

# Agreement with, and feasibility of, the emerging recommendations from the Living with Breathlessness study

Findings from an online stakeholder survey

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# Preface

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The Living with Breathlessness study followed more than 500 people with advanced chronic obstructive pulmonary disease (COPD), their informal carers, and healthcare professionals. The over-arching aim of this study, funded by the National Institute for Health Research and Marie Curie, is to identify new approaches to improving care and support for people living with advanced COPD.

Six recommendations emerged from the Living with Breathlessness study work, which were road-tested in a stakeholder workshop at the end of October 2015. This report contains the summary findings from an online survey of wider stakeholders who work with people living with advanced COPD, which was carried out following this workshop in order to further explore these six recommendations.

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<sup>1</sup> On behalf of the Living with Breathlessness study team  
<http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/study-team/>

# Abstract

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Chronic obstructive pulmonary disease (COPD) carries a high symptom burden. Management of patients with advanced COPD should address patients' symptoms and care needs, optimise daily functioning and stabilise health status. The Living with Breathlessness study explored the question of how patients' and carers' needs change along the trajectory of advanced COPD and how guidelines should be amended to meet these changing needs.

Six recommendations emerged from the study, which were road-tested in a stakeholder workshop at the end of October 2015. Following the workshop, we carried out an online survey of wider stakeholders who work with people living with advanced COPD in order to explore further whether they agreed that the recommendations would improve care for people with COPD and what their opinions were on the ease of implementation of such recommendations in their place of work.

Responses were received from 83 stakeholders, including allied health professionals, doctors and nurses, working across primary and secondary care. Overall there was high agreement that all of the recommendations would improve care and support for people with advanced COPD; however, the survey also revealed caution around the ease of implementing some of these recommendations, as well as variation in responses among professional groups and settings. Concerns largely focused on the time and resources needed to implement the recommendations and, in particular, the resources needed to respond appropriately to any unmet needs identified through the more patient-focused and holistic analysis of patient and carer needs that these recommendations represent.

The evidence from this survey suggests that there is a significant level of support for these recommendations among healthcare practitioners working with people with COPD. The vast majority of survey respondents agreed that each of the recommendations has the potential to improve the quality of life for COPD patients.

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<sup>2</sup> <http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/study-team/>



# Abbreviations

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CCG	Clinical commissioning group
COPD	Chronic obstructive pulmonary disease
CSNAT	Carer Support Needs Assessment Tool
NHS	National Health Service
PPI	Patient and Public Involvement



# 1. Introduction

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Chronic obstructive pulmonary disease (COPD) is a chronic progressive condition with a high symptom burden and a high informal carer burden, accounting for one death every 20 minutes in England and Wales.<sup>3</sup> National strategy documents<sup>4</sup> state that quality end-of-life care should be available to patients with any condition, yet, in practice, professionals who work with people with advanced non-malignant disease such as COPD usually rely on planning tools, pathways and service frameworks developed for cancer, which has a different, more predictable, trajectory. Most people with advanced COPD access medical support in primary care, with most general practices likely to have some COPD patients in their practice population. In secondary care, people with COPD are seen by respiratory or general physicians. Community-, practice- and secondary care-based nurses (both respiratory nurses and generalists) are involved in the review and support of patients. Allied health professionals (often referred to as AHP), including physiotherapists and occupational therapists, also have a role, and hospices will also play a role in palliative and end-of-life care, although access to these is limited.

The limited knowledge of support needs and preferences for care in advanced COPD have created uncertainty around the timing and types of relevant and effective supportive interventions. An alternative approach is urgently required based on recognition of the slow, relentless progression of non-malignant disease and its effect on patients and on the informal carers who support them.

To inform this alternative approach, the Living with Breathlessness study was designed to identify new evidence on support needs and care preferences of patients with advanced COPD and their informal carers in order to inform recommendations to improve care and support. This research, carried out in the UK, used a mixed-method, multi-perspective (patients, carers, clinicians), longitudinal approach, incorporating surveys, a discrete choice experiment and both structured and semi-structured interviews. The Living with Breathlessness study is a programme of work led by University of Cambridge, in collaboration with RAND Europe. Full details of this research programme, including the composition of

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<sup>3</sup> Westminster Health Forum. 2011. Moving Towards a National Strategy for Chronic Obstructive Pulmonary Disease (COPD). Westminster Health Forum Keynote Seminar Transcript, 25 January 2011.

<sup>4</sup> Department of Health. 2008. End of Life Care Strategy: Promoting high Quality Care for All Adults at the End of Life. London: The Stationery Office; Department of Health. 2009. End of Life Care Strategy: Quality Markers and Measures for End of Life Care. London: The Stationery Office.

the study team and advisory board, are available on the study website.<sup>5</sup> The over-arching aim is to report variation in experiences and outcomes of care in advanced COPD in relation to:

- i. changing physical, psychological and social support needs of patients and informal carers from patients', informal carers' and health care professionals' perspectives;
- ii. care preferences (places and sources of care); and
- iii. barriers to and facilitators of health care professionals' ability to meet needs.

The findings from the different strands of the Living with Breathlessness research programme led to six emerging recommendations for improving care and support of patients with advanced COPD and their informal carers (these are described in Chapter 2). The target audiences for the recommendations are practitioners working with people with COPD, people involved in commissioning and designing services, and policymakers involved in national strategy. The most relevant audience varies across recommendations, although all will be broadly relevant. These recommendations were reviewed, debated and endorsed by an expert multidisciplinary group (the Living with Breathlessness Study Programme Advisory Group). A summary of the study findings was developed, containing the six emerging recommendations and action points to enable their delivery, as well as the rationale behind each recommendation (the study findings that led to them). A national stakeholder workshop (held in London on 27 October 2015) then considered the suitability, feasibility and acceptability of the six proposed recommendations and action points.

As a follow-up from this workshop, we carried out an online survey of wider stakeholders who work with people with advanced COPD, from both primary and secondary care, with mainly clinical, allied health professional and nursing backgrounds. This report describes the findings from this survey. The specific aims are to:

- i. understand whether there was agreement that the recommendations, if implemented, would improve the care for and support of people living with advance COPD, and whether there was any variation in levels of agreement among professional groups and work settings; and
- ii. gauge how easy or difficult it might be to implement these recommendations in practice.

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<sup>5</sup> Department of Public Health and Primary Care, University of Cambridge. 2016. 'Living with Breathlessness Study.' As of 12 April 2016: <http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/>

## 2. Methods

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In this chapter, the methods for the survey development, mail-out and analysis are described.

