

## ACCEPTED VERSION

G.B. Crawford, M.A. Brooksbank, M. Brown, T.A. Burgess and M. Young  
**Unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia**  
Internal Medicine Journal, 2013; 43(2):183-190  
© 2012 The Authors; Internal Medicine Journal © 2012 Royal Australasian College of Physicians

This is the peer reviewed version of the following article: G.B. Crawford, M.A. Brooksbank, M. Brown, T.A. Burgess and M. Young  
**Unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia**  
Internal Medicine Journal, 2013; 43(2):183-190

Which has been published in final form at <http://dx.doi.org/10.1111/j.1445-5994.2012.02791.x>

This article may be used for non-commercial purposes in accordance with [Wiley Terms and Conditions for Self-Archiving](#).

### PERMISSIONS

<http://olabout.wiley.com/WileyCDA/Section/id-828039.html>

### Publishing in a subscription based journal

#### Accepted (peer-reviewed) Version

Self-archiving of the accepted version is subject to an embargo period of 12-24 months. The embargo period is 12 months for scientific, technical, and medical (STM) journals and 24 months for social science and humanities (SSH) journals following publication of the final article.

The accepted version may be placed on:

- the author's personal website
- the author's company/institutional repository or archive
- certain not for profit subject-based repositories such as PubMed Central as [listed below](#)

Articles may be deposited into repositories on acceptance, but access to the article is subject to the embargo period.

The version posted must include the following notice on the first page:

***"This is the peer reviewed version of the following article: [FULL CITE], which has been published in final form at [Link to final article using the DOI]. This article may be used for non-commercial purposes in accordance with [Wiley Terms and Conditions for Self-Archiving](#)."***

**28 June, 2016**

<http://hdl.handle.net/2440/77385>



**The unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia.**

Journal:	<i>Internal Medicine Journal</i>
Manuscript ID:	IMJ-0557-2011.R1
Manuscript Type:	Original Article
Date Submitted by the Author:	n/a
Complete List of Authors:	Crawford, Gregory; University of Adelaide, Discipline of Medicine Brooksbank, Mary; University of Adelaide, Medicine Brown, Margaret; University of South Australia, Hawke Research Institute Burgess, Teresa; University of Adelaide, Discipline of Public Health Young, Mary; Royal Adelaide Hospital, Transitional & Community Service
Keywords:	Chronic Obstructive Pulmonary Disease (COPD), model of care, palliative approach, end-of-life care, policy change
Abstract:	<p><b>Background</b> Chronic Obstructive Pulmonary Disease (COPD) is an increasing cause of mortality. However, people with COPD are unlikely to receive care that meets the needs of themselves or their carers at the end-of-life.</p> <p><b>Aims</b> To explore the needs of people with end-stage COPD in South Australia and develop recommendations for a model of care.</p> <p><b>Methods</b> Three related studies were undertaken: in Study 1, fifteen people with advanced COPD and their carers were interviewed twice, six months apart; Study 2 investigated views of an Expert Panel and Study 3 conducted focus groups and interviews with service providers and community groups to examine service availability and accessibility.</p> <p><b>Results</b> This project demonstrated that the needs of people with COPD are not being met. There was an absence of a co-ordinated pathway for support. Care was fragmented, episodic and reactive. The role of carers was poorly recognised. Health professionals identified the lack of a clear transition to an end-stage and significant barriers to obtaining support for activities of daily living. Communication issues were identified in all studies, including the absence of advance care planning conversations.</p> <p><b>Conclusions</b> A flexible model of care is needed that assists people with COPD to navigate the health system. This should be patient-centred, and co-ordinated across primary, acute and community sectors. Neither respiratory nor palliative care services alone can adequately support people with COPD. The integration of a multidisciplinary palliative approach within</p>

	a chronic disease management strategy will be central for the best care for people living with advanced COPD.

SCHOLARONE™  
Manuscripts

For Peer Review

**Title page**

The unmet needs of people with end-stage chronic obstructive pulmonary disease:  
recommendations for change in Australia.

