

# Advance care planning in COPD: guidance development for healthcare professionals

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## ABSTRACT

**Objectives** To examine current practices, attitudes and levels of confidence related to advance care planning (ACP) in patients with chronic obstructive pulmonary disease (COPD) among healthcare professionals working in Ireland. This will inform future clinical guidance development.

**Methods** A cross-sectional survey of healthcare professionals.

**Results** There were 143 participants (109 general practitioners, 25 nurses, 7 physiotherapists and 2 consultant physicians). The majority (82%, n=117) cared for patients with COPD weekly, but only 23% (n=33) had initiated ACP with a patient with COPD over the previous 6 months. Overall, 59% (n=85) answered ≥6 of 8 general knowledge questions correctly. Participants demonstrated positive attitudes towards ACP (mean score 3.6/5.0), but confidence levels were low (2.2/4.0). Most thought ACP was appropriate for patients with severe or very severe COPD (71%, n=101%, and 91%, n=130, respectively) but were unsure or felt that it was not appropriate for those with mild–moderate COPD. However, almost all participants (97%, n=139) stated that if a patient expressed a desire to have ACP discussions, they would comply. Topics most likely to be discussed related to diagnosis and treatment options. Death and end-of-life issues were rarely discussed. The death of a family member or friend and participation in support groups were identified as new ‘triggers’ for initiating ACP.

**Conclusions** Targeted education to improve general knowledge and confidence levels among healthcare professionals, together with initiatives to increase public awareness of ACP so that patients themselves might be more inclined to start the discussion, may help increase the uptake of ACP for this patient group.

## BACKGROUND

Chronic obstructive pulmonary disease (COPD) is a common progressive lung disease characterised by airflow limitation and persistent respiratory symptoms, including dyspnoea, cough and sputum production.<sup>1</sup> COPD is progressive, unpredictable and incurable, and for patients with advanced disease, the final years of life are often characterised by functional decline, frequent acute exacerbations, poor quality of life and increasing dependency on informal caregivers.<sup>2,3</sup> It is estimated that 328 million people have COPD worldwide, and it is predicted that it will become the leading cause of death within 15 years.<sup>4</sup>

Among patients with COPD, comorbidities are common, including cardiovascular diseases, osteoporosis, depression and anxiety.<sup>5</sup> Estimating prognosis can be difficult, but comorbidities, particularly cardiovascular diseases, are a strong predictor of mortality in COPD.<sup>6,7</sup> Using the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines, we categorise patients according to symptoms and history of exacerbations. Using this system, we categorise airflow limitation as mild (GOLD 1), moderate (GOLD 2), severe (GOLD 3) or very severe (GOLD 4), and overall symptom burden as low risk (groups A and B) or high risk (groups C and D). The management and treatment of COPD is often based on the GOLD guidelines, with the goals of treatment being to reduce current symptoms and to prevent future exacerbations.<sup>8</sup>

Advance care planning (ACP) is the process of enabling individuals to define their personal goals and preferences for future care, to discuss these with their family and care providers, and to record and review them as required.<sup>9</sup> There is

growing evidence that ACP is associated with positive outcomes, including improvements in the quality of end-of-life care, but most studies to date have been observational and performed with elderly patients, nursing home residents and hospital inpatients.<sup>10–12</sup> For patients with chronic diseases, including COPD, ACP remains uncommon, but evidence is emerging from experimental studies that ACP interventions may lead to improvements in patient–physician communication<sup>13</sup> and COPD symptoms.<sup>14</sup> Qualitative studies with patients with COPD have found that the absence of ACP leads to distressing discussions about resuscitation during acute exacerbations,<sup>15 16</sup> and in general, patients want to make informed decisions about their treatment.<sup>17 18</sup>

There have been few experimental studies in this area to date, and as a consequence, a lack of evidence for whether ACP improves other outcomes for patients with COPD. In addition, healthcare professionals face multiple barriers when trying to implement it into practice.<sup>19</sup> For general practitioners (GPs) in particular, limited time and resources available in primary care are important barriers.<sup>20</sup> For patients with COPD, one of the main barriers to implementing ACP into routine management is the uncertainty around prognosis and the unpredictable disease trajectory.<sup>21 22</sup> Other barriers for this patient group include variability over time in patients' wishes regarding care, concerns about dashing patients' hopes, and a lack of patient and family readiness for discussing the topic.<sup>23 24</sup> Therefore, while there is mounting evidence for the benefits of ACP, it remains an evolving concept, with some complexities and challenges.

