SUPPLEMENTARY FILE

S-BOX 1   Search strategy in Medline for the current systematic review

(exp "Advance Care Planning"/ OR ((("Decision Making"/ AND Patients/)) AND ("terminal care"/ OR "palliative care"/ OR "Terminally Ill"/)) OR (((Advance) ADJ3 (plan* OR directive*)) OR ((living) ADJ3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) ADJ6 (terminal* OR "end of life" OR palliativ* OR (life ADJ3 (saving OR saver* OR sustain* OR Prolong*))))).ab,ti.) AND (Pulmonary Medicine/ OR exp "Respiratory Tract Diseases"/ OR exp lung/ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) ADJ3 (disease* OR disorder*))).ab,ti.) NOT ((exp child/ OR exp infant/ OR (child* OR infan* OR adolescen* OR pediatr* OR paediatr*).ab,ti.) NOT (exp adult/ OR (adult OR older OR elderl*).ab,ti.))

S-BOX 2   Search strategy in Embase for the current systematic review

('living will'/exp OR (('patient decision making'/exp) AND ('terminal care'/exp OR 'palliative therapy'/exp OR 'terminally ill patient'/exp OR 'terminal disease'/de)) OR (((Advance) NEAR/3 (plan* OR directive*)) OR ((living) NEAR/3 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 (terminal* OR 'end of life' OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 life NEAR/3 (saving OR saver* OR sustain*))))):ab,ti AND (pulmonology/exp OR 'respiratory tract disease'/exp OR 'lung surgery'/exp OR lung/exp OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/3 (disease* OR disorder*))):ab,ti) NOT ((juvenile/exp OR (child* OR infan* OR adolescen* OR pediatr* OR paediatr*):ab,ti) NOT (adult/exp OR (adult OR older OR elderl*):ab,ti))

S-BOX 3   Search strategy in PsychINFO for the current systematic review

(exp "Advance Directives"/ OR ((("Decision Making"/ AND Patients/)) AND ("Terminally Ill Patients"/ OR "Palliative Care"/)) OR (((Advance) ADJ3 (plan* OR directive*)) OR ((living) ADJ3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) ADJ6 (terminal* OR "end of life" OR palliativ* OR (life ADJ3 (saving OR saver* OR sustain* OR Prolong*))))).ab,ti.) AND (exp "Lung Disorders"/ OR exp lung/ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) ADJ3 (disease* OR disorder*))).ab,ti.) NOT ((100.ag. OR 200.ag. OR (child* OR infan* OR adolescen* OR pediatr* OR paediatr*).ab,ti.) NOT (300.ag. OR (adult OR older OR elderl*).ab,ti.))

S-BOX 4   Search strategy in Cochrane Library for the current systematic review

((((Advance) NEAR/3 (plan* OR directive*)) OR ((living) NEAR/3 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 (terminal* OR 'end of life' OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish*OR dilemma* OR refus* OR choos* OR choice*) NEAR/6 life NEAR/3 (saving OR saver* OR sustain*))))):ab,ti) AND ((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/3 (disease* OR disorder*))):ab,ti) NOT (((child* OR infan* OR adolescen* OR pediatr* OR paediatr*):ab,ti) NOT ((adult OR older OR elderl*):ab,ti))

S-BOX 5   Search strategy in Web-of-science for the current systematic review

TS=(((((Advance) NEAR/2 (plan* OR directive*)) OR ((living) NEAR/2 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/5 (terminal* OR "end of life" OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) NEAR/5 life NEAR/2 (saving OR saver* OR sustain*)))))) AND ((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) NEAR/2 (disease* OR disorder*)))) NOT (((child* OR infan* OR adolescen* OR pediatr* OR paediatr*)) NOT ((adult OR older OR elderl*))))

S-BOX 6   Search strategy in Scopus for the current systematic review

TITLE-ABS-KEY(((((Advance) W/2 (plan* OR directive*)) OR ((living) W/2 (will*)) OR (patient* AND (((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) W/5 (terminal* OR "end of life" OR palliativ*)) OR ((decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) W/5 life W/2 (saving OR saver* OR sustain*)))))) AND ((copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) W/2 (disease* OR disorder*)))) AND NOT (((child* OR infan* OR adolescen* OR pediatr* OR paediatr*)) AND NOT ((adult OR older OR elderl*))))