**Word count** Abstract 250 Text 2861

**Short title:** Unmet need of people with end-stage COPD

**Authors full names and positions:**

Gregory B Crawford,

Mary Potter A/Professor of Palliative Medicine

Discipline of Medicine

University of Adelaide, Australia

Mary A Brooksbank AM,

Honorary Fellow

Discipline of Medicine

University of Adelaide, Australia

Margaret Brown

Adjunct Research Fellow

Hawke Research Institute

University of South Australia, Australia

Teresa A Burgess

Senior Lecturer

Discipline of Public Health

University of Adelaide, Australia

Mary Young

COPD Clinical Practice Consultant

Transitional & Community Service

Royal Adelaide Hospital, Australia

**Corresponding author**

A/Prof GB Crawford

University of Adelaide

C/- 89 Strangways Terrace

North Adelaide South Australia 5006

Ph +61 8 8239 9117

Fax +61 8 8239 9186

[gregory.crawford@adelaide.edu.au](mailto:gregory.crawford@adelaide.edu.au)

#### **Acknowledgement of grants and other funding**

This research was funded by the National Health and Medical Research Council, Australia, Study No. 519359.

#### **Contribution of authors**

All authors shared equally in intellectual planning, intellectual analysis and writing of this paper. MAB and MB took primary responsibility for Study 1 data collection and analysis. MY recruited all the participants in Study 1. MB undertook the interviews in Study 1. GC took primary responsibility for Study 2. GC and TB undertook analysis of Study 2. TB took primary responsibility for Study 3. GC and TB conducted the majority of the interviews and TB undertook the analysis of Study 3.

## Abstract

### Background

Chronic Obstructive Pulmonary Disease (COPD) is an increasing cause of mortality. However, people with COPD are unlikely to receive care that meets the needs of themselves or their carers at the end-of-life.

### Aims

To explore the needs of people with end-stage COPD in South Australia and develop recommendations for a model of care.

### Methods

Three related studies were undertaken: in Study 1, fifteen people with advanced COPD and their carers were interviewed twice, six months apart; Study 2 investigated views of an Expert Panel and Study 3 conducted focus groups and interviews with service providers and community groups to examine service availability and accessibility.

### Results

This project demonstrated that the needs of people with COPD are not being met. There was an absence of a co-ordinated pathway for support. Care was fragmented, episodic and reactive. The role of carers was poorly recognised.

Health professionals identified the lack of a clear transition to an end-stage and significant barriers to obtaining support for activities of daily living. Communication issues were identified in all studies, including the absence of advance care planning conversations.

### Conclusions

A flexible model of care is needed that assists people with COPD to navigate the health system. This should be patient-centred, and co-ordinated across primary, acute and

community sectors. Neither respiratory nor palliative care services alone can adequately support people with COPD. The integration of a multidisciplinary palliative approach within a chronic disease management strategy will be central for the best care for people living with advanced COPD.

### **Key Words**

Chronic Obstructive Pulmonary Disease (COPD); model of care; palliative approach; end-of-life care; policy change.



## The unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia.

### Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a major and increasing cause of mortality both in Australia and internationally<sup>1,2</sup> with COPD and allied diseases associated with 3.7% of all deaths in Australia in 2005.<sup>1</sup> In 2008 the estimated financial cost of COPD in Australia was \$8.8 billion with care both in hospital and in the community becoming an increasing burden. It was also estimated that a further \$89 billion was lost due to disability and premature death.<sup>3</sup>

The needs of people with COPD and their carers are becoming more clearly documented<sup>4,5</sup> and patients dying of chronic lung disease may experience physical symptoms and psychosocial distress at least as severe as patients with lung cancer.<sup>6</sup> Nevertheless they are less likely to gain adequate symptom control or receive care that meets the needs of themselves or their carers at the end-of-life.<sup>4,5</sup>

Current models of palliative care have developed almost exclusively around the needs of people with cancer<sup>7</sup> with no consensus in the literature about which aspects of palliative care best meet the needs of *non-cancer* patients.<sup>7</sup> It is increasingly being recognised that a palliative approach should be an integral part of health care provision and available to all who need it.<sup>8</sup> [The Australian COPD-X guidelines highlight that](#)

[“Unlike the cancer trajectory, the intermittent and potentially reversible acute exacerbations of COPD make palliative referral and discussion about end of life care difficult to initiate.”<sup>9</sup> The guidelines point to clinical indicators of shortened survival and in the presence of functional deterioration, a staged approach to adjusting the goals of care.<sup>9</sup> Whilst they recognise the role of specialist palliative care services and the](#)

