 methodology

Note: The ILD evidence-base represents data from 56 original studies: 4 systematic reviews reporting 46 original papers (blue box), plus 10 primary studies not included in the systematic reviews: all adding novel insights not identified in the systematic reviews (green box)