### 2.1. Survey development

The over-arching aim during the survey development process was to design a short, low-burden survey tool which captured information about levels of agreement with the Living with Breathlessness study recommendations and information about how easy stakeholders felt it would be to implement these recommendations in practice. During the development process, all questions were reviewed and iteratively revised within the project team. The survey was not piloted externally, but we took a phased approach to the mail-out across the period that the survey was available online, allowing one clarification to be introduced (see Table 1, below). The full survey text is included in Section 5.1.

#### *2.1.1. Summary text for each recommendation*

For each recommendation, a brief, three- to four-line summary of the evidence was developed from the research summaries presented in the 'Living with Breathlessness Study – Improving Care and Support in Advanced COPD: Confidential Summary Report for Stakeholder Workshop'. The aim was to provide summary information about the research evidence underlying each recommendation for respondents who may not necessarily be familiar with the study, while keeping the survey as short as possible. The final text for each recommendation (as used in the survey) is presented in the Appendix.

Following the initial deployment of the survey, after around 40 responses had been received, the wording for the summary text for recommendation 1 was clarified by adding the final sentence, 'Instead, access to care and support should be driven by need'. This edit is simply a clarification and does not change the meaning of the text, and so we did not account for this later change during the analysis, and only the final text is presented below.

**Table 1. Evidence summary for each recommendation**

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Evidence summary for recommendation 1: It is difficult to predict future prognosis or disease trajectories for individuals living with advanced COPD, and we identified this as an important barrier to meeting patients' current support and care needs. Instead, access to care and support should be driven by need.

*Recommendation 1: Stop the continual focus on the challenge of prognosis and unpredictability of trajectories as barriers to meeting needs.*

Evidence summary for recommendation 2: Our research identified that service contacts across primary and secondary care settings were valued by patients and important, but were characterised as largely reactive and brief, with annual reviews focused on clinical assessment, driven by targets. We identified annual reviews in primary care for people living with advanced COPD as a particular opportunity where person-centred care could be incentivised.

*Recommendation 2: Change targets to incentivise patient-centred care within existing services.*

Evidence summary for recommendation 3: In our research we identified wide variation in patients' ability to spontaneously articulate their needs. When we asked patients a direct question about what was the most helpful thing someone could do for them 40% didn't think that there was anything anyone could do, despite a wealth of expressions of need elsewhere in our interviews, particularly when patients self-completed a prototype tool for identifying unmet needs.

*Recommendation 3: Enable identification and response to patient support needs (through evidence-based tools and approaches).*

Evidence summary for recommendation 4: We found that 88% of patients with advanced COPD had an informal carer: a quarter of whom provided help for more than 50 hours a week. Healthcare professionals rarely knew who these carers were, or their support needs. Evidence-based approaches such as the Carer Support Needs Assessment Tool (CSNAT) are available to assess carer support needs; using CSNAT we found most carers identified unmet needs.

*Recommendation 4: Identify and support patients' informal carers (through evidence-based tools and approaches).*

Evidence summary for recommendation 5: Our research found that about half of all patients with advanced COPD reported anxiety or depression, and around half of these had not mentioned this to any healthcare professional. A similar proportion of carers were anxious or depressed.

*Recommendation 5: Identify and respond to psychological morbidity in patients and informal carers.*

Evidence summary for recommendation 6: COPD has a low public profile compared to cancer. We identified the pervasive effect of guilt and stigma of smoking-related conditions on patients and their families. Patients were embarrassed by the reactions of others to their breathlessness in public settings. We found limited understanding of palliative care, and of the role and support needs of informal carers.

*Recommendation 6: Change societal attitudes and understandings of COPD, breathlessness, palliative care and informal carer support.*

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### 2.1.2. Likert scale options

We used two questions with Likert scale response options to measure the strength of agreement with the recommendations and assessment of the implementation of these recommendations in practice. The same two questions were used for each of the six recommendations.

**Table 2. Likert scale response options**

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Please describe your level of agreement with the following statement:

Implementing this recommendation would improve care and support for people with advanced COPD

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

How easy would it be to implement this recommendation in your place of work?<sup>6</sup>

- Very Easy
  - Easy
  - Neutral
  - Difficult
  - Very Difficult
- 

### *2.1.3. Free-text questions*

For each recommendation, an open-ended question was included in order to capture other comments. A final free-text question was also included at the end of the survey.

### *2.1.4. Respondent characteristics*

Three questions designed to capture respondent characteristics were developed. A question about professional groups was developed from the nine (plus ‘other’) high-level staff groups included in the annual NHS staff survey.<sup>7</sup> A question about face-to-face contact with people with COPD was also included, as a modified version of a similar (general) question in the NHS staff survey: ‘As part of your employment do you have face-to-face contact with people with COPD?’ with response options: Yes, regularly; Yes, occasionally; and No. Respondents were also asked whether they work in primary or secondary care, with an ‘other’ response option also available.

Although best practice in survey development suggests that demographic information about participants should be collected at the end of a survey,<sup>8</sup> this has to be balanced against wanting to collect this information for survey respondents who may not finish the entire online survey and wanting to start the survey with a simple, easy-to-answer question. For this reason, and because only a small amount of

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<sup>6</sup> For consistency across recommendations, we asked this question for recommendation 6, even though this recommendation would probably need broader implementation than in individual workplaces.

<sup>7</sup> Picker Institute Europe and NHS. 2015. ‘NHS Staff Survey 2015.’ As of 12 April 2016: <http://www.nhsstaffsurveys.com/>

<sup>8</sup> Edwards, P., I. Roberts, M. Clarke, C. DiGiuseppi, S. Pratap, R. Wentz, & I. Kwan. 2002. Increasing Response Rates to Postal Questionnaires: Systematic Review. *BMJ* 324: 1183.

demographic information was being collected, which was judged to be of a not very sensitive nature, these questions were included on the first page of the online questionnaire.

## 2.2. Stakeholder identification

Stakeholders who work with people with advanced COPD were identified through five different routes.

Route 1: Nine organisations (the British Association of Occupational Therapists and College of Occupational Therapists, Specialist Section, HIV Oncology and Palliative Care; the CHAIN [contact, help, advice, information] Network; the Association for Palliative Medicine; the British Thoracic Society; the Royal College of Physicians; the Association of Chartered Physiotherapists in Respiratory Care; the Association of Respiratory Nurse Specialists; the Primary Care Respiratory Society UK; and the Royal College of General Practitioners) were contacted and asked to circulate the survey link to their contact lists or members.