~~importance of incorporating a palliative approach, to date, there is no Australian model of COPD care which incorporates this and specifically addresses the needs of people with end-stage COPD. In the latest version of the Australian COPD X guidelines, end-of-life care for people with end-stage COPD identifies the difficulty with determining prognosis.<sup>9</sup> The guidelines state that “palliative care is not synonymous with terminal care ... Palliative care is concerned about how patients are living their lives facing terminal illness.”<sup>9, p59</sup> However to date, there is no Australian model of COPD care which incorporates a palliative approach and specifically addresses the needs of people with end-stage COPD.~~

## Method

A qualitative multi-perspective approach was chosen to ensure that any model of care was informed by the voices of people with COPD and their carers and key service providers, including professionals from respiratory health, palliative care, primary care and community based services in order to develop practical recommendations.<sup>10</sup>

~~Kendall et al<sup>10</sup> note the value of multi-perspective qualitative interviews in understanding the needs of both patients and service providers and in the development of practical recommendations.~~ Three separate related studies were undertaken:

### *a. Study One: People living with COPD and their carers: Exploring their needs.*

**Selection:** People with advanced COPD and their carers were recruited through a major urban hospital and its rural outreach clinic. Rigorous selection criteria informed by a literature review and expert opinion were developed. A purposive sample was recruited by the respiratory nurse specialist who reviewed case notes and approached eligible patients. Participants with COPD were over 18 years of age, fluent in English, had been hospitalised at least twice in the past 12 months with a respiratory illness, satisfied

GOLD Stage IV classification for COPD severity,<sup>11</sup> were sufficiently robust to tolerate an interview and were free from obvious cognitive impairment. Exclusion criteria included active treatment for lung cancer in the past five years or any metastatic cancer, lung transplantation or living in residential care.

**Data Collection:** Issues associated with the participants' care needs and their experiences of living in the community with severe COPD were explored by an experienced qualitative researcher (MB) in two in-depth interviews six months apart. Carers were offered a separate interview but generally joined with their partner. Data were collected about performance status,<sup>12</sup> the degree of dyspnoea<sup>13</sup> and impact of the illness on quality of life.<sup>14</sup> Participants and carers knowledge of advance directives and experience of advance care planning was also discussed. All interviews were recorded, transcribed and combined with field notes.

~~**Data Analysis:** Transcripts were coded by two authors (MB, MAB) and thematic analysis undertaken. Coding disagreements were discussed until consensus was achieved identifying key themes. This allowed a flexible, evidence-based approach despite the density of the data obtained from the interviews.<sup>15, 16</sup>~~

*Study Two: Issues and challenges associated with advanced COPD: The views of specialist health professionals.*

**Selection:** The aim of Study 2 was to establish an Expert Panel of respiratory, palliative medicine, general medical practitioners (GP) and specialist respiratory and palliative care nurses. ~~The Project Team identified four respiratory physicians, two respiratory nurse specialists, one palliative care nurse specialist, one general practitioner (GP) and two palliative care specialists from across Adelaide who were approached by GC and invited to participate in two Expert Panel Sessions.~~

**Data Collection:** The Expert Panel met twice to refine COPD morbidity and mortality data in order to identify a transition to the end-of-life period for use in policy planning and service development. ~~The discussion in the first session was facilitated by GC and the second session was facilitated by a palliative care nurse specialist. Both Expert Panels were held in a major Adelaide teaching hospital and each lasted for approximately 90mins.~~ Questions in Panel 1 focused on identifying the transition to end-of-life care and referrals to palliative care whilst Panel 2 focussed on the needs of the person with COPD as the end-of-life approached and how these might be assessed; the organisational changes needed for managing advanced disease; what assessment tools might be used and by whom and when symptom control should become the focus of care. Both Expert Panel discussions were audio-recorded, and notes were taken of key issues arising throughout the discussions.