We undertook a programme of research that aimed to develop guidance for healthcare professionals on incorporating ACP into routine COPD management in the Irish context. In this paper, we will focus on the methodology and findings of a cross-sectional survey of healthcare professionals, the aim of which was to examine current practices, attitudes and levels of confidence related to ACP in COPD among healthcare professionals working in Ireland. A brief overview of how this knowledge was used to develop guidance for healthcare professionals will also be provided.

## METHODS

An expert working group was convened to support, guide and oversee the project. The group comprised professionals from clinical (medical and nursing), managerial, research and educational backgrounds relevant to this study, and had representatives from universities, hospitals, hospices and palliative care organisations. The group met monthly to develop the study methodology and provided advice regarding survey design, participant recruitment, analysis of data and dissemination of findings.

## Survey development

After a thorough review of the literature located no appropriate survey, the expert working group developed a survey by selecting items from two existing surveys<sup>25 26</sup> and generating one additional question based on relevant literature.<sup>8 27 28</sup> The group reviewed all items for content validity. Wording that was not consistent with Irish practice and legislation was modified accordingly.

The survey addressed six themes, which were selected by the expert working group and informed by a literature review and the group's clinical expertise: (1) ACP practices, (2) ACP knowledge, (3) attitudes towards ACP, (4) confidence discussing ACP, (5) ACP topics discussed and (6) COPD transition points. Themes 1–4 were addressed using items taken from the survey developed by Detering *et al.*<sup>25</sup> Specifically, current practices were measured using four questions related to the initiation of ACP discussions, completion of advance care plans, acting as a witness for an advance care plan and caring for a patient with an advance care plan. General knowledge was assessed with eight statements requiring responses of true, false or not sure; attitudes were assessed with 10 statements and a 5-point Likert scale; and confidence was assessed using eight statements and a 4-point Likert scale. To explore topics discussed, an item from the survey developed by Smith *et al* was used.<sup>26</sup> Participants were presented with 16 ACP topics and were asked to indicate how often they discussed each topic with patients with COPD.

The question generated by the expert working group related to COPD transition points. Participants were presented with a list of four COPD stages according to the GOLD system of categorisation<sup>8</sup> and 10 additional milestones that were based on existing literature.<sup>27 28</sup> They were asked whether ACP should be introduced at each of those time points. Participants were asked an open-ended question about other transition points or milestones that they felt triggered ACP. Demographic data were also collected (see online supplementary file 1 for the full survey).

## Participant recruitment

In order to strengthen the validity of the study findings, a purposeful sampling approach was used to obtain a heterogeneous sample. The expert working group identified that in order to optimise response from GPs, it would be necessary to send postal surveys to this group. Using postal addresses from the Irish Medical Directory, 472 GPs from two counties in the south of Ireland were mailed surveys and a stamped addressed envelope. Other healthcare professionals, including palliative care and respiratory physicians, nurses and physiotherapists, were recruited online through various networks. This group could complete the survey online, using the LimeSurvey platform. LimeSurvey is an interactive and secure web application for

creating, managing and monitoring online surveys.<sup>29</sup> Two weeks following the initial email invitation, one reminder email was sent. The online survey remained active for 6 weeks. Those that were sent a postal survey did not receive a reminder (due to time and budget restraints) and had 6 weeks to return the completed survey. An information sheet was provided to everyone who was invited to participate, and completion of the survey indicated consent to participate.

### Data analysis

Descriptive statistics, including frequencies and percentages, were used to describe participant characteristics and responses to the questions related to ACP experience and practices. Total general knowledge scores (maximum score=8.0) were calculated for each participant. Respondents who did not answer or who responded 'not sure' were coded as incorrect for those items. General knowledge related to ACP was categorised as 'good' if a participant had  $\geq 6$  correct answers.<sup>25</sup>

Responses to the attitudes and confidence statements were tabulated. Mean scores were calculated for each statement. The maximum mean score for each of the 10 attitude statements was 5, and the maximum score for each of the eight confidence statements was 4 (reflective of the 5-point and 4-point Likert scales used). Total mean attitudes and confidence scores were calculated by adding the mean scores for each statement and then dividing by the number of statements. Participants who did not respond to one or more of the items were excluded. SDs for the means were also presented. Data analysis was carried out using SPSS software V.24.

