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)

Questions
Q7  How do we implement palliative care with routine clinical care for people with COPD and ILD and their informal caregivers?
Q8  How do we implement ACP in routine clinical care for people with COPD and ILD?

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>
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<tr>
<td>Broese 2021(^1) Mixed methods narrative review</td>
<td>• Hospitalisation for acute exacerbation</td>
<td>• Barriers: Relies on being referred by HCPs.</td>
<td>For this vulnerable patient group care needs to be easily accessible (e.g. assessments during home visits and monitoring needs by phone.</td>
<td>Acceptability of the palliative care interventions 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>Multidisciplinary interventions but often led by a specialist nurse. Consistent staffing by knowledgeable people aware of the programme goals contributed to a smooth implementation of the innovation</td>
<td>Multicomponent interventions (short or long-term) typically community-based</td>
<td>Most frequently named barriers were uncertainty about the timing of referral due to the unpredictable disease trajectory (referrers), time availability (providers) and accessibility (patients). General conditions such as sufficient time, financial resources and personnel are required for successful implementation</td>
<td>Components of the interventions that were highly valued included being listened to and direct access to a professional for support, continuity of the relationship and education about breathlessness management.</td>
<td>Positive effects were found on outcomes related to ACP and perceived symptom control and self-management, but not on health outcomes. ACP choices were more often documented in intervention groups</td>
</tr>
<tr>
<td>31 papers (20 interventions) including 4 RCTs</td>
<td>• Severe reduction in lung function</td>
<td>• Functional limitation</td>
<td>• Oxygen therapy</td>
<td>• Depression</td>
<td>• Poor nutrition</td>
<td>• Comorbidities</td>
<td>• Surprise question</td>
<td>• Advance care planning should be</td>
<td>• A comprehensive approach is required to address the complex and varied needs of individuals with end-stage COPD and their families. A collaborative palliative care approach would assist patients in utilising supports</td>
</tr>
<tr>
<td>Disler 2012(^2) Integrative review 118 papers, 25 RCTs, 19 qual, 21 reviews</td>
<td>• Hospitalisations</td>
<td>• Severe reduction in lung function</td>
<td>• Functional limitation</td>
<td>• Oxygen therapy</td>
<td>• Depression</td>
<td>• Poor nutrition</td>
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<td>• Surprise question</td>
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**COPD-relevant systematic reviews**

- **Broese 2021**
  - Mixed methods narrative review
  - 31 papers (20 interventions) including 4 RCTs
  - To review multi-component palliative care interventions targeting patients with advanced COPD and their informal caregivers.
  - [Framework ‘referrers, providers and patients’](http://example.com)