Route 2: Attendees at the Living with Breathlessness stakeholder workshop, held on 27 October 2015, were asked to complete the survey and to circulate the survey link to their contacts.

Route 3: Clinical commissioning group (CCG) medical director and CCG chief executive email contacts were identified via public websites.

Route 4: The survey was promoted via Twitter through personal accounts (Morag Farquhar and Katie Saunders) and the Cambridge Centre for Health Services Research account.

Route 5: Ad hoc contacts of the research team were also used.

There are obvious limitations to the approach taken, with respondents identified using a convenience sample designed to invite respondents across a range of relevant stakeholders, rather than through any systematic sampling scheme. Responses were received from across professional groups and settings, and, where appropriate, are reported separately by group, and the approach taken was able to identify a range of perspectives. Potential implications of this selection strategy are discussed alongside the conclusions in Chapter 4.

## 2.3. Survey mail-out

Survey invitees (both organisations and individuals) were sent a personalised email invitation from Professor Tom Ling and Dr Morag Farquhar. Organisations that did not respond initially were followed up with two phone call reminders. The surveys were administered using the RAND in-house survey tool Select Survey.<sup>9</sup>

Initial survey invitations were sent on 27 November 2015, with one follow-up phone call to organisations before and one after Christmas. Workshop invitees were sent an email reminder in January 2016, and in this reminder they were asked to cascade the survey link to relevant contacts. Invitations were emailed to CCG contacts in January 2016, and the survey was promoted via Twitter in January 2016. The survey

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<sup>9</sup> SelectSurvey.NETv4.126.000, ClassApps.com, Overland Park, USA.

was available online from the end of November 2015 (after the first email invitations) to the end of January 2016.

## 2.4. Analysis

All responses where at least one question about the Living with Breathlessness recommendations was completed were included in the analysis; 39 out of 122 responses (32.0%) where the respondent only completed questions about the respondent's role or place of work (the first page of the survey) were excluded. Where respondents did not respond to a particular question, this response was excluded from the analysis on a question-by-question basis. The number of survey respondents therefore varies slightly across recommendations; these are reported in the detailed analysis.

Because of small numbers, particularly for the comparisons in responses across professional groups and places of work, we grouped the question responses for the two Likert scale option for analysis. For the question 'Implementing this recommendation would improve care and support for people with advanced COPD', the 'Strongly Agree' and 'Agree' responses were grouped as a single group and compared with the 'Neutral', 'Disagree' and 'Strongly Disagree' responses also grouped together. For the question 'How easy would it be to implement this recommendation in your place of work?' the 'Very Easy' and 'Easy' responses were grouped and compared with the 'Neutral', 'Difficult' and 'Very Difficult' responses. Preliminary analyses (not shown) did not identify any substantially different patterns of findings when 'Neutral' options were included in the 'Easy' group. For the sake of completeness, responses for all options are presented in the Appendix.

For the 'face-to-face contact with people with advanced COPD' question, the 'Occasional' and 'Never' responses were grouped because of small numbers. For the question about professional background, the three groups with the highest numbers of responses (Medical, Nursing, and Allied Health Professional) were included as separate groups, with all other professional backgrounds included as 'Other'. A large number of different responses to the 'place of work' question were received. Of the free-text responses, 'Palliative care/Hospices' and 'Community' were the most frequently identified 'Other' settings, and these were included separately in addition to 'Primary care' and 'Secondary care'. All 'Other' places of work (including integrated care providers, working across more than one setting, university/research workplaces, and all other responses) were included in a final group.

Quantitative responses were summarised using percentages and reported separately by role, contact with people with COPD and place of work using Stata 13.0 and Excel for analysis. Free-text responses were summarised using a narrative synthesis approach, which is an approach to the synthesis of evidence that relies primarily on the use of words and text to summarise and explain – to 'tell the story' – of the findings, using Microsoft Excel 2010 and Microsoft Word 2010.

Finally, for reporting, we developed short-form or synoptic versions of the recommendations, presented in Table 3, and we used these in the following chapter.

**Table 3. Short-form and full recommendation wording**

Recommendation number	Short-form wording	Full wording
1	Stop focusing on prognosis	Stop the continual focus on the challenge of prognosis and unpredictability of trajectories as barriers to meeting needs.
2	Incentivise person-centred care	Change targets to incentivise person-centred care within existing services.
3	Identify and respond to patient support needs	Enable identification and response to patient support needs (through evidence-based tools and approaches).
4	Identify and support carers	Identify and support patients' informal carers (through evidence-based tools and approaches).
5	Respond to psychological morbidity	Identify and respond to psychological morbidity in patients and informal carers.
6	Change societal attitudes	Change societal attitudes and understandings of COPD, breathlessness, palliative care and informal carer support.

## 3. Findings

### 3.1. Survey respondents

This was a small survey; in total 83 full or partial survey responses were received. These included 23 from attendees at the October stakeholder workshop and 14 additional responses from snowballing of the survey link by this group. Twenty nine responses were received via the link sent to the British Association of Occupational Therapists and College of Occupational Therapists, Specialist Section, HIV Oncology and Palliative Care (Table 4).

**Table 4. Survey invitations and responses**

Respondents <sup>1</sup>	Invitations sent <sup>2</sup>	Responses received	Responses from invitation snowballing
Workshop invitees	39	23 (response rate 59.0%)	14 (total, 37)
British Association of Occupational Therapists and College of Occupational Therapists, Specialist Section, HIV Oncology and Palliative Care	Mailing list	29	
CHAIN Network	Mailing list	3	
Mailing list of CCG contacts	226	4 (response rate 1.8%)	1 (total, 5)
Twitter	Approximately 30 tweets/re-tweets and 400–500 click-throughs to survey link	8	
Other	6	1 (response rate 1.7%)	

1. The Association for Palliative Medicine, British Thoracic Society, Royal College of Physicians, Association of Chartered Physiotherapists in Respiratory Care, Association of Respiratory Nurse Specialists, Primary Care Respiratory Society UK, and the Royal College of General Practitioners did not respond/were not able to share the survey link with their members. (response rate from mailing list invitations, 2 out of 9 lists, 22.2%)

2. This figure excludes those invitations which were sent but where the email address was no longer valid, in line with the American Association for Public Opinion Research recommendations for estimating response rates.<sup>10</sup>

<sup>10</sup>American Association for Public Opinion Research (AAPOR). 2016. 'Response Rates – An Overview.' As of 12 April 2016: <http://www.aapor.org/Education-Resources/For-Researchers/Poll-Survey-FAQ/Response-Rates-An-Overview.aspx>

### 3.2. Respondent characteristics

The largest professional group among survey respondents was Allied Health Professionals (30 responses, 36.5%). Medical (21 responses, 25.6%) and nursing (18 responses, 22.0%) professional groups were also represented. A total of 23 respondents (28.4%) reported working in secondary care and 28 (34.6%) in primary care. Of the 82 respondents, 59 (72.0%) who provided information on frequency of contact with people with COPD reported regular contact as part of their work.