S-BOX 7   Search strategy in Cinahl for the current systematic review

(MH "Advance Care Planning+" OR (MH "Decision Making, Patient+" AND (MH "terminal Care" OR MH "Palliative Care" OR MH "Terminally Ill Patients+")) OR (((Advance) N3 (plan* OR directive*)) OR ((living) N3 (will*)) OR (patient* AND (decision* OR decid* OR attitude* OR plan* OR preference* OR want OR wish* OR dilemma* OR refus* OR choos* OR choice*) N6 (terminal* OR "end of life" OR palliativ* OR (life N3 (saving OR saver* OR sustain* OR Prolong*)))))) AND (MH "Respiratory Tract Diseases+" OR MH lung+ OR (copd OR bronchi* OR pulmon* OR ((lung* OR respirat*) N3 (disease* OR disorder*)))) NOT ((MH child+ OR MH infant+ OR (child* OR infan* OR adolescen* OR pediatr* OR paediatr*)) NOT (MH adult+ OR (adult OR older OR elderl*)))

S-BOX 8   Search strategy in PubMed publisher for the current systematic review

("Advance Care Planning"[mh] OR ((("Decision Making"[mh] AND Patients[mh])) AND ("terminal care"[mh] OR "palliative therapy"[mh] OR "Terminally Ill"[mh])) OR (Advance care plan*[tiab] OR Advance directive*[tiab] OR living will*[tiab] OR (patient*[tiab] AND (decision*[tiab] OR decid*[tiab] OR preference*[tiab] OR dilemma*[tiab] OR refus*[tiab] OR choos*[tiab] OR choice*[tiab]) AND (terminal*[tiab] OR "end of life" OR palliativ*[tiab] OR life saving*[tiab] OR life saver*[tiab] OR life sustain*[tiab] OR life Prolong*[tiab])))))) AND (Pulmonary Medicine[mh] OR "Respiratory Tract Diseases"[mh] OR lung[mh] OR (copd OR bronchi*[tiab] OR pulmon*[tiab] OR ((lung*[tiab] OR respirat*[tiab]) AND (disease*[tiab] OR disorder*[tiab])))) NOT ((child[mh] OR infant[mh] OR (child*[tiab] OR infan*[tiab] OR adolescen*[tiab] OR pediatr*[tiab] OR paediatr*[tiab])) NOT (adult[mh] OR (adult OR older OR elderl*[tiab]))) AND publisher[sb]

S-BOX 9   Search strategy in Google scholar for the current systematic review

"Advance directive|directives"|"advance * plan|planning"|"living will|wills" copd|pulmonary|lung|respiratory

S-BOX 10   Search strategy in Scielo for the current systematic review

("Advance directive" OR "Advance directives" OR "advance care plan" OR "advance care planning" OR "living will" OR "living wills") AND (copd OR pulmonary OR lung OR respiratory)

S-BOX 11   Search strategy in ProQuest for the current systematic review

(ti("Advance directive" OR "Advance directives" OR "advance care plan" OR "advance care planning" OR "living will" OR "living wills") OR ab("Advance directive" OR "Advance directives" OR "advance care plan" OR "advance care planning" OR "living will" OR "living wills")) AND (ti(copd OR pulmonary OR lung OR respiratory) OR ab(copd OR pulmonary OR lung OR respiratory))

S-TABLE 1 Results of the risk of bias assessment of the quantitative studies

1st author (year)	Au (2012)[18]	Heffner (1997)[21]	Heffner (1996)[22]	Janssen (2011)[23]	Sawicki (2008)[26]	Janssen (2011)[24]	Knauft (2005)[25]	Gaspar (2014)[19]	Heffner (1996)[20]	Smith (2014)[27]
Research hypothesis	1	1	1	1	1	1	1	0	1	0
Study population	1	1	1	1	1	1	1	1	1	0
Selection bias	1	1	1	?	1	1	0	0	1	0
Exposure assessment	1	1	1	1	1	1	1	1	1	1
Outcome	1	1	1	1	0	1	1	1	0	1
Confounding	0	?	?	1	0	1	1	1	?	0
General opinion	1	1	0	1	1	1	1	1	0	0
Total quality score	6	6	5	6	5	7	6	5	4	2