**Data Analysis:** ~~Coding was undertaken by TB, using the notes from the Panel sessions and the recordings. Codes were collated into themes, which were reviewed and agreed by TB and GC. Relevant quotes which illustrated the themes were identified for inclusion in the report. An initial thematic analysis of Expert Panel 1 was undertaken, identifying four key themes which formed the basis of questions for Panel 2. Panel 2 was also thematically analysed and again, four key themes were identified. The results of both Panels were then combined and recommendations identified arising from this analysis.~~

*Study Three: Service availability and accessibility for people with advanced COPD and their carers.*

**Selection:** It was agreed that key service providers in the areas of respiratory and palliative care could provide detailed ~~and accurate~~ insights into the accessibility and

availability of services for people with advanced COPD. A purposive sampling technique was used to identify participants from a variety of professions and disciplines across the community, primary care and acute care systems and information was supplemented by input from a community-based consumer support group and from Carers SA.

**Data Collection:** A series of discipline-specific focus groups, interviews and group meetings were undertaken. *(See Table 1)* An interview schedule was developed aimed at identifying the perspective of each group on the issues facing people with COPD; the provision of care; barriers to access; service restrictions; functioning of services and service co-ordination issues. ~~Focus groups and interviews were between 45 and 60 minutes and were undertaken at a venue and time nominated by the participants. Focus groups and interviews were facilitated by members of the project team.~~

**Data Analysis:** ~~Transcripts were coded by authors responsible for each Study using thematic analysis. In Study 1 coding disagreements were discussed until consensus was achieved identifying key themes. This allowed a flexible, evidence-based approach despite the density of the data obtained from the interviews.<sup>15, 16</sup> In Study 2 an initial thematic analysis of Expert Panel 1 was undertaken, identifying four key themes which formed the basis of questions for Panel 2. The results of both Panels were then combined and recommendations identified arising from this analysis. In Study 3 data were analysed deductively, and a constant comparative process was used to form broad themes.<sup>17</sup> The themes from all three studies were then compared and collated to identify the final key themes arising from the data.~~ ~~All focus groups and interviews were audio-recorded, notes taken, listened to a number of times, and coded by TB. Data were analysed inductively, and a constant comparative process was used to analyse the data~~

~~in order to establish analytical categories which were then grouped to form broad themes.<sup>17</sup> These broad themes were then further analysed to identify the final key themes arising from the data.~~

**Ethics approval:** Ethics approval for this project was given by the Research Ethics Committees of the Royal Adelaide Hospital and University of Adelaide, Australia.

## Results

**Study One:** Fifteen people with advanced COPD and ~~their eight carers, when available,~~ participated in the interviews. (*Table 1*) One participant died before the second interview.

COPD had a devastating impact on these peoples' lives, both in terms of physical functioning and social roles. All participants had left the workforce and no one had private health insurance. Breathlessness meant that basic tasks such as personal care, cooking, and cleaning were a struggle for all and impossible for many, and activities outside the home were restricted. While home-oxygen enabled participants to remain at home and provided some relief from breathlessness, maintaining oxygen supplies was a source of anxiety, and equipment added to physical restriction and isolation. The sense of panic due to breathlessness was a strong theme.

Participants with carers were concerned about how much their carer did for them, and it was obvious how heavily burdened carers were, and how limited respite options were for them. For those who lived alone, social isolation and the challenges of managing day-to-day were even greater. Although participants received a range of support from community services, participants were unclear about their entitlements and those who were aged less than 65 years experienced significant difficulties in accessing many services.

Life for participants with end-stage COPD was inextricably linked with the health system. The most obvious theme from the data was the absence of a clear co-ordinated pathway to obtaining support and advice. Attendance at GP, specialist and hospital outpatient appointments was difficult, particularly if these were scheduled early in the day. For some, a GP filled the role of care co-ordinator, but for most, services were experienced as fragmented. Care appeared episodic and reactive, often involving emergency hospitalisation in a crisis. Even in the face of advanced disease with poor prognosis, there was an absence of conversations about future wishes or any advance care planning. Participants described many of their experiences of communicating with health professionals in terms of “*not being listened to.*” Concerns were also expressed about the level of communication between GPs and hospital specialists. The opportunity to discuss their situation, including advance care planning, with the interviewer was welcomed.