- **Disler 2012**
  - Integrative review
  - 118 papers, 25 RCTs, 19 qual, 21 reviews
  - Aim: To review interventions to support a palliative care approach in...
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<td>patients with end-stage COPD [Framework: ‘personal, provider and system elements’ to achieve healthcare reform]</td>
<td>The progressive deterioration, punctuated with potentially fatal deteriorations decreases providers’ confidence in the appropriate timing of referral of patients to palliative care</td>
<td>commenced early to ensure care is commensurate with individuals’ needs</td>
<td>and interventions that enable them to balance the demands of their disease while maximising involvement and enjoyment in pursuits that give them pleasure</td>
<td>reliable information Community nurses are skills based Training is required to support providers in commencing ACP discussions.</td>
<td>discrete elements of palliative management in COPD, but there is limited evidence for models that integrate the multiple domains of palliative care with active management.</td>
<td>planning has been a well-documented barrier Lack of research Some patients and HCPs actively avoid discussions around death</td>
<td>interventions which address the needs of COPD patients</td>
<td>need for timely ACP, however few initiate such discussions Improving providers’ confidence in initiating end-of-life discussions, would assist in implementing ACP</td>
</tr>
<tr>
<td>Fusi-Schmidhauser 2019³ Mixed methods integrative review 24 papers</td>
<td>To explore how palliative care is provided in advanced COPD and to identify elements defining integrated palliative care [Framework: palliative care involvement; holistic needs assessment; management; ACP]</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 Congress care Treating GP refers to specialist for all supportive care. Integrated care. Continuity of care provided by a palliative care team Healthcare policy should support novel care models.</td>
<td>Disease unpredictability Misconception about palliative care being only for cancer and only relevant in the last days of life</td>
<td>Need for enhanced communication (advance care planning, end-of-life care) Open and honest communication between patients, their families and HCPs</td>
<td>Advance care planning is a core component of integrated care</td>
</tr>
<tr>
<td>Jabbarian 2018⁴ 21 papers (13 COPD; 5 mixed CRD) mixed</td>
<td>Providing patients with information about their disease can help meeting their needs.</td>
<td>Training and professional experience of end-of life in CRD Identification of trigger points, and clarity on whose responsibility it is to initiate</td>
<td>Complex disease course of CRD and ambivalence of both patients and HCPs to engage in</td>
<td>ACP is uncommon in CRD.</td>
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<td>Methods</td>
<td>Aim: to describe ACP practice in CRD</td>
<td>transition points and specific triggers (such as hospital admission) may be useful for conducting holistic needs assessment</td>
<td>Care interventions need to be based on patient preferences rather than professionally driven</td>
<td>Treatment optimisation (drug and rehabilitation) improves clinical outcomes</td>
<td>Holistic care across physical, psychosocial and spiritual domains</td>
<td>Uncertain disease trajectory and timing of intervention.</td>
<td>Positive (lay) communication improve patient understanding Use of technology (e.g. a Web-based ACP tool for lung disease) was potentially useful and acceptable.</td>
<td>Key conversations to establish personal preferences and timely information on COPD was a recurrent theme</td>
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<tr>
<td>Mathews 2017&lt;sup&gt;5&lt;/sup&gt;</td>
<td>Rapid review (Not an SR) 19 papers</td>
<td>repetitions 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>Meehan 2020&lt;sup&gt;6&lt;/sup&gt;</td>
<td>28 papers</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</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</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</td>
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<td>Momen 2012&lt;sup&gt;7&lt;/sup&gt;</td>
<td>30 papers</td>
<td>Patient preferences and goals of care</td>
<td>Professional Staff training and composition</td>
<td>Organisational Place/sector and model of care</td>
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<td>Aim: to explore end-of-life care conversations in COPD</td>
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<td>Oishi 2014[^8]</td>
<td>30 qualitative or mixed methods studies (719 patients, 605 carers and over 400 professionals)</td>
<td>Barriers include unpredictable illness trajectory</td>
<td>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>to have these discussions</td>
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| Ora 2019[^9] | 6 papers (4RCTs + 2 unpublished) | Nurse-led holistic assessment | Holistic care delivered more routinely throughout the life-long course of COPD was recommended | There is potential for specialist palliative nurses to lead palliative care teams, however, this would seem an underutilised resource | Two main types of nurse-led palliative care. Led by:
• Specialist palliative care nurses
• Palliative care trained specialist respiratory nurses | Nurse-led ACP intervention improved quality of patient–physician end-of-life care communication | | |
<p>| Ora 2021[^10] | 7 papers | Right timing varies for each individual, and views change over time | Patient readiness and willingness for ACP discussions (including after PR sessions) | 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. | Patients needed rapport and open communication with a trusted health professional who knew them and had a good understanding of their illness. | Patients want HCPs to discuss their concerns for the future, and revisit previously stated preferences as they change over time. | | |
| Singer 2016[^11] | 124 RCTs (19 in COPD) | Most services were home based. Strongest evidence for benefit was in cancer, CHF, and COPD. | Advanced nurse practitioners provided case management, treatment of symptoms and | Nurse-led services, 26% including multidisciplinary teams | 48% involved technology (e.g. telephone, and a few used video consulting). Reinforces a focus | | | |</p>
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<td></td>
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<td>counselling</td>
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<td>on improving communication and psychosocial support</td>
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| Stephen 2013<sup>12</sup> | 14 papers (CRD but all included COPD)  
Aim: highlight key challenges for conducting ACP in nonmalignant CRD |  |  |  |  |  |  |  |
|  |  | Determine patient preferences |  |  |  |  |  |  |
|  |  | Typically triggered by admission, provision of LTOT or deterioration in condition. Barriers included perception of palliative care as end of life |  |  |  |  |  |  |
|  |  | Facilitators included trusting patient/clinician relationship |  |  |  |  |  |  |
|  |  | Uncertain prognosis; unclear point for starting discussion  
Lack of time  
Limited capacity of palliative care services |  |  |  |  |  |  |
|  |  | Frequency and quality of palliative care conversations is generally poor.  
When discussions did happen, they occurred at an advanced stage of illness and in acute wards and ICUs |  |  |  |  |  |  |
|  |  | Patients and physicians identified many barriers and important topics were not discussed. Patients and clinicians reported tension between remaining hopeful and the reality of the condition. |  |  |  |  |  |  |