1 = Criterion has been met sufficiently

0 = Criterion had not been met sufficiently

? = Information for rating the criterion was lacking

S-TABLE 2   Quality evaluation of included studies according to the COREQ checklist

1st author (year)	Brown (2012)[30]	Dellon (2010)[28]	MacPherson (2012)[36]	Seamark (2012)[34]	Simpson (2011)[35]	Nguyen (2013)[33]	Burge (2013)[37]	Bajwah (2012)[38]	Hajizadeh (2014)[29]	Crawford (2010)[31]	Gott (2009)[32]
Domain 1: Research team and reflexivity											
Interviewer/ facilitator	+	+	+	-	-	-	-	-	-	-	-
Credentials	+	+	-	-	-	-	-	+ / -	-	-	-
Occupation	+	-	+	+	-	-	-	-	+ / -	-	-
Gender	+	+	+	-	-	-	-	-	-	-	-
Experience & training	+	-	+	+	-	-	-	-	+	-	-
Relationship established	-	-	+	-	-	-	-	-	-	-	-
Participants knowledge of the interviewer	-	-	+	-	-	-	-	-	-	-	-
Interviewer characteristics	-	-	+	-	-	-	-	-	-	-	-
Domain 2: Study design											
Methodological orientation and theory	+	-	+	+ / -	+	+	+	+ / -	+	+	+ / -
Sampling	+	+ / -	+	+ / -	+ / -	+ / -	+	+	-	+	+
Method of approach	+ / -	+	+	+	+	+	+	+	-	-	-
Sample size	+	+	+	+	+	+	+	+	+	+	+
Non-participation	-	+	+	+ / -	-	-	+	+	+	-	-
Setting of data collection	+	+	+	+	+	+	+	-	+	+	+
Presence of non-participants	-	+ / -	+	+	+	+	+ / -	+	-	+ / -	+
Description of sample	+	+	+	+	+	+	+	+	+	-	+
Interview guide	+ / -	+ / -	+ / -	+	+	+	+ / -	+	+ / -	+ / -	+ / -
Repeated interviews	+	-	-	-	+	+	-	-	-	-	-
Recording	+	+	+	+	+	+	+	+	+ / -	+	+
Field notes	+	-	+	+	+	+	-	-	-	-	+
Duration	-	+	+	-	-	-	-	-	+	+	-
Data saturation	-	-	+	-	-	-	+	-	-	-	-
Transcripts returned	-	-	-	-	-	-	-	-	-	-	-

6

Domain 3: Analysis and findings

Number of data coders	+	-	+	+	-	-	+	+	-	-	+
Description of the coding tree	-	-	+ / -	-	-	-	+ / -	+ / -	+ / -	+ / -	+ / -
Derivation of themes	+	-	+	+ / -	+ / -	+ / -	+	+	+	+ / -	+
Software	-	-	+	-	-	-	-	+	+	+ / -	+
Participant checking	-	-	-	-	-	-	-	-	-	-	-
Quotations present	+ / -	+ / -	+ / -	+	+	+	+	+	+	+	+
Data and findings consistent	+	+	+	+	+	+	+	+	+	+	+
Clarity of major themes	+	+	+	+	+	+	+	+	+	+	+
Clarity of minor themes	+ / -	-	+	+	+	+	+	+ / -	+	+ / -	+ / -
Total +	17	12	25	15	14	14	15	14	13	9	13
Total + / -	4	4	3	4	2	2	3	4	4	6	4
Total -	11	16	4	13	16	16	14	14	15	17	15
Total score	19.0	14.0	26.5	17.0	15.0	16.0	16.5	16.0	15.0	12.0	15.0