**Table 5. Survey respondents**

	Responses	
	(N)	%
<b>All</b>	83	
<b>Professional group (n=82)</b>		
Medical	21	25.6
Nursing	18	22.0
Allied Health Professional	30	36.6
Other*	13	15.9
<b>Place of work (n=81)</b>		
Secondary care	23	28.4
Primary care	28	34.6
Community	7	8.6
Hospice/Palliative care	9	11.1
Other**	14	17.3
<b>Contact with people with COPD (n=82)</b>		
Regular	59	72.0
Occasional/None	23	28.0

\*Free-text responses (professional group, other) include Academic (3), Charity (3), General Management (3), Policy (1), Public health (1), Nurse and patient (1) and Other (1).

\*\*Free-text responses (place of work, other) include University/Research (5), Integrated/both primary and secondary care (4), Charity (2), National government (1), Private practice (1) and Other (1).

### 3.3. Headline findings

Overall there was high agreement that all of the recommendations would improve care and support for people with advanced COPD (from 82.9% for recommendation 1, ‘Stop focusing on prognosis’, to 100% for recommendation 5, ‘Respond to psychological morbidity’). However, only between 20% (recommendation 6, ‘Change societal attitudes’) and 53.4% (recommendation 4, ‘Identify and support carers’) of respondents thought that it would be easy or very easy to implement the recommendations where they work (Table 6).

**Table 6. Headline findings on agreement with and ease of implementation of recommendations**

Recommendation number and short-form wording	Responses (N)	Agree would improve care (%) <sup>1</sup>	Responses (N)	Say would be easy to implement (%) <sup>2</sup>
1. Stop focusing on prognosis	82	82.9	82	43.9
2. Incentivise person-centred care	78	93.6	78	46.2
3. Identify and respond to patient support needs	75	85.3	75	52.0
4. Identify and support carers	75	98.7	73	53.4
5. Respond to psychological morbidity	74	100	75	52.0
6. Change societal attitudes	75	94.7	75	20.0

1. Percentage of respondents who 'Agree' or 'Strongly Agree' that implementing the recommendation would improve care and support for people living with advanced COPD.

2. Percentage of 'Very Easy' or 'Easy' responses to the question 'How easy would it be to implement the recommendation in your own place of work?'

### 3.4. Findings by recommendation

In this section, the findings for each recommendation are reported in turn, with a breakdown of responses by role, place of work and frequency of contact with people with COPD.

#### *3.4.1. Recommendation 1: Stop the continual focus on the challenge of prognosis and unpredictability of trajectories as barriers to meeting needs*

Overall 82.9% of respondents agree or strongly agree that implementing this recommendation would improve care and support for people with COPD. However, the responses varied strongly among professional groups, with agreement ranging from 93.3% of Allied Health Professionals to only 61.9% of doctors. Overall, 43.9% of respondents answered that it would be easy or very easy to implement in their place of work.

**Table 7. 'Stop focusing on prognosis': Findings by role and place of work**

	Responses (N)	Agree would improve care (%) <sup>1</sup>	Responses (N)	Say would be easy to implement (%) <sup>2</sup>
<b>All</b>	82	82.9	82	43.9
<b>Professional group</b>	82			
Medical	21	61.9	21	47.6
Nursing	18	88.9	18	38.9
Allied Health Professional	30	93.3	30	53.3
Other	13	84.6	13	23.1
<b>Place of work</b>	81			
Secondary care	23	87.0	23	34.8
Primary care	28	78.6	28	39.3
Community	7	100	7	71.4
Hospice/Palliative care	9	77.8	9	55.6
Other	14	85.7	14	50.0
<b>Contact with people with COPD</b>	82			
Regular	59	83.1	59	45.8
Occasional/None	23	82.6	23	39.1

1. Percentage of respondents who 'Agree' or 'Strongly Agree' that implementing the recommendation would improve care and support for people living with advanced COPD.

2. Percentage of 'Very Easy' or 'Easy' responses to the question 'How easy would it be to implement the recommendation in your own place of work?'

Forty free-text responses were received. Many respondents suggested that this recommendation was already reflected in their current practice; however, respondents also highlighted that often patients and families do want to have some idea about prognosis (for example, for understanding whether family support is sustainable), and that some assessment of prognosis may be helpful for future care planning, particularly in end-of-life care.

Responses also identified the issue of appropriate services, for example, when hospice care is appropriate, or where services are only appropriate for people with a particularly high level of disease severity; without prognosis, respondents may inappropriately receive high levels of (the wrong) support too early. Respondents also identified the link between funding (for example, 'Continuing Care', the higher levels of supportive funding available in the last months of life), and prognosis.

### *3.4.2. Recommendation 2: Change targets to incentivise patient-centred care within existing services*

Overall, 93.6% of respondents agreed that implementing this recommendation would improve care, and 46.2% reported that it would be easy to implement. This varied strongly across settings, from 37.5% of respondents who work in palliative care to 59.3% of respondents who work in primary care. The lower percentage of people working in 'Other' settings (23.1%) is likely to reflect that most of these settings are

not directly involved in patient care (including universities and policy settings, for example), and so the implementation of the recommendation is less relevant in this group.

**Table 8. 'Incentivise person-centred care': Findings by role and place of work**

	Responses (N)	Agree would improve care (%) <sup>1</sup>	Responses (N)	Say would be easy to implement (%) <sup>2</sup>
All	78	93.6	78	46.2
<b>Professional group</b>	78			
Medical	21	85.7	21	47.6
Nursing	17	100	17	52.9
Allied Health Professional	28	92.9	28	50.0
Other	12	100	12	25.0
<b>Place of work</b>	77			
Secondary care	22	90.9	22	40.9
Primary care	27	92.6	27	59.3
Community	7	100	7	57.1
Hospice/Palliative care	8	87.5	8	37.5
Other	13	100	13	23.1
<b>Contact with people with COPD</b>	78			
Regular	56	92.9	56	48.2
Occasional/None	22	95.5	22	40.9

1. Percentage of respondents who 'Agree' or 'Strongly Agree' that implementing the recommendation would improve care and support for people living with advanced COPD.