Abbreviations: ACP= Advance care planning; CRD=Chronic Respiratory Disease; GP= General Practitioner; HCP= healthcare professional; ICU= Intensive Care Unit.
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<td>Ates 2018&lt;sup&gt;st&lt;/sup&gt;</td>
<td>Survey and qualitative interviews with carers (31% COPD: 6 European countries)</td>
<td>Emotional support, empathy and practical support (e.g. provision of respite care, access to resources) were highly valued</td>
<td>Named contact, continuity of care</td>
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<td>Consistent communication: information sharing, was inversely related to carers’ burden</td>
<td>Need to know what to expect and support available.</td>
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<td>Back 2009&lt;sup&gt;st&lt;/sup&gt;</td>
<td>Serial qualitative interviews with 31 HCPs and 55 patients (half with COPD; US)</td>
<td>Abandonment worries related to loss of continuity between patient and physician; After death, feelings of abandonment resulted from lack of closure</td>
<td>Physicians reported lack of closure, but did not discuss this as abandonment</td>
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<td>Carlucci 2016&lt;sup&gt;st&lt;/sup&gt;</td>
<td>Prospective study of 43 patients’ preferences and outcomes</td>
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<td>Crawford 2013&lt;sup&gt;st&lt;/sup&gt;</td>
<td>Qualitative interviews with patients/carers + expert panel +</td>
<td>Lack of a clear transition to an end-stage</td>
<td>Care was perceived as fragmented, episodic and reactive. The role of carers was poorly recognised.</td>
<td>Multidisciplinary palliative approach within disease management Recognition that active disease</td>
<td>Need a flexible model of care that assists people living with advanced COPD to navigate the acute</td>
<td>Absence of a coordinated pathway for support</td>
<td>Coordinated across the primary, acute and community sectors</td>
<td>Absence of ACP conversations.</td>
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<td>Focus groups. (COPD: Australia).</td>
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<td>Management and palliation are complementary, not mutually exclusive.</td>
<td>Healthcare and community support systems, that is patient centred</td>
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<td>den Herder-van der Eerden 2017¹⁸</td>
<td></td>
<td>Need to develop reliable screening and needs assessment tools</td>
<td>Collaborative integrated palliative care initiatives were related to consistent and coherent care</td>
<td>Lack of continuity of care (especially with GPs)</td>
<td>Need a few trusted HCPs who are available, provide multidisciplinary care and regularly transfer information to all HCPs involved</td>
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<tr>
<td>Longitudinal qualitative study with 152 patients and carers (24% COPD; 5 European countries)</td>
<td></td>
<td>Patients and their carers have unmet needs for managing uncertainty and fear, daily living, and finances.</td>
<td>HCP with palliative care mindsets. Embedded psychological care</td>
<td>Integrating palliative with primary care, sharing of information, holistic services</td>
<td>Misconception of palliative care</td>
<td>Communication skills were perceived to be important by HCP</td>
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<td>Fu 2021¹⁹</td>
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<td>A standardized screening and needs assessment tool is required to improve timely palliative care</td>
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<td>Qualitative interviews with 20 COPD patients, 6 carers, 25 HCPs</td>
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| Fusi-Schmidhauser 2021²⁰              | Focus on patients: Multidimensional needs’ assessment should consider:  
patients’ needs  
palliative care timing  
identification of palliative care recipients | Focus on professionals: HCP’s education should:  
theoretical knowledge  
practical knowledge  
experiential knowledge |                                |                              |                                           |              |                               |
<p>| COPD Participatory action research with key professional stakeholders | Focus on care delivery: interdisciplinary team meetings should be a fundamental component of service provision in the integrated palliative care model | Focus on care delivery: interdisciplinary team meetings should be a fundamental component of service provision in the integrated palliative care model |                              |                              |                                           |              |                               |
| Gadoud 2020²¹                        |                  |                                                    |                              |                              |                                           |              |                               |
| Sequential cross-sectional study of deceased adults (including COPD) |                  |                                                    |                              |                              |                                           |              |                               |</p>
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<td>Gardener 2019a22 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>