The qualitative data collected from participants' responses to open-ended questions about COPD milestones and triggers for ACP were analysed using content analysis.<sup>30</sup> Components of the statements were highlighted and grouped accordingly. These data were presented in table format for ease of interpretation, and further commonalities were assembled. Codes were then developed to reflect the meaning of frequently occurring statements. Common emerging codes were grouped to form themes.

## RESULTS

### Overview of participants

A total of 143 healthcare professionals completed the survey. This included 109 GPs, which represented 23% of all GPs that were sent postal surveys. The total number of consultant physicians, physiotherapists and nurses who were invited could not be determined as they were recruited via email through various online networks. Therefore, the associated response rates cannot be calculated.

Of the 143 participants, 78% (n=111) worked primarily in a GP practice and 15% (n=22) worked in a hospital setting. Two-thirds (n=97) were female,

**Table 1** Participant characteristics (n=143)

	n (%)
<b>Profession</b>	
GP	109 (76.2)
Nurse	25 (17.5)
Physiotherapist	7 (4.9)
Consultant physician (respiratory or palliative care)	2 (1.4)
<b>Primary workplace</b>	
GP practice	111 (77.7)
Hospital	22 (15.4)
Hospice	1 (0.7)
Other	9 (6.3)
<b>Sex</b>	
Female	97 (67.8)
Male	46 (32.2)
<b>Age (years)</b>	
21–30	3 (2.1)
31–40	31 (21.7)
41–50	52 (36.4)
51–60	38 (26.6)
>60	19 (13.3)
<b>Number of years in current role</b>	
0–10	45 (31.5)
11–20	46 (32.2)
21–30	35 (24.5)
>30	17 (11.9)

GP, general practitioner.

60% (n=100) were aged 41–60 years, and 69% (n=98) reported being in their current role for more than 10 years (table 1).

### Current practices

Overall, 82% (n=117) of participants cared for patients with COPD weekly, and 15% (n=22) had cared for a patient with COPD that had an advance care plan over the previous 6 months. Relatively few participants had been involved in the ACP process with their patients with COPD, with only 23% (n=33) reporting that they had initiated an ACP discussion and less than 4% (n=5) having actually completed an advance care plan with a patient with COPD over the previous 6 months (table 2).

### Knowledge, attitudes and confidence

Overall, 59% of participants (n=85) answered six or more of the eight ACP general knowledge questions correctly (see online supplementary file 2). The overall mean attitude score was 3.57 (out of 5.0). The majority of participants agreed with the statements related to patient autonomy, including 'Patients with decision making capacity who are not terminally ill should have a right to refuse treatment even if that decision may lead to death' (4.20) and 'Healthcare professionals should comply with a patient's wishes even if they conflict with the family's wishes' (4.19).

**Table 2** Participants' experience of ACP in COPD (N=143)

	n (%)
Frequency of caring for patients with COPD	
Weekly	117 (81.8)
Fortnightly	9 (6.3)
Monthly	13 (9.1)
Annually	2 (1.4)
Unknown/missing	2
Cared for patient with COPD that had an advance care plan over the previous 6 months	
Yes	22 (15.4)
No	121 (84.6)
Initiated an ACP discussion with a patient with COPD over the previous 6 months	
Yes	33 (23.1)
No	110 (76.9)
Completed an advance care plan for a patient with COPD over the previous 6 months	
Yes	5 (3.5)
No	138 (96.5)
Acted as a witness for an advance care plan for a patient with COPD over the previous 6 months	
Yes	6 (4.2)
No	137 (95.8)

ACP, advance care planning; COPD, chronic obstructive pulmonary disease.

Participants had some concerns with the practical elements of ACP, with only 39% agreeing with the statement 'The information in an advance care plan is

usually sufficient to guide treatment', and more than one-half agreeing that 'helping patients complete and advance care plan is emotionally draining' (55%). These two statements had mean attitude scores that were lower than the average (3.24 and 2.19, respectively) (table 3).

Levels of self-reported confidence to undertake ACP discussions were relatively low, with a mean confidence score of 2.23 (out of 4.0). Self-reported confidence levels were particularly low in the areas of understanding the roles of decision-making support persons (1.80) and in knowing about the *Assisted Decision-Making (Capacity) Act* (1.61) (table 4).