2. Percentage of 'Very Easy' or 'Easy' responses to the question 'How easy would it be to implement the recommendation in your own place of work?'

We received 36 free-text responses regarding this recommendation. Broadly the responses were supportive, with 17 of the responses suggesting that this approach was likely to be important or add value. Where criticism of this recommendation did arise (4 responses), this largely focused around how patient-centred care might be implemented. One concern raised was workload, and how this would fit into already overburdened schedules or short appointment slots. Another was that this would introduce even more targets that healthcare professionals would have to meet. This concern around targets or patient-centred care becoming a 'tick-box exercise' was expressed more widely, having been mentioned by 6 respondents in total, including several respondents who were largely supportive of the recommendation overall. For example, one respondent suggest that 'It is difficult to incentivise [patient-centred care] and expect good outcomes. [For example] when we have been given incentives to discuss preference place of care it becomes tick box'.

In addition, concern was expressed by respondents about whether appropriate targets could be developed for patient-centred care, and indeed whether it was clear what patient-centred care should look like in practice. One respondent summarised this as follows: 'Completely agree – if we know what patient centred care is!' More generally, five respondents suggested that support and training may be needed to

bring this into practice. For example, one respondent suggested that ‘Nurses need more time and training. They need confidence to discuss mental health issues and end of life conversations’. In particular, primary care was identified as an area that can be target-focused and where some culture change was needed to implement more patient-centred care. However, despite some of these concerns, 12 respondents noted that they already use a patient-centred approach. Some comments suggested that this type of approach is more widely employed in hospice settings at present, though based on the responses received, it is clear to us that this is by no means exclusively the case.

### 3.4.3. Recommendation 3: Enable identification and response to patient support needs (through evidence-based tools and approaches)

Overall, 85.3% of respondents agreed that implementing this recommendation would improve care, and 52.0% reported that it would be easy to implement in their place of work. Views on ease of implementation varied strongly among settings, with 38.1% of respondents from secondary care, 57.7% from primary care and 83.3% (5 out of 6) respondents from community settings reporting that it would be easy to implement. The primarily non-patient-facing roles in the other professional groups (25.0%) and settings (38.5%) reported that the recommendation would be less easy to implement for them.

**Table 9. ‘Identify and respond to patient support needs’: Findings by role and place of work**

	Responses (N)	Agree would improve care (%) <sup>1</sup>	Responses (N)	Say would be easy to implement (%) <sup>2</sup>
<b>All</b>	75	85.3	75	52.0
<b>Professional group</b>	75			
Medical	21	85.7	21	42.9
Nursing	16	87.5	16	62.5
Allied Health Professional	26	84.6	26	65.4
Other	12	83.3	12	25.0
<b>Place of work</b>	74			
Secondary care	21	81.0	21	38.1
Primary care	26	88.5	26	57.7
Community	6	100.0	6	83.3
Hospice/Palliative care	8	87.5	8	75.0
Other	13	76.9	13	38.5
<b>Contact with people with COPD</b>	75			
Regular	54	88.9	54	57.4
Occasional/None	21	76.2	21	38.1

1. Percentage of respondents who ‘Agree’ or ‘Strongly Agree’ that implementing the recommendation would improve care and support for people living with advanced COPD.

2. Percentage of ‘Very Easy’ or ‘Easy’ responses to the question ‘How easy would it be to implement the recommendation in your own place of work?’

We received 29 free-text responses regarding this recommendation, with a range of concerns. One of the most commonly raised concerns was the need for culture change to put the recommendation into practice

and the challenges inherent in such changes (7 responses), alongside concerns about time pressures, both in terms of using the specific tools and in terms of following up on the needs identified. The need for follow-up in particular was identified by four respondents, with one stating that ‘it is the work and change generated following the identified unmet need which will be a challenge to manage’.

Six respondents suggested that they were already using, or had used in the past, a tool to identify wider patient needs, though the specific tools used differed among respondents. Two further respondents noted a need for training to support the implementation of any such tool.

#### *3.4.4. Recommendation 4: Identify and support patients’ informal carers (through evidence-based tools and approaches)*

There was very strong agreement (98.7%) that implementing this recommendation could improve care and support for people with advanced COPD. Overall, 53.4% agreed that it would be easy to implement, ranging from 75% (6 out of 8 responses) in a hospice setting to 47.6% in secondary care. Again people in other (generally non-patient-facing) professional groups (41.7%) and settings (46.2%) were less likely to agree that the recommendation would be easy to implement.

**Table 10. ‘Identify and support carers’: Findings by role and place of work**

	Responses (N)	Agree would improve care (%) <sup>1</sup>	Responses (N)	Say would be easy to implement (%) <sup>2</sup>
<b>All</b>	75	98.7	73	53.4
<b>Professional group</b>	75			
Medical	21	100	20	35.0
Nursing	16	93.8	15	46.7
Allied Health Professional	26	100	26	76.9
Other	12	100	12	41.7
<b>Place of work</b>	74			
Secondary care	21	100	21	47.6
Primary care	26	100	25	52.0
Community	6	83.3	5	60.0
Hospice/Palliative care	8	100	8	75.0
Other	13	100	13	46.2
<b>Contact with people with COPD</b>	75			
Regular	54	98.1	52	57.7
Occasional/None	21	100.0	21	42.9

1. Percentage of respondents who ‘Agree’ or ‘Strongly Agree’ that implementing the recommendation would improve care and support for people living with advanced COPD.

2. Percentage of ‘Very Easy’ or ‘Easy’ responses to the question ‘How easy would it be to implement the recommendation in your own place of work?’

We received 29 free-text responses regarding this recommendation. A number of respondents (12) suggested that they do address carers’ needs, though to differing extents, using a range of existing tools.

However, two suggested that this is not always done well and that there is scope for improvement in this area.

Four respondents raised concerns about whether identified needs could be acted upon, suggesting that this could be challenging and hence limit the utility of specific tools in practice. Two respondents expressed concern over the number of different questionnaire tools available, and whether this could be burdensome for both respondents and practitioners. Again, concerns around the time and resources to implement such a tool were expressed (by eight respondents), in terms of the direct use of the tool, but more notably in terms of the ability to follow up needs identified. Awareness raising was also noted as an issue by two respondents. For example, one respondent was involved in the provision of a carers support service but felt that more needed to be done to ensure that carers were aware that it was available. In addition, one respondent pointed to the importance of healthcare practitioners being aware of the range of services available and recommending these to patients and carers, based on their own professional judgement. Finally, one respondent identified the need for training if specific tools are to be implemented.