<td>The SNAP tool asks patients to consider whether they need more support in 15 broad areas.</td>
<td>Clinical stakeholders broadly endorsed the tool’s content and wording</td>
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<td>the introduction of the UK End-of-Life Care Strategy</td>
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<td>Goodridge 200823 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>
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<td>Grossman 201924 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>
<td>Discussing ACP in a group (relevant information, sharing fears, wishes, tradeoffs) was well-received. Two patients reported drawbacks (‘depressing topic’ and ‘a lot of information’).</td>
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<td>Huntley 202025 Quantitative and qualitative</td>
<td>Identified from primary care records as meeting</td>
<td>Joint consultations with respiratory and palliative care</td>
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<td>Hosting the clinic at the hospice helped break the</td>
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<th>Barriers to provision of palliative care</th>
<th>Communication</th>
<th>Q8: Advance care planning (ACP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>evaluation of 107 users of combined respiratory (COPD 71%) and palliative care service</td>
<td>Gold Standard Framework prognostic indicators.</td>
<td>specialists – supported by a community nurse</td>
<td>stigma attached to hospice settings</td>
<td></td>
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<tr>
<td>Iyer 2019²⁶ 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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<tr>
<td>Kelleher 2020²⁷ E-Delphi 38 HCPs to achieve consensus on training requirements</td>
<td>Professional training in ACP should include legal issues</td>
<td></td>
<td>Need information on the best timing and content of ACP discussions with patients with COPD.</td>
<td></td>
<td></td>
<td>Training to enable HCPs to incorporate ACP into routine COPD management</td>
<td>Prognostic awareness, illness burden, and existential concerns delineated how patients made decisions about resuscitation</td>
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<tr>
<td>Pang 2004²⁸ Documentary review of 68 patients and 19 case studies</td>
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<tr>
<td>Payne 2018²⁹ 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>Hospices supported and supplemented other local services; some supplanted other services by providing in-patient facilities.</td>
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<tr>
<td>Philip 2007³⁰ Entry to palliative</td>
<td>Tasks include</td>
<td>Tasks include</td>
<td>Transition to</td>
<td>Care is embedded</td>
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<tr>
<td>Original paper (listed alphabetically)</td>
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<tr>
<td>Development of a conceptual model of care</td>
<td>care occurs routinely triggered by clinical transitions in care</td>
<td>screening for physical and psychological symptoms, social and community support.</td>
<td>provision of information, and discussions around goals and preferences for care</td>
<td>palliative care services is facilitated as the patient nears death</td>
<td>in routine ambulatory respiratory care, ensuring that it is regarded as “usual” care by patients and clinicians alike</td>
<td></td>
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</tr>
<tr>
<td>Sinclair 2020[31] Preference trial of nurse-led ACP (n=149: 95 had COPD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></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>
<td></td>
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<tr>
<td>Smallwood 2019[32] Survey of 64 users of an integrated respiratory and palliative care service (60 COPD)</td>
<td></td>
<td>Continuity of care, high quality communication and feeling cared for were greatly valued.</td>
<td></td>
<td></td>
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<tr>
<td>Tavares 2020[33] Interviews with 33 UK COPD patients</td>
<td>A sudden deterioration in the patient's condition may be a suitable trigger</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>
</tr>
<tr>
<td>Van Gurp 2016[34] Observation of teleconsultations (n=18 patients: 2 with COPD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Teleconsultations improved interprofessional understanding</td>
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</tbody>
</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>• Triggers that initiate palliative care involvement</th>
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<tbody>
<tr>
<td>Beernaert 201435 (HCP: Generic)</td>
<td>Early palliative care approach</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 201436 (HCP: COPD)</td>
<td>Holistic assessment</td>
<td></td>
<td>Multidisciplinary team</td>
<td>Coordinated care</td>
<td></td>
<td></td>
<td>ACP</td>
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<tr>
<td>Broese 202137 (HCP: COPD)</td>
<td>Uncertain timing of referral</td>
<td></td>
<td></td>
<td>Unstructured and little formalised</td>
<td>Lack of time; uncertain prognosis</td>
<td>Communication across services</td>
<td>Reluctance to start conversations</td>
<td></td>
</tr>
<tr>
<td>den Herder 201838 (Patient: COPD 25%)</td>
<td></td>
<td></td>