+ = Criterion had been properly described

+ / - = Description of the criterion was incomplete

- = Description of the criterion was unclearly

S-TABLE 3   Incidence of and attitudes towards ACP: patient perspective

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Au (2012)[18]	Discussing EOL care - 68% would like to discuss EOL care preferences with their HCPs.	Discussing EOL care - 15% had EOL discussions.
Heffner (1996)[22]	Discussing EOL care - 69% wished to learn more explicit details about life-sustaining treatment options. - Most patients wished to actively participate in decisions about life support. Documenting patients' wishes - 89% were interested in learning more about ADs. - 78% found discussions about ADs informative. - 22% found discussions about ADs anxiety provoking but worthwhile. - 99% found discussions with HCPs about ADs acceptable. - 86% wanted to learn more about ADs, 12% had initiated these discussions. - 51% felt that physicians should initiate discussions about ADs. 68% found that discussions about ADs and life-support should occur in the outpatient setting.	Discussing EOL care - 15% had discussions about life-support. - 14% believed physicians understood their wishes. Documenting patients' wishes - 95% heard of ADs. - 42 % completed ADs. - 19% had discussed ADs with HCPs.

Janssen (2011)[23]		Discussing EOL care
		- 12-18% discussed life-sustaining treatments with HCPs.
		- Quality of EOL care communication was rated very low (median score 1.1 (IQR 0.0-2.9) for patients with mild to moderate COPD and median score 1.4 (IQR 0.0-3.4) for patients with severe to very severe COPD).
		- HCPs did not ask about:
		   ○ feelings about getting sicker (53-73%)
		   ○ important things in life (85-80%)
		   ○ what dying might be like (89-92%)
		   ○ spiritual, religious beliefs (87-91%).
		- 69-84% reported no involvement in treatment discussion.

Sawicki (2008)[26]	Discussing EOL care - 50% thought that the clinician should initiate the discussion on EOL care. - Patients felt necessity of considering their treatment options, vast majority considered treatment preferences.	Discussing EOL care - 74% spoke to someone about treatment preferences. - 13% talked with their CF clinician about treatment preferences. - 28% were asked by their CF clinicians if they would want to make decisions about their medical care if they became too ill to make their own decisions. - 79% felt comfortable talking to a CF clinician about EOL care preferences. Clarifying values & goals - 58% had specific wishes about medical treatment.. Documenting patients' wishes - 30% completed an AD. Involving a personal representative - 65% thought about whom they would like to make their healthcare proxy.
Janssen (2011)[24]		Discussing EOL care - Quality of EOL care communication was rated very low (median score 0.0). Clarifying values and goals - Patients reported that HCPs did not address religious beliefs (93%) or important things in the patients' life (83%). - 85% of patients reported no involvement in treatment discussions.
Knauft (2005)[25]		Discussing EOL care - 32% were involved in treatment discussions. Clarifying value sand goals - 75% thought physicians probably/ definitely knew their treatment preferences.
Qualitative study design		
Brown (2012)[30]	Discussing EOL care - Patients would like to discuss EOL care preferences, if sensitively introduced by well-informed HCP.	Discussing EOL care - 2 out of 15 patients had conversations with HCPs about resuscitation. Documenting patients' wishes - 11 out of 15 patients had not seen ADs before.
MacPherson (2012)[36]	Documenting patients' wishes - Patients had doubts about documenting 'preferred priorities of care' due to uncertainty about stability of preferences. - Patients had doubts on usefulness of ADs.	Discussing EOL care - Most reported perceived lack of communication around time of diagnosis. - 2 out of 10 patients reported some discussion about future. - 1 out of 10 patients had discussed ACP with HCPs. - 14 out of 10 patients described consultations with HCPs being very focused on the present/ current problem; future/ treatment preferences were never discussed. - Participants had not discussed general care preferences with HCPs, but all stated they would be comfortable with doing so when asked.