#### *3.4.5. Recommendation 5: Identify and respond to psychological morbidity in patients and informal carers*

All (100%) of respondents agreed that implementing this recommendation would improve care and support for people with COPD. Of these, 52% agreed that it would be easy to implement, with 65.4% of those respondents working in primary care and 42.9% of respondents working in secondary care. Again, 'Other' groups reported the lowest agreement.

**Table 11. 'Respond to psychological morbidity': Findings by role and place of work**

	Responses (N)	Agree would improve care (%) <sup>1</sup>	Responses (N)	Say would be easy to implement (%) <sup>2</sup>
<b>All</b>	74	100	75	52.0
<b>Professional group</b>	73			
Medical	20	100	21	42.9
Nursing	16	100	16	68.8
Allied Health Professional	26	100	26	57.7
Other	11	100	11	36.4
<b>Place of work</b>	72			
Secondary care	21	100	21	42.9
Primary care	25	100	26	65.4
Community	5	100	5	80.0
Hospice/Palliative care	8	100	8	50.0
Other	13	100	13	30.8
<b>Contact with people with COPD</b>	73			
Regular	53	100	54	57.4
Occasional/None	20	100	20	40.0

1. Percentage of respondents who 'Agree' or 'Strongly Agree' that implementing the recommendation would improve care and support for people living with advanced COPD.

2. Percentage of 'Very Easy' or 'Easy' responses to the question 'How easy would it be to implement the recommendation in your own place of work?'

We received 32 free-text responses regarding this recommendation. A major concern expressed here was around the ability to provide appropriate care where needs are identified. Identifying psychological morbidity was not considered to be challenging, and many respondents (8) suggested that tools were already available to do this (even if they are not used as widely as they should be); however, the limiting factor identified by 11 respondents was the ability to then support those needs. For example, one respondent suggested that for this recommendation to be implemented, there would need to be 'adequate and accessible local mental health support, including for those housebound', also stating that 'plenty of measures to support assessment [are] available'.

In addition, four respondents identified the need for additional support or training to implement this recommendation. For example, one respondent suggested that 'HCPs [Health Care Professionals] feel they don't have the skills to start these conversations and raise these issues'. Several respondents also identified the time to carry out such assessments as being an issue. However, seven respondents indicated that they already identify and respond to such needs as part of their existing practice; the specific services available and approaches used differed among respondents.

### *3.4.6. Recommendation 6: Change societal attitudes and understandings of COPD, breathlessness, palliative care and informal carer support*

Overall, 94.7% of respondents agreed that implementing this recommendation would improve care and support for people with advanced COPD. Only 20% believe it would be easy to implement in their place

of work, of whom zero respondents from the ‘Medical’ professional group and 7.7% of people working in primary care settings.

**Table 12. ‘Change societal attitudes’: Findings by role and place of work**

	Responses (N)	Agree would improve care (%) <sup>1</sup>	Responses (N)	Say would be easy to implement (%) <sup>2</sup>
<b>All</b>	75	94.7	75	20.0
<b>Professional group</b>	74			
Medical	21	95.2	21	0.0
Nursing	16	93.8	16	18.8
Allied Health Professional	26	92.3	26	38.5
Other	11	100	11	18.2
<b>Place of work</b>	73			
Secondary care	21	95.2	21	23.8
Primary care	26	92.3	26	7.7
Community	5	100	5	20.0
Hospice/Palliative care	8	87.5	8	37.5
Other	13	100	13	30.8
<b>Contact with people with COPD</b>	74			
Regular	54	92.6	54	22.2
Occasional/None	20	100.0	20	15.0

1. Percentage of respondents who ‘Agree’ or ‘Strongly Agree’ that implementing the recommendation would improve care and support for people living with advanced COPD.

2. Percentage of ‘Very Easy’ or ‘Easy’ responses to the question ‘How easy would it be to implement the recommendation in your own place of work?’

We received 30 free-text responses regarding this recommendation. All but one of these responses was generally supportive of this as an aspiration, but doubts were cast by many on the feasibility of being able to facilitate a change in public attitudes (9 respondents). It was suggested by several respondents that a change in public attitudes is not something that can be effected at an individual workplace, but that this requires a wider national level strategy. Perhaps this explains why only 20% of respondents felt that it would be easy to implement this recommendation in their workplace.

A range of suggestions around how this recommendation could be put into practice were offered, ranging from a marketing campaign led by Macmillan Cancer Support or the British Lung Foundation to having a character on the television series *Coronation Street* with COPD. One individual suggested that a change of name from COPD to chronic lung disease could help facilitate public engagement, because even the acronym COPD can make public engagement more challenging. Several respondents reflected that they had observed feelings of guilt or shame among their own patients (4 respondents), and a number commented that public awareness and understanding of the disease is low (4 respondents). Several respondents (7) stressed the importance of this recommendation, even if it is likely to be a more challenging, longer-term goal.

## 4. Conclusions

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### 4.1. Main findings

The evidence from this survey suggests that there is a significant level of support for these recommendations among healthcare practitioners and others working with people with COPD. The vast majority of respondents agreed that each of the recommendations would have the potential to improve quality of life for COPD patients, but respondents also expressed caution around ease of implementation of these recommendations, with only around half of respondents indicating that implementation would be straightforward in most cases. Concerns largely focus on the time and resources needed to implement these findings and, in particular, to respond appropriately to any unmet needs identified through more patient-focused and holistic analysis of patient and carer needs. There was also a notable dissatisfaction with ‘tick box’ or target-led approaches, so care would need to be taken to ensure that any adopted recommendations do not just add another item to the list of targets practitioners have to meet. Many respondents felt that they were already incorporating many elements of these recommendations into their existing practice, suggesting that, although there may be some challenges in implementing these recommendations, they are not insurmountable.

There was some variation in agreement among the six recommendations. In particular, agreement for the recommendation to ‘Stop focusing on prognosis’ was lower than for other recommendations, and free-text responses identified several areas where prognosis was important – identifying that further explanation may be needed around this recommendation to increase support across all groups if it is to be successfully translated into practice. In general, respondents felt that the recommendation to ‘Change societal attitudes’ would be very hard to implement (at least on an individual level or in their place of work), although there was strong support for this as a longer-term goal.

There was also some variation in support for the recommendations among the different professional groups. People with a medical background were less likely to agree that recommendation 1 (‘Stop focusing on prognosis’) would improve care and support for people with COPD. For recommendations 2 (‘Incentivise person-centred care’), 3 (‘Identify and respond to patient support needs’) and 5 (‘Respond to psychological morbidity’), people working in primary care were more likely to report that it would be easy to implement than were people working in secondary care. However, only 7% of people working in primary care thought it would be easy to implement recommendation 6 (‘Change societal attitudes’).