<td>Relationship with professionals</td>
<td>One lead professional</td>
<td>Continuity of care</td>
<td></td>
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<tr>
<td>Fairlamb 202139 (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>
<td>Unclear who and when</td>
</tr>
<tr>
<td>Fuseya 201940 (Patient: COPD)</td>
<td></td>
<td></td>
<td>Lack of disease knowledge</td>
<td></td>
<td></td>
<td></td>
<td>Patients/physician communication gap</td>
<td>ACP</td>
</tr>
<tr>
<td>Gardener 201941 (Patient: COPD)</td>
<td>Needs assessment tool</td>
<td>Information and practical needs</td>
<td></td>
<td></td>
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<tr>
<td>Goodridge 201942 (HCP: respiratory)</td>
<td>Uncertain prognosis</td>
<td></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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<tr>
<td>Green 201943 (patient: COPD)</td>
<td></td>
<td></td>
<td></td>
<td>Continuity of care</td>
<td>Need clearer signposting</td>
<td>Communication across services</td>
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<tr>
<td>Hirakawa 202144 (HCP: COPD)</td>
<td></td>
<td>Information sharing</td>
<td>Professional training</td>
<td></td>
<td>Communication advanced skills</td>
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<td>Hyden 202045 (Patient: resp)</td>
<td>Uncertain timing of referral</td>
<td>Information and practical needs</td>
<td></td>
<td>Community/home-based care</td>
<td>Lack of time</td>
<td>Care co-ordination, spiritual needs</td>
<td>ACP</td>
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<tr>
<td>Iyer 202046</td>
<td></td>
<td></td>
<td></td>
<td>Clearly defined</td>
<td>Consensus referral</td>
<td>Synonymous with</td>
<td></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>(HCP: COPD)</td>
<td>hospitalisations</td>
<td></td>
<td>roles</td>
<td>criteria</td>
<td>end-of-life</td>
<td>Lack of information from HCPs</td>
<td>Unprepared for death.</td>
<td></td>
</tr>
<tr>
<td>McVeigh 2018^17 (Carer: respiratory)</td>
<td>Uncertain prognosis</td>
<td>Carer: Information/practical needs</td>
<td>Fragmented and variable</td>
<td></td>
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<tr>
<td>Meehan 2019^18 (HCP: COPD)</td>
<td>Increase public awareness of ACP</td>
<td>Professional training</td>
<td></td>
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<tr>
<td>Mousing 2018a^19 (HCP: 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 team communication</td>
<td>Reluctance to start conversations</td>
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<tr>
<td>Mousing 2018b^20 (patient: COPD)</td>
<td></td>
<td>Anxieties about future</td>
<td>Valued continuity of care</td>
<td></td>
<td></td>
<td>Wanted HCP to start discussions</td>
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<tr>
<td>Roberts 2008^21 (HCP: COPD)</td>
<td>Episode of respiratory failure</td>
<td>Multidisciplinary teams</td>
<td></td>
<td></td>
<td></td>
<td>Joint meetings</td>
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<tr>
<td>Rosenfeld 2003^22 (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>
<td></td>
</tr>
<tr>
<td>Scheerens 2018^23 (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 2018^24 (HCP: COPD)</td>
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<td>Professional training</td>
<td></td>
<td>Synonymous with end-of-life</td>
<td></td>
<td>Interprofessional communication</td>
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<tr>
<td>Smallwood 2018^25 (HCP: COPD)</td>
<td>Patient and carer support</td>
<td>Multidisciplinary organisation</td>
<td></td>
<td></td>
<td></td>
<td>Collaborative ACP practice</td>
<td></td>
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<tr>
<td>Sorensen 2020^26 (HCP: respiratory)</td>
<td>Uncertain prognosis</td>
<td>Need awareness of cultural context</td>
<td>Aware of ACP, but rarely conduct</td>
<td>Need multidisciplinary setting</td>
<td>Lack of time;</td>
<td>Barriers to ACP</td>
<td></td>
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<tr>
<td>Thoonsen 2016^27 (HCP: generic)</td>
<td>Uncertain timing of ACP challenging</td>
<td>Professional training</td>
<td></td>
<td>ACP discussions 'difficult'</td>
<td></td>
<td>Training to deliver ACP</td>
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<tr>
<td>Van Scoy 2016^28 (patient: COPD)</td>
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<td></td>
<td>On-line ACP aid is feasible/acceptable</td>
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<tr>
<td>Wichman 2018^29 (HCP: generic)</td>
<td>Uncertain timing of ACP challenging</td>
<td>ACP needs to be individually tailored</td>
<td></td>
<td></td>
<td>Need to allow for changing views</td>
<td>ACP is a ‘hot topic’</td>
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</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, or 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.\(^1\text{-}3,20,35,36,39,42,49,52-54,56,57\) Specific skills required included ability to optimise treatment,\(^2\text{-}5,17\) provide holistic care,\(^2\text{-}5,17,19,20\) and discuss prognosis and ACP.\(^1\text{-}3,9,19,20,23,26,39,45,47,52,56\) in advance of critical events.\(^23\) Lead/co-ordinating professionals could be from specialist respiratory or palliative care disciplines, general practitioners or community nurses,\(^1\text{-}3,8,9\) but continuity of care was described as crucial enabling a trusted relationship to form.\(^2\text{-}3,14,29,35,50\)