Seamark (2012)[34]	**Discussing EOL care** - All patients were willing to discuss ACP and related issues such as resuscitation. - Discussing ACP was seen as a difficult but worthwhile. - Having to make concrete decisions about EOL care was perceived as being hard.	**Discussing EOL care** - No one recalled discussion in hospital about life prolonging treatment. - Patients recalled admission as being hurried with minimum of discussion with the ambulance crew or attending GP. - Actual inpatient stay was seen as chaotic by most patients with lack of recall about where care took place and by whom. **Documenting patients' wishes** - 1 out of 16 patients had a DNR order at home, however form did not accompany patient to hospital.
Bajwah (2012)[38]	**Discussing EOL care** - Patients would like to discuss EOL care preferences. - Patients felt a need for further information on e.g. prognosis. - All realised importance of discussions about EOL care preferences, but did not know how to initiate them. - Patients felt that HCPs should be able to best judge when discussions about EOL care preferences should take place.	**Documenting patients' wishes** - No patients had formulated EOL plans or considered EOL preferences.
Hajizadeh (2014)[29]	**Discussing EOL care** - Those who had not discussed EOL decisions with their physicians were willing to do it. - Most agreed that their physicians should be involved in the EOL decision-making process. - 8 out of 11 patients found that physicians should talk about their patient's chance of dying from their disease. - 10 out of 11 patients found that physicians should talk about patients' EOL treatment options . - Patients felt that conversations should take place in advance of acute disease. - Importance of EOL decision making mostly related to experience with a family member. **Documenting patients' wishes** - Most expressed desire to complete an AD. - 7 out of 11 patients found that physicians should help patients to make ADs.	**Discussing EOL care** - 8 out of 11 patients knew that they have the right to say no to a breathing machine. - 9 out of 11 patients knew that they have the right to say no to be taken to the hospital. - 1 out of 11 patients had ever talked with HCPs physician about chance of dying from the disease. - 4 out of 11 patients had ever talked about EOL decisions with HCP. **Involving a personal representative** - All patients had heard of a health-care proxy. **Documenting patients' wishes** - 3 out of 11 patients had heard of an AD.

ACP = advance care planning

AD = advance directive

EOL = end-of-life

HCP = healthcare professional

COPD = chronic obstructive pulmonary disease

CF = cystic fibrosis

GP = general practitioner

DNR = do-not-resuscitate

S-TABLE 4   Incidence of and attitudes towards ACP: healthcare professional perspective

First author (year)	Attitudes towards ACP	Experiences with ACP
Quantitative study design		
Janssen (2011)[24]		Discussing EOL care - 6% of both patients and physicians reported having discussed preferences regarding life-sustaining treatment. - 20% talked about life-sustaining interventions with their patients.
Gaspar (2014)[19]	Discussing EOL care - 77% found it very important to discuss EOL care preferences with advanced COPD patients. - 89% found it (very) difficult to discuss EOL care preferences with their patients. - 99% would like EOL care preferences to be further discussed in scientific meetings.	Discussing EOL care - 62% rarely/ never initiated EOL communication. - 68% rarely/ never suggested patients to make decisions about invasive mechanical ventilation/ intubation. - 81% rarely/ never suggested patients to indicate preferences about cardio-pulmonary resuscitation. - 76% rarely/ never suggested patients to make decisions about place of death. Clarifying values and goals - 82% rarely/ never addressed spiritual/ religious beliefs. Documenting patients' wishes - 80% never suggested ADs.
Heffner (1996)[20]	Discussing EOL care - 42% programmes affirmed obligation of HCPs to inform patients regarding all aspects of health care. Documenting patients' wishes - 86% would initiate educational sessions on ADs into their programmes if supplied with appropriate teaching materials.	Documenting patients' wishes: - 33% asked patients about ADs. - 33% presented educational sessions on ADs. - 42% gave written materials on ADs. - Most rehabilitation programmes had no knowledge of their patients' ADs.
Smith (2014)[27]	Discussing EOL care - 69% thought that most patients with advanced COPD wanted to know about their diagnosis, prognosis, and available care options - 41% thought that most patients with advanced COPD, if asked, wanted to discuss their wishes for EOL care. - 76% thought all adult patients with COPD should be offered the opportunity to discuss ACP. - 94% thought that ACP can improve patients' and families' satisfaction about EOL care.	Discussing EOL care - 13% discussed ACP with most patients, 56% with few/ (almost) none. - >50% discussed most/ all of the time diagnosis, incurability of disease, purpose of medical treatment, symptom management options. - 47% preferred discussing ACP in outpatient setting, 80% discussed it in hospital. - 6% felt that ACP makes patients losing confidence in physicians' care. Clarifying values & goals and Involving a p - <30% discussed most/ all of the time appointment of health-care proxy, palliative care options, patients' goals, values and beliefs.