#### COPD transition points and milestones

The majority of participants (87%) felt that ACP should be implemented into the management of patients with very severe airflow limitation (GOLD 4), but 17%–22% of all participants reported that they were 'unsure' about whether it should be introduced for these patients with mild, moderate or severe airflow limitation (GOLD 1–3). In relation to other COPD milestones, there was widespread agreement that ACP should be implemented if patients express a wish to have such discussions (97%), if severe comorbidities are present (92%), if there have been requirements for changes to the home environment due to health decline (87%), if there are increased episodes of acute care (87%) or if long-term oxygen treatment has commenced (85%). However, in relation to a number of other time points, including when unplanned weight

**Table 3** Self-reported attitudes to advance care planning, patient participation and decision-making

	Strongly agree/agree		Neither agree nor disagree		Disagree/strongly disagree		Mean attitude score (SD)
	n (%)		n (%)		n (%)		
Patients with decision-making capacity who are not terminally ill should have a right to refuse treatment even if that decision may lead to death.	129 (90.2)	7 (4.9)	7 (4.9)				4.20 (0.74)
Most of the time patients do not know enough about healthcare to prepare advance care plans.	41 (28.7)	27 (18.9)	75 (52.4)				3.06 (1.19)
Healthcare professionals should comply with a patient's wishes even if they conflict with the family's wishes.	126 (88.1)	16 (11.2)	1 (0.7)				4.19 (0.65)
Healthcare professionals should be actively involved in helping patients complete advance care plans.	115 (80.4)	24 (16.8)	4 (2.8)				3.97 (0.69)
Healthcare professionals should ignore or overrule a patient's advance care plan if they think treatment might be beneficial.*	5 (3.5)	23 (16.1)	114 (79.7)				3.81 (0.99)
Healthcare professionals should help inform patients about their condition and treatment alternatives when preparing an advance care plan.*	138 (96.5)	2 (1.4)	1 (0.7)				4.38 (0.56)
Healthcare professionals usually know the wishes of their patients regarding end-of-life care without discussion or formal documentation.	11 (7.7)	20 (14.0)	112 (78.3)				3.73 (0.99)
The information in an advance care plan is usually sufficient to guide treatment.	56 (39.2)	63 (44.1)	24 (16.8)				3.24 (0.75)
Most of the time, family members know the patient's preferences regarding end-of-life care.	37 (25.9)	40 (28.0)	66 (46.2)				2.93 (1.05)
Helping patients complete an advance care plan is emotionally draining.	78 (54.5)	41 (28.7)	24 (16.8)				2.19 (0.89)
Mean attitudes score across all 10 items.							3.57 (0.35)

\*Some non-responses, thus n<143.

**Table 4** Self-reported confidence related to ACP skills, roles and responsibilities

	Not confident/ somewhat confident	Very confident/ confident	Mean confidence score (SD)
	n (%)	n (%)	
Initiating ACP discussions with a patient	82 (57.3)	61 (42.7)	2.36 (0.90)
Discussing a patient's illness and treatment options in relation to ACP*	71 (49.7)	71 (49.7)	2.54 (0.83)
Having the skills to discuss ACP	85 (59.4)	58 (40.6)	2.36 (0.83)
Understanding the role of the assisted decision-maker, co-decision-maker, decision-making representative, enduring power of attorney and designated healthcare representative*	117 (81.8)	25 (17.5)	1.80 (0.84)
Answering patients' questions about advance care plans*	85 (59.4)	57 (39.9)	2.32 (0.86)
Answering family members' questions about advance care plans*	88 (61.5)	54 (37.8)	2.27 (0.85)
Complying with a patient's advance care plan*	63 (44.1)	79 (55.2)	2.60 (0.82)
Knowledge of the Assisted Decision-Making (Capacity) Act 2015*	124 (86.7)	17 (11.9)	1.61 (0.82)
Mean confidence score across all eight items			<b>2.23 (0.70)</b>

\*Some non-responses, thus n<143.

ACP, advance care planning.

loss, panic attacks or a loss of ability to participate in recreation activities occur, 21%–25% of participants reported that they were unsure about whether ACP should be introduced at these times (table 5).

Forty-five participants responded to the open-ended question about other milestones. Two main themes emerged from these responses: (1) the death of a family member or friend and (2) COPD support groups. Of the 45 responses, 9 (20%) focused on how the death of a family member or friend, particularly if this person played a role in the patient's care, often triggers ACP discussions in patients with COPD. Five other responses (11%) centred on the role of COPD support groups and how joining such a group may

trigger ACP discussions if a patient witnesses other group members die or experience acute exacerbations that require ventilation. It was also suggested that it may be more acceptable for some patients and carers to be introduced to ACP topics in a group setting.