• **Flexible, multidisciplinary organisation.** Models of care delivery varied, but key considerations are a service that is accessible (often community-based),\(^1\text{-}2,45\) flexible (to respond to individual needs and a fluctuating clinical condition),\(^2\text{-}17\) and adequately resourced to be able to provide sufficient professional time,\(^1\text{-}3,8,35,39,42,45,49,52,56\) and links to the range of services required to meet physical, psychological, social and spiritual care needs of people with COPD.\(^1\text{-}2,5,14,30,36,45,51\) Multidisciplinary teams need to be collaborative, co-ordinated with good communication and defined referral channels for specialist support as required.\(^2\text{-}3,8,17,18,29,36,37,39,45,46,49,53,55\) Fostering relationships with one - or a very few - trusted professionals was widely emphasised, enabling a sense of continuity within the wider multidisciplinary team.\(^1\text{-}3,14,29,32,33,38,43,49,50,52\)

**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,\(^17,39,47,49\) included allocating a named professional who is accessible and able to signpost resources,\(^1\text{-}4,14,18,29,43\) regular multidisciplinary team meetings,\(^20,29,51,53\) joint consultations,\(^25\) and case management.\(^5\) 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.\(^2\text{-}3,14,18,23,32,35,39,47\) Some studies have suggested that digital communication may be useful including phone calls to check progress,\(^11\) telemonitoring of status,\(^1\) teleconsultations,\(^34\) web-based counselling or support for ACP.\(^5\)