- 77% felt comfortable discussing issues related to death and dying with patients with advanced COPD and their families.
- 71% thought it is appropriate to discuss ACP with seriously ill patients who may recover.
- 35% felt that ACP could destroy a patients' sense of hope.
- 12% were concerned that having ACP discussions with COPD patients would lead to them not returning for further follow up.
- 18% felt that ACP conflicted with other chronic disease management goals.
- 18% felt that discussing ACP conflicts with responsibility to advocate for ICU levels care/ intubation for COPD patients.
- 81% felt comfortable discussing ACP with patients with advanced COPD.
- 77% thought it is essential to discuss ACP after recovery in patients with respiratory failure requiring non-invasive ventilation.
- 94% felt comfortable discussing DNR orders with patients.
- 59% found that ACP should be discussed as a routine outpatient visit.
- 71% thought that ACP is a specialist physician's responsibility.
- 82% felt supported by colleagues in discussing ACP with patients and families.
- 71% felt sufficiently knowledgeable about how to conduct ACP conversations with patients and their families.
- 81% reported interest in further ACP education.

- 65% had previous ACP education, 81% learnt ACP skills by adopting ACP skills from others.

Qualitative study design		
Bajwah (2012)[38]	Discussing EOL care - HCPs did not know when to best initiate discussions about EOL care preferences. - Recognized complexities of delivering information while preserving balance between hope and realism.	Discussing EOL care - Frustrations about poor communication among HCPs and recognition for needed improvement to ensure adequate coordination of end of life care.
Hajizadeh (2014)[29]	Discussing EOL care - All interviewees endorsed the need of having discussions about EOL care preferences, most expressed discomfort and/ or resistance discussing prognostic estimates such as life expectancy with their patients. - 4 out of 5 doctors found that physicians should be involved in	Discussing EOL care - All doctors had discussions about EOL care preferences with patients, mostly in the context of intensive care. - All doctors discussed decision-making or preparation for EOL with patients with severe chronic diseases.

	decision making about EOL care preferences. - 3 out of 5 doctors found that physicians should be required to initiate discussions about EOL care preferences with their patients. - 3 out of 5 doctors believed that discussions about EOL care preferences should take place during outpatient clinic visits. <u>Clarifying values and goals</u> - EOL discussions should address the following topics: patients' possible outcomes and their impact on their quality of life, patients' treatment preferences in term of treatment, patients' preferences in the case of no reasonable chance of recovery, whether patients would like to identify a health-care proxy or surrogate, whether they have previous ADs and the option of not receiving treatment.	
Crawford (2010)[31]	<u>Discussing EOL care</u> - Timing of EOL discussions was crucially dependent on patients' disease pathway. - Language distinctions: 'cancer' has terminal associations; COPD is a medical label with little meaning to patients. - Avoidance of 'death' and 'dying' words from staff and tendency to soften impact of information given to COPD patients; when patients directly asked about death, physicians were unprepared and described anxiety and discomfort. - Lung cancer patients were usually prepared for discussing EOL care preferences by 'planting a seed in their mind'. - COPD patients were not provided with the opportunity for discussing/to discuss EOL care preferences, rather HCPs look for 'cues' to start the discussion. - Patient-initiated discussions were perceived as easier. - Moral and ethical dilemmas were reported: what, who, how, when to tell, while maintaining balance between truth and hope.	
Gott (2009)[32]	<u>Discussing EOL care</u> - Not discussing EOL could limit patient choice. - No consensus on appropriateness of rarely discussing EOL. - Majority thought that whilst they might be the right person to initiate the discussion on EOL care preferences (due to long standing relationship with the patient), there were factors	<u>Discussing EOL care</u> - Discussions about EOL care preferences were rare. - Small minority of GP participants initiate discussions about EOL care preferences earlier in the disease process; typically it was 'too late' for patient to be well enough to make care choices. Most felt that people with COPD receive inadequate information about