#### ACP topics discussed

The ACP topics discussed and the frequency at which they are discussed with patients with COPD are presented in table 6. The topics that were most frequently reported by participants to be discussed all or almost all of the time were diagnosis (41%), purpose of medical treatment (34%) and symptom management options (34%). The topics that were most likely

**Table 5** Participants' responses to the question of whether or not ACP should be introduced at the specified stages and milestones\*

	Yes	No	Unsure
	n (%)	n (%)	n (%)
Stages of COPD and spirometric classifications			
GOLD 4: very severe; FEV <sub>1</sub> <30%, predicted	130 (90.9)	6 (4.2)	4 (2.8)
GOLD 3: severe; FEV <sub>1</sub> 30%–49%, predicted	101 (70.6)	14 (9.8)	25 (17.5)
GOLD 2: moderate; FEV <sub>1</sub> 50%–79%, predicted	31 (21.7)	78 (54.5)	31 (21.7)
GOLD 1: mild; FEV <sub>1</sub> ≥80%, predicted	12 (8.4)	104 (72.7)	24 (16.8)
Additional milestones			
Patient expressed wish to have ACP discussions	139 (97.2)	0 0	2 (1.4)
Presence of severe comorbidities	131 (91.6)	4 (2.8)	6 (4.2)
Change in home environment due to health decline	125 (87.4)	10 (7.0)	5 (3.5)
Increasing episodes of acute care	124 (86.7)	8 (5.6)	10 (7.0)
Commencement of long-term oxygen treatment	122 (85.3)	11 (7.7)	8 (5.6)
Clinician's feelings that the time is right	113 (79.0)	11 (7.7)	16 (11.2)
Assistance with self-care due to health decline	109 (76.2)	16 (11.2)	15 (10.5)
Unplanned weight loss	91 (63.6)	16 (11.2)	33 (23.1)
Loss of recreation due to health decline	72 (50.3)	32 (22.4)	35 (24.5)
Patient experiencing panic attacks	61 (42.7)	49 (34.3)	30 (21.0)

\*Non-responses to some items, thus n<143.

ACP, advance care planning; COPD, chronic obstructive pulmonary disease; FEV<sub>1</sub>, forced expiratory volume in one second; GOLD, Global Initiative for Chronic Obstructive Lung Disease.

**Table 6** Advance care planning topics and frequency discussed with patients with chronic obstructive pulmonary disease\*

	All or almost all of the time	Most of the time	About half of the time	Some of the time	Almost none of the time	I do not discuss
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Diagnosis	58 (40.6)	45 (31.5)	12 (8.4)	20 (14.0)	3 (2.1)	1 (0.7)
Incurability of disease	28 (19.6)	37 (25.9)	21 (14.7)	33 (23.1)	17 (11.9)	2 (1.4)
Life expectancy	3 (2.1)	12 (8.4)	13 (9.1)	47 (32.9)	53 (37.1)	11 (7.7)
Possible complications	14 (9.8)	55 (38.5)	27 (18.9)	38 (26.6)	3 (2.1)	0 (0)
Purpose of medical treatment	48 (33.6)	63 (44.1)	17 (11.9)	10 (7.0)	2 (1.4)	0 (0)
Possible need for ventilator assistance	4 (2.8)	8 (5.6)	6 (4.2)	30 (21.1)	63 (44.1)	29 (20.3)
Withholding/withdrawal of medical treatment	1 (0.7)	8 (5.6)	7 (4.9)	21 (14.7)	76 (53.1)	26 (18.2)
Goals, values and personal beliefs	14 (9.8)	24 (16.8)	22 (15.4)	43 (30.1)	27 (18.9)	8 (5.6)
Symptom management options	49 (34.3)	59 (41.3)	20 (14.0)	9 (6.3)	1 (0.7)	0 (0)
Palliative care options	16 (11.2)	22 (15.4)	18 (12.6)	54 (37.8)	25 (17.5)	4 (2.8)
Patient's thoughts on family needs for support	18 (12.6)	25 (17.5)	23 (16.1)	37 (25.9)	32 (22.4)	5 (3.5)
Emotional problems	23 (16.1)	39 (27.3)	25 (17.5)	43 (30.1)	7 (4.9)	1 (0.7)
Social problems	21 (14.7)	40 (28.0)	27 (18.9)	41 (28.7)	8 (5.6)	2 (1.4)
What dying may be like	4 (2.8)	4 (2.8)	8 (5.6)	28 (19.6)	73 (51.0)	22 (15.4)
Spiritual/existential issues	4 (2.8)	4 (2.8)	9 (6.3)	30 (21.0)	63 (44.1)	29 (20.3)
Appointment of designated healthcare representative	4 (2.8)	5 (3.5)	7 (4.9)	35 (24.5)	56 (39.2)	33 (23.1)