**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,\(^1\text{-}3,5,17,39,42,47,53\) 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.\(^1,17\text{-}19,29,30\) A key advantage was facilitating early provision of holistic care, specifically including early discussions of prognosis and ACP.\(^26,35\) 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,\(^26\) recognising that active disease management and palliation are complementary in a lifelong condition.\(^9,17\)

There is limited evidence for the best approach to integrating the multiple domains of palliative care with active management,\(^2\) but strategies described include joint respiratory/palliative care clinics,\(^25\) providing respiratory clinicians with palliative care skills,\(^19,39,42\) regular inter-professional communication,\(^2,29,52\) 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. The intention was that involvement of a palliative care approach should be regarded as “usual” care by people with COPD and clinicians alike. Underpinning these initiatives was the support of healthcare policy for organisational change and re-alignment of services.

**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. 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. Systematic provision of ACP improved involvement in the treatment decisions made, and recording of wishes of the person with COPD, though with the caveat that pre-stated wishes could change in the acute situation and were not always respected. Benefits of ACP included a positive impact on perceived control, and confidence in self-managing symptoms, but not necessarily health outcomes such as unscheduled care and quality of life which showed variable outcomes.

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 the person with COPD and informal caregiver may be different, and careful discussion may be needed to identify preferences. A significant minority of people with COPD avoid discussion about prognosis, and even if they want information rarely initiate the conversation. Group sessions (e.g. within a pulmonary rehabilitation course) may have some advantages for broaching discussions as they were often perceived as less threatening than individual discussions, though a few found them ‘depressing’.

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. 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.

ACP should be started early, and incorporated into routine COPD care. Organisational barriers to delivering ACP include lack of time and capacity, and lack of clarity on who is responsible for initiating ACP conversations. The identification of triggers (such as repeated need for acute care) that might indicate appropriate timing, and repeating offers of ACP discussions as preferences may change after such events. Use of technology (e.g. a Web-based ACP tool for lung disease) was potentially useful and acceptable.
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 2012</td>
<td>Generic systematic review, no COPD-specific data</td>
</tr>
<tr>
<td>Beraza 2015</td>
<td>Highlights needs but no insights into improved care</td>
</tr>
<tr>
<td>Bigger 2019</td>
<td>Generic systematic review, no COPD-specific data</td>
</tr>
<tr>
<td>Clari 2018</td>
<td>Highlights needs but no insights into improved care</td>
</tr>
<tr>
<td>Dalgaard 2014</td>
<td>Generic systematic review, limited COPD-specific data</td>
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<tr>
<td>Habraken 2007</td>
<td>Highlights needs but no insights into improved care</td>
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<tr>
<td>Janssen 2012</td>
<td>Not a systematic review (Clinical review)</td>
</tr>
<tr>
<td>Oczkowski 2016</td>
<td>Generic systematic review, no COPD-specific data</td>
</tr>
<tr>
<td>Patel 2012</td>
<td>Not a systematic review (Clinical review)</td>
</tr>
<tr>
<td>Phongtankuel 2016</td>
<td>Generic review of current status; minimal COPD data</td>
</tr>
<tr>
<td>Rajnoveanu 2920</td>
<td>Meta review, and not done to SR methodology</td>
</tr>
<tr>
<td>Siouta 2016</td>
<td>Overview of existing guidelines</td>
</tr>
<tr>
<td>Smith 2020</td>
<td>Not palliative care (about components of PR)</td>
</tr>
<tr>
<td>Williams 2020</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