One of the consistent findings from across the survey recommendations is that the ‘Other’ professional group and people working in ‘Other’ settings were less likely to agree that the recommendation would improve care and were less likely to agree that it would be easy to implement the recommendation in

practice. Although any finding related to ‘Other’ groups is generally difficult to interpret because this category contains the responses of people from diverse backgrounds, the free-text responses given by the ‘Other’ group primarily identify non-patient-facing roles and settings, and so these findings are likely to indirectly reflect the fact there is less agreement with recommendations among groups for which these recommendations are perhaps less relevant. This should be taken into account in the future dissemination of the recommendations.

Finally, in the course of this research and our reporting on it – as well as during the review of this report by independent quality assurance reviewers at RAND Europe – it became clear that in a couple of cases the wording of the recommendation or evidence summary could be improved upon. These are set out below, with changes highlighted in italics.

- Evidence summary for recommendation 2: Our research identified that service contacts across primary and secondary care settings were valued by patients and important, but were characterised as largely reactive and brief, with annual reviews focused on clinical assessment, driven by targets. We identified annual reviews in primary care for people living with advanced COPD as a particular opportunity where person-centred care could be incentivised.
- Recommendation 3: Enable identification *of* and response to patient support needs (through evidence-based tools and approaches).
- Recommendation 6: Change societal attitudes *to* and understandings of COPD, breathlessness, palliative care and informal carer support.

We do not expect that the original wording of the phrases for which minor wording changes are proposed above will have led to substantial misunderstanding among survey responders; however, the realisation that the wording could be improved upon does present the opportunity to clarify the wording of the recommendations and evidence summaries prior to any future dissemination and implementation efforts. It is also worth noting that people from a range of backgrounds in the field were able to understand and engage with these short descriptions and express opinions and concerns around them. This suggests that once they have been refined and finalised, the evidence summaries may serve as useful tools in further communication and implementation of the recommendations.

## 4.2. Context

It is important to consider the findings from this research in the context of the NHS in the UK in 2016, particularly considering the pressure on and competing demands in primary care, the increase in the burden of chronic disease, the challenges of care integration, and issues of continuity of care with a disease that includes episodes of exacerbation and hospitalisation. The strong agreement with recommendations to improve care and support for people with advanced COPD, accompanied by caution around ease of implementation, probably reflects the high professional values and aspirations of health service professionals to provide the best care possible, but also the pressured and difficult context in which they work. This is reflected in many of the concerns around implementation that were raised, such as lack of time and resources.

### 4.3. Limitations of the research

There are some limitations to the research presented, primarily relating to the survey sampling. Although a range of responses were received across professional groups, working across both primary and secondary care and wider settings, use of a convenience sample limits the generalisability of the findings. The main concern with this type of sampling is that people who are more interested in the topic of a survey are more likely to answer,<sup>11</sup> and in the context of this research this may mean that people who are more likely to support the recommendations, perhaps those with a good understanding of holistic, patient-centred care, are over-represented among respondents. However, the variation in agreement identified among the different groups of respondents gives important insight into areas of higher or lower support for the recommendations even if absolute levels of agreement may be over-estimated. The generalisability of the survey findings is also limited by the size of the sample. This is a small survey and as such cannot be generalised to the full population of relevant stakeholders at a national level. Rather, it gives some impression of the kinds of concerns and views we might expect to see among some practitioners and other stakeholders in the field.

### 4.4. Recommendations

The findings of this research suggest three areas which may support or increase the future dissemination, take up and translation into practice of these recommendations.

- Ensure that each recommendation is clearly targeted at the most relevant groups for implementation. For example, recommending that a clinician or nurse change policy will be less effective than targeting this recommendation at policymakers, whereas recommending the careful and appropriate use of incentives may be most effectively targeted at commissioners.
- Consider and address the concerns of stakeholders expressed in the free-text responses. Although in this survey the support for the recommendations was very high, concerns were expressed, particularly (though not exclusively) around the likely ease of implementation. Although these concerns may or may not be founded, they are concerns that may be shared across groups, and so addressing them head-on is likely to increase and improve wider support for and uptake of these recommendations in practice.
- Consider focal changes to, and professional copyediting of, the wording of some recommendations before they are used in the future – particularly the three-line evidence summaries if they are going to be used more widely. This work suggests that these summaries might be useful tools to support the wider discussion of the recommendations. If they are to be used in this way, the wording should be piloted among people completely removed from the study and the study context. This may identify issues that are less apparent to people more closely involved with the research and study findings.

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<sup>11</sup> Saunders, C.L. 2016. 'Taking an Interest: What Makes Someone Respond to a Survey.' Statistics Views. As of 12 April 2016: <http://www.statisticsviews.com/details/feature/8739491/Taking-an-Interest-What-Makes-Someone-Respond-to-a-Survey.html?platform=hootsuite>

## 4.5. Concluding remarks

COPD is a chronic progressive condition with both a high symptom burden and a high informal carer burden. Through the Living with Breathlessness study, six recommendations have been identified for improving care and support for people with COPD, and these have been further tested out through wider stakeholder engagement, by means of a survey. The findings from this survey will hopefully increase the impact of the Living with Breathlessness study in the jump from high-quality academic research designed to address an evidence gap to practical translation and implementation of the findings into practice.

## 5. Appendix

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### 5.1. Full survey wording

**Survey title (appeared on each page):** Improving Care and Support for people with COPD

**PAGE 1:**

The Living with Breathlessness study followed over 500 people with advanced COPD, their informal carers, and healthcare professionals. The over-arching aim of this NIHR and Marie Curie funded study is to identify new approaches to improve care and support in advanced COPD.

Six recommendations emerged which were road-tested in a stakeholder workshop at the end of October 2015. This survey is designed to further test these recommendations, with a wider group of stakeholders who work with people with COPD.

This survey will take about 15 minutes to complete, and your responses will help develop and refine these recommendations. We would be very grateful for your response.

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**PAGE 2:**

1. How would you describe your professional group?
  - Medical
  - Nursing
  - Allied Health Professional
  - Social Care
  - Commissioning
  - General Management
  - Academic
  - Public Health
  - Policy
  - Other, please specify
2. Would you describe your place of work as ...?
  - Primary care
  - Secondary care
  - Other, please specify
3. As part of your employment do you have face-to-face contact with people with COPD?
  - Yes, regularly
  - Yes, occasionally
  - No

**PAGE 3:**

We will present each recommendation in turn, prefaced with a very brief summary of the underpinning research findings, and ask for your assessment of:

- 1) Whether implementing the recommendation would improve care and support for people living with advanced COPD.
- 2) How easy it would be to implement the recommendation in your own place of work.