identified preventing them from fulfilling this role.
- Practice nurses did not feel that it was their responsibility to start the discussions on EOL care preferences, some reporting that they did not see the very 'terminal' COPD patients because these patients received home visits from the GP, and that they had never received any training in breaking bad news and therefore were ill equipped to manage such discussions.
- Respiratory nurses did identify that they often 'knew' patients well and acted as a more constant point of contact in secondary care than medical staff.
- Acute admission was not seen as a good time for EOL issues to be discussed.

their condition. HCPs often use euphemisms when disclosing a diagnosis of COPD.

ACP = advance care planning

EOL = end-of-life

COPD = chronic obstructive pulmonary disease

AD = advance directive

ICU = intensive care unit

HCP = healthcare professional

S-TABLE 5 Effects of ACP programmes: Outcomes from the interventional studies (n=6)

First author (year)	ACP programme	Study groups (n=participants)	Behavioural outcome
Quantitative study design			
Au (2012)[18]	Based on a patients' questionnaire responses, the HCP and the patient received a one-page patient specific feedback form to stimulate an ACP conversation	Intervention group (n=151) vs control group (n=155)	- Intervention group: threefold rate of EOL discussions with physicians (absolute difference 18.6%, p<.001), higher quality of EOL communication (difference 5.7 points (scale 0-100), p=.03; Cohen effect size 0.21) - No significant effect on number of discussions about patients' feelings about getting sicker, prognosis, what dying might be like, family involvement, asking about things important to patient.
Heffner (1997)[21]	Educational workshop on ADs and other EOL topics	Patients receiving workshop vs care as usual	- Educational group: significant increase (p<0.05) in number of completed living wills (OR=3.6, 95%CI 1.1,12.9), AD discussions (OR = 2.9, 95% CI 1.1,8.3), discussions with physicians about life-support (OR=2.7, 95% 1.0,7.7) and assurance that physicians understand their preferences (OR=3.7, 95%CI 1.3,13.4).
Qualitative study design			
Simpson (2011)[35]	Two loosely structured sessions based on a conversation guide. Each family also got the local health district's brochure on ACP	n=8 (+ 7 informal caregivers)	- 1 patient expressed appreciation for the sessions in terms of social interaction and opportunity for learning. - 1 patient found that the AD template offered a way to ensure that her family member, spouse and very uncertain substitute decision-maker, would have a tangible guidance about the wishes. - Between study visits 1 patient used the template to develop an AD and planned to follow-up by talking about it with her children. - 1 patient pointed out the appreciation for the facilitator's approach.
Nguyen (2013)[33]	A DVD movie to help build patients' knowledge about EOL options and to facilitate patient-physician discussion	n=12	- Most felt DVD did a good job of fulfilling information needs. - Words as 'scary' and 'shocking' were used to describe the visual portrayal of the intubation and tracheostomy processes. Nevertheless most agreed that it was necessary to gain a thorough understanding of the reality of these treatments. - Those who struggled with their diagnosis and prognosis tended to dislike the DVD and not wanting to watch it at all. Generally, the further the participant had progressed in their stages of readiness, the more they expressed that the DVD met their needs.
Burge (2013)[37]	ACP sessions	"attendees" (n=44) vs "non-attendees" (n=23) of the ACP sessions	- 17 described PR&M programmes as appropriate to receive information about ACP and preferable to an acute hospital setting. - 38 patients found information valuable and gave 'peace of mind' in relation to future care. - 34 patients felt that information about ACP is best presented in a group. - No consensus on which health professional should

	present the ACP information. 12 patients of the community-based group and 8 of the hospital-based group followed up with the ACP facilitators, 21 participants went on to complete documentation.