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## Systematic review

### Included paper

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<td>Broese 2021</td>
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<td>Dikior 2019</td>
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<td>Jahberan 2015</td>
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<td>Mathews 2017</td>
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- Shipman 2009
- Simpson 2011
- Simpson 2012
- Sinclair 2017
- Skilbeck 1998
- Smallwood 2019
- Smith 2014
- Smith 2017
- Spathis 2008
- Spence 2009
- Steinel 2003
- Steinhauser 2008
- Stephens 2018
- Strang 2013
- Sullivan 1996
- Szmuilowicz 2010
- Teno 2005
- Thoonsen 2015
- Tierney 2001
- Tzounis 2016
- Uhler 2015
- van Dam van Isselt 2014
- Verma 2018
- Vitacca 2019
- Weber 2014
- Wenrich 2001
- You 2014

### Additional Table COPD-A3. Table of excluded original studies:

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<td>Bushor 2009</td>
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<tr>
<td>Chandramouli 2011</td>
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<tr>
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<tr>
<td>Cohen 2009</td>
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<tr>
<td>Connor DA</td>
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</tr>
<tr>
<td>David 2020</td>
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<tr>
<td>Detering 2016</td>
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<tr>
<td>Duenk 2017</td>
<td>Prediction of mortality post-admission</td>
</tr>
<tr>
<td>Ek 2008</td>
<td>Description of living with COPD, no insights into care provision</td>
</tr>
<tr>
<td>Enguidanos 2018</td>
<td>Conference abstract</td>
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<td>Fleuren 2014</td>
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<td>Systematic review</td>
<td>Reason for exclusion</td>
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<tr>
<td>Cerulus 2022</td>
<td>Generic systematic review, no COPD-specific data</td>
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<tr>
<td>Chyr 2022</td>
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<tr>
<td>Fusi Schmidhauser 2021</td>
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**Additional Table COPD-A4. Table of excluded systematic reviews from the update search:**

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<td>Fried 2016</td>
<td>Generic, no COPD outcomes</td>
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<tr>
<td>Gainza-Miranda 2019</td>
<td>Highlights needs but no insights into improved care</td>
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<tr>
<td>Griffiths 2021</td>
<td>Letter; ACP claims data</td>
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<tr>
<td>Grudzen 2019</td>
<td>Protocol (no report identified); generic ‘non-malignant disease’</td>
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<tr>
<td>Hajizadeh 2010</td>
<td>Modelling outcomes</td>
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<tr>
<td>Hjorth 2020</td>
<td>Generic; majority cancer</td>
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<td>Hung 2013</td>
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<td>Hyden 2019</td>
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<td>Jerpseth 2017</td>
<td>Nursing roles. Not ACP</td>
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<tr>
<td>Kendall 2015</td>
<td>Generic, overview of qualitative studies</td>
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<tr>
<td>Leiter 2018</td>
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<td>Loomer 2021</td>
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<td>McVeigh 2014</td>
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<td>Michaud-Young 2009</td>
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<td>Monteiro 2018</td>
<td>Survey of decisions (CRD), but no insights into improved care</td>
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<tr>
<td>Nava 2007</td>
<td>Survey of decisions (CRD), but no insights into improved care</td>
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<tr>
<td>Pesut 2017</td>
<td>Generic; only one participant had COPD</td>
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<tr>
<td>Reinke 2010</td>
<td>Highlights shortcomings but no insights into improved care</td>
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<td>Rosenwax 2016</td>
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<td>Generic; unclear how many were COPD</td>
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<td>Shangher 2017</td>
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<tr>
<td>Winthereik 2018</td>
<td>Generic palliative care training; no mention of COPD</td>
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</table>
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