\*Non-responses to some items, thus n<143.

to have been discussed by participants almost none of the time were life expectancy (37%), the possible need for ventilator assistance (44%), and the withholding or withdrawal of treatment (53%). What dying may be like and spiritual or existential issues were rarely discussed, with most participants reporting that they discussed these topics almost none of the time or not at all (tables 6 and 7).

## DISCUSSION

This study sought to improve our understanding about current practices, attitudes, and levels of confidence and knowledge related to ACP for individuals with COPD among healthcare professionals working in Ireland. This is particularly timely in light of the introduction of legislation around capacity and healthcare decision-making,<sup>31</sup> about which there has been much discussion.<sup>32 33</sup> Among the most important findings of this study were that (1) although Irish healthcare professionals have positive attitudes towards ACP, self-reported confidence levels in initiating discussions

are low, and relatively few are actually initiating ACP discussions with patients with COPD; (2) while most healthcare professionals agree that ACP should be part of the management of patients with severe COPD, there is some uncertainty around whether it should be introduced for patients with less severe disease; and (3) levels of confidence related to interpreting the relevant ACP legislation and the roles of decision-making support persons are particularly low.

Levels of general knowledge related to ACP were lower in this Irish sample than in a sample of Australian doctors who were asked the same eight general knowledge questions.<sup>25</sup> In the Australian sample, almost 90% of doctors answered at least six of the eight items correctly (prior to receiving ACP training), compared with less than 60% of participants in the current study. Self-reported confidence levels on all eight items measured were also lower in this Irish sample compared with the Australian group, with one of the biggest differences between the Irish and Australian samples being self-reported confidence in

**Table 7** Advance care planning topics most likely and least likely to be discussed with patients with chronic obstructive pulmonary disease

Topics most likely to be discussed (% of participants reporting to discuss the topic 'all or almost all of the time' or 'most of the time')	Topics least likely to be discussed (% of participants reporting to discuss the topic 'all or almost all of the time' or 'most of the time')
Purpose of medical treatment (78%)	Withholding/withdrawal of medical treatment (6%)
Symptom management options (76%)	What dying may be like (6%)
Diagnosis (72%)	Spiritual/existential issues (6%)
Possible complications (48%)	Appointment of designated healthcare representative (6%)
Incurability of disease (46%)	Possible need for ventilator assistance (8%)

understanding the local ACP legislation. This may reflect the fact that ACP legislation has existed in all Australian states and territories for a number of years.<sup>34</sup> By contrast, in Ireland, the *Assisted Decision Making (Capacity) Act 2015* has yet to be fully enacted. Key sections of the Act, including the introduction of new decision-making support options, are due to be rolled out in 2020.<sup>35</sup> The current study provides some confirmation that healthcare professionals working in Ireland require clarity around their legal responsibilities in relation to ACP. This finding replicates what has been reported in other published studies.<sup>12</sup>

It was apparent from participants' responses that, in general, they were confident in complying with a patient's advance care plan when one existed, but were not confident in initiating ACP discussions and even less so in completing advance care plans. Less than one-quarter of participants had initiated an ACP discussion with a patient with COPD over the previous 6 months, and only 5% had completed an advance care plan, despite the fact that more than three-quarters reported caring for patients with COPD on a weekly basis. One explanation for this is the fact that the vast majority of participants were GPs who face additional barriers to hospital-based physicians when attempting to engage in ACP.<sup>20</sup> In the Irish healthcare system, GPs are the major providers of primary healthcare. What differentiates general practice in Ireland apart from many other countries is the fact that here, GPs are usually self-employed professionals who care for public and private patients in the same setting. Around 60% of citizens are classified as private patients and pay a fee at each GP visit, while the remaining 40% are entitled to free GP care due to age, means or medical diagnosis.<sup>36</sup> The majority of patients with COPD fall into the latter category and are cared for under the terms of the general medical services (GMS) contract between GPs and the government. Under this contract, GPs are not resourced to proactively manage chronic conditions, including COPD, or to routinely engage in ACP discussions. The findings of this study indicate positive attitudes and a desire from GPs to be involved in ACP; however, it is likely that their current GMS contract and the associated time and resource constraints act as a barrier to doing so. Similar operational-level barriers to implementing ACP have been reported widely in previous studies.<sup>12</sup>