More details of the Living with Breathlessness study can be found [here](#). Please use the box following each recommendation for any additional comments

**PAGE 4:**

It is difficult to predict future prognosis or disease trajectories for individuals living with advanced COPD, and we identified this as an important barrier to meeting patients' current support and care needs. Instead, access to care and support should be driven by need.

Recommendation 1: Stop the continual focus on the challenge of prognosis and unpredictability of trajectories as barriers to meeting needs

4. Please describe your level of agreement with the following statement:

Implementing this recommendation would improve care and support for people with advanced COPD

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

5. How easy would it be to implement this recommendation in your place of work?

- Very Easy
- Easy
- Neutral
- Difficult
- Very Difficult

6. Additional comments (optional)

**PAGE 5:**

Our research identified that service contacts across primary and secondary care settings were valued by patients and important, but were characterised as largely reactive and brief, with annual reviews focused on clinical assessment, driven by targets. We identified annual reviews in primary care for people living with advanced COPD as a particular opportunity where person-centred care could be incentivised.

Recommendation 2: Change targets to incentivise patient-centred care within existing services

7. Please describe your level of agreement with the following statement:

Implementing this recommendation would improve care and support for people with advanced COPD

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

8. How easy would it be to implement this recommendation in your place of work?
  - Very Easy
  - Easy
  - Neutral
  - Difficult
  - Very Difficult
9. Additional comments (optional)

**PAGE 6:**

In our research we identified wide variation in patients' ability to spontaneously articulate their needs. When we asked patients a direct question about what was the most helpful thing someone could do for them 40% didn't think that there was anything anyone could do, despite a wealth of expressions of need elsewhere in our interviews, particularly when patients self-completed a prototype tool for identifying unmet needs.

Recommendation 3: Enable identification and response to patient support needs (through evidence-based tools and approaches)

10. Please describe your level of agreement with the following statement:  
Implementing this recommendation would improve care and support for people with advanced COPD
  - Strongly Agree
  - Agree
  - Neutral
  - Disagree
  - Strongly Disagree

11. How easy would it be to implement this recommendation in your place of work?
  - Very Easy
  - Easy
  - Neutral
  - Difficult
  - Very Difficult
12. Additional comments (optional)

**PAGE 7:**

We found that 88% of patients with advanced COPD had an informal carer, and a quarter of whom provided help for more than 50 hours a week. Healthcare professionals rarely knew who these carers were, or their support needs. Evidence-based approaches such as the Carer Support Needs Assessment Tool

(CSNAT) are available to assess carer support needs; using CSNAT we found most carers identified unmet needs.

Recommendation 4: Identify and support patients' informal carers (through evidence-based tools and approaches)

13. Please describe your level of agreement with the following statement:

Implementing this recommendation would improve care and support for people with advanced COPD

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

14. How easy would it be to implement this recommendation in your place of work?

- Very Easy
- Easy
- Neutral
- Difficult
- Very Difficult

15. Additional comments (optional)

**PAGE 8:**

Our research found that about half of all patients with advanced COPD reported anxiety or depression, and around half of these had not mentioned this to any healthcare professional. A similar proportion of carers were anxious or depressed.

Recommendation 5: Identify and respond to psychological morbidity in patients and informal carers

16. Please describe your level of agreement with the following statement:

Implementing this recommendation would improve care and support for people with advanced COPD

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

17. How easy would it be to implement this recommendation in your place of work?

- Very Easy
- Easy
- Neutral
- Difficult
- Very Difficult

18. Additional comments (optional)

**PAGE 9:**

COPD has a low public profile compared to cancer. We identified the pervasive effect of guilt and stigma of smoking-related conditions on patients and their families. Patients were embarrassed by the reactions of others to their breathlessness in public settings. We found limited understanding of palliative care, and of the role and support needs of informal carers.

Recommendation 6: Change societal attitudes and understandings of COPD, breathlessness, palliative care and informal carer support

19. Please describe your level of agreement with the following statement:

Implementing this recommendation would improve care and support for people with advanced COPD

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

20. How easy would it be to implement this recommendation in your place of work?

- Very Easy
- Easy
- Neutral
- Difficult
- Very Difficult

21. Additional comments (optional)

**PAGE 10:**

Thank you for completing the survey.

22. Please do add any final comments about these recommendations here (optional):

## 5.2. Full question responses

Numeric responses are presented below by recommendation.

**Table 13. Full question responses**

<b>Agree would improve care</b>		<b>Ease of implementation</b>	
<b>Recommendation 1. Stop focusing on prognosis</b>			
Strongly Agree	32	Very Easy	10
Agree	36	Easy	26
Neutral	10	Neutral	30
Disagree	4	Difficult	16
Strongly Disagree	0	Very Difficult	0
<i>Total</i>	82	<i>Total</i>	82
<b>Recommendation 2. Incentivise person-centred care</b>			
Strongly Agree	48	Very Easy	11
Agree	25	Easy	25
Neutral	4	Neutral	25
Disagree	1	Difficult	16
Strongly Disagree	0	Very Difficult	1
<i>Total</i>	78	<i>Total</i>	78
<b>Recommendation 3. Identify and respond to patient support needs</b>			
Strongly Agree	42	Very Easy	7
Agree	22	Easy	32
Neutral	11	Neutral	22
Disagree	0	Difficult	12
Strongly Disagree	0	Very Difficult	2
<i>Total</i>	75	<i>Total</i>	75
<b>Recommendation 4. Identify and support carers</b>			
Strongly Agree	44	Very Easy	9
Agree	30	Easy	30
Neutral	1	Neutral	23
Disagree	0	Difficult	11
Strongly Disagree	0	Very Difficult	0
<i>Total</i>	75	<i>Total</i>	73
<b>Recommendation 5. Respond to psychological morbidity</b>			
Strongly Agree	57	Very Easy	16
Agree	17	Easy	23
Neutral	0	Neutral	18
Disagree	0	Difficult	15
Strongly Disagree	0	Very Difficult	3
<i>Total</i>	74	<i>Total</i>	75
<b>Recommendation 6. Change societal attitudes</b>			

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Strongly Agree	46	Very Easy	5
Agree	25	Easy	10
Neutral	3	Neutral	19
Disagree	1	Difficult	26
Strongly Disagree	0	Very Difficult	15
<i>Total</i>	75	<i>Total</i>	75