With regard to COPD stages and milestones that might 'trigger' ACP discussions, the majority of participants were supportive of having ACP discussions with patients who have severe COPD and experience other severe comorbidities and frequent exacerbations. There was some uncertainty among participants around whether ACP discussions should take place with patients who have mild or moderate COPD, with participants being very unlikely to introduce ACP topics to these patients. However, it is usually recommended that in order to be most effective for patients

with COPD, ACP is initiated early and during a stable course of the disease.<sup>2</sup> Of note, almost all participants agreed that ACP topics should be introduced if a patient expresses a wish to have the discussions. These findings support the idea that a combination of increasing awareness among healthcare professionals of the importance of holding these conversations in a timely way, together with increasing public awareness of ACP, may ensure these conversations are prioritised and implemented into routine care where appropriate.<sup>37</sup> There is some evidence that community groups are well placed to promote and increase awareness of ACP among members of the public,<sup>38</sup> while general public awareness campaigns that are based on clear and shared terminology and use a range of media platforms to target different age groups are also effective at improving public awareness.<sup>39</sup>

In analysing participants' responses to an open-ended question, we identified two additional milestones or triggers: the death of a family member or friend and participation in COPD support groups. There is some evidence that group visits in a primary care setting are a feasible and effective way of facilitating discussions about ACP.<sup>40 41</sup> Group visits may represent a practical solution to the problem of implementing ACP discussions in the primary care setting by expanding primary care providers' capacity to engage in such topics with patients. For patients, peer support and the group dynamic may promote engagement in ACP. The results of one small pilot randomised controlled trial carried out in the UK suggest that participation in a self-management course comprising attendance at group sessions at a local community centre is a feasible and cost-effective way of delivering education to patients with COPD and may improve general health outcomes.<sup>42</sup> However, whether this is an effective and feasible way of delivering ACP education has not been established definitively and these initial findings will need to be verified.

#### Future directions

In order to build on the findings of this survey and to gain a greater insight into perceived gaps in current knowledge and education, an e-Delphi survey with two rounds of rating was carried out with healthcare professionals. This enabled us to further prioritise the content of a guidance document for healthcare professionals on incorporating ACP into routine COPD management in the Irish context. The guidance in the document focused on three key areas: (1) ACP legislation, (2) COPD transition points, and (3) ACP discussions and documentation. On completion, the draft guidance document and associated fact sheets were made available to relevant stakeholder organisations and professional bodies for national consultation and feedback over a 4-week period. Feedback was collated and considered by the project team, and modifications were made as necessary. The documents were officially

launched and final versions were again made available to all healthcare professionals. This guidance document will exist alongside an online training module for Irish healthcare professionals. It must be acknowledged, however, that without an adequate legislative framework for ACP, many healthcare professionals will continue to be reluctant to undertake ACP.

### Limitations

This study benefited from a relatively large sample size. However, because the majority of participants were GPs, we were unable to investigate differences between professional groups. It is likely that members of different professional groups have different perceptions of whose role it is to initiate and complete ACP; greater participation from other professional groups, including hospital-based consultants, would have allowed us to explore this further. There were also likely to have been some important differences between responders and non-responders that may have influenced the results. As participation was voluntary, it is possible that this was a biased sample with relatively positive attitudes towards ACP, hence their willingness to participate. Nonetheless, this study offers an important insight into the current state of practice related to ACP in COPD care in Ireland.

### CONCLUSIONS

This study found that healthcare professionals working in Ireland have positive attitudes towards ACP for patients with COPD. However, low levels of confidence in relation to many ACP topics, together with a lack of time and resources, are likely contributing to the relatively low numbers of healthcare professionals that are initiating ACP with patients with COPD. Targeted education related to ACP and COPD for healthcare professionals who work with individuals with COPD, combined with increasing patient awareness of ACP, and a multidisciplinary approach to the delivery of ACP may help increase the uptake of ACP for this patient group.

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analysis plan, analysed the data and drafted the manuscript. All authors read, revised and approved the final version of the manuscript.

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