The information and skills obtained at pulmonary rehabilitation were valued by the few who were able to complete the program, but access was difficult and it was apparent that the timing should have been earlier in the illness. During the course of the study, two participants were referred for specialist palliative care support. This did not include the participant who died before the second interview. All participants recognised that smoking had contributed to their illness and some described a sense of abandonment or judgement from their doctors. Despite the profound changes COPD had wrought in participants' lives, there was a strong sense of “*battling on.*” Although some described their life as being over, and some recognised the terminal nature of the illness, they still remained engaged in this day-to-day struggle.

**Study Two:** ~~The Expert Panel was convened on two occasions. (Table 2) Six specialists agreed to participate in Panel One; three respiratory specialist physicians, one palliative medicine physician, one general practitioner and one respiratory scientist/academic. Seven specialists participated in Panel Two; two respiratory physicians, one palliative medicine physician, two respiratory nurse specialists, one palliative care nurse specialist and one general practitioner.~~

It was evident, that there was no easily identifiable transition to end-stage COPD, therefore the original objective of Study Two was not realised. ~~For both policy makers and people working with advanced COPD, It was determined that~~ refining morbidity ~~and mortality~~ data for policy makers was not possible, nor was it as important as addressing the symptoms and needs of people with advanced COPD. All participating health professionals identified that the key issues ~~for them working with people with advanced COPD~~ were to provide support for activities of daily living (ADL), to treat physical and psychological symptoms, to provide better co-ordination of care and to emphasise the importance of advance care planning as vital for best practice care.

**Study Three:** Five focus groups, two interviews and two group sessions were undertaken. (Table 2) Thirteen major themes were identified from the data, which were refined to four major themes.

**The impact of the trajectory of the illness:** The trajectory of COPD, with its acute exacerbations, long periods of relative maintenance and the length of time that people may be seriously ill, has a major impact on service provision, particularly planning and access, as well as on the family and carers.

**Access issues:** Current levels of services and supports for people with COPD were not commensurate with the impact of the illness and current funding structures do not



support care for prolonged periods of time. Despite a willingness by specialist palliative care services to be involved, a lack of flexibility between current service providers considerably disadvantaged people with COPD. Palliative care and home support services were often linked to prognosis rather than need. Clinicians were forced to 'manipulate the system' by referring to specialist palliative care services as a means of gaining services and supports which would otherwise not be available to patients with chronic disease. Accessing community care options such as ADL support was particularly problematic for people aged less than 65 years.

**Communication:** Communication between health service providers and people with COPD and between health service providers themselves was highlighted as a major issue. This was particularly so between the acute care and the primary care sector.

**The role of carers.** The role of carers was not adequately recognised in the health system nor their need for respite. Consumers, carers and health professionals all emphasised the importance of recognising and addressing the psychosocial needs of people with COPD as this disease has a major impact on the financial, emotional, mental and physical aspects of life for individuals and families. i.e. access issues; the impact of the trajectory of the illness; the role of carers; and the importance of communication. Three lesser themes were use of oxygen; mental health issues; and spiritual and emotional well-being.

Participants identified that the current level of services and supports available to people living with COPD was not commensurate with the impact of the illness. Clinicians openly admitted to "manipulating the system" at times to gain the services that patients needed. All programs that provided long term support for showering, dressing and other household activities required the recipient to be aged over 65 years of age. For people

who were less than 65 years, this was a significant barrier and precluded many community care options. The role of carers was specifically identified as being unrecognised and the need for respite emphasised. This was linked to the major financial burden caused by COPD, as both people with COPD and their carers usually had ceased paid work. Communication between health service providers and people with COPD and between health service providers themselves was highlighted as a major issue, and this was particularly so between the acute care and the primary care sector. Health professionals identified the necessity for implementing a chronic disease management approach to care for people with COPD (specifically incorporating the development of models of co-ordinated care and the early introduction of health literacy programs). Consumers, carers and health professionals all emphasised the need to recognise and address the psychosocial needs of people with COPD. Despite a willingness by specialist palliative care services to be involved, a lack of flexibility between current service providers in the face of an inherently fluctuating disease course, created barriers to referral.

## Discussion

This project demonstrated that the needs of people with COPD are not being met and that neither respiratory nor palliative care services alone can adequately support people with COPD. An outstanding finding from this research was the consistent and recurring messages that came from all three studies. The Expert Panel and professional focus groups echoed the findings from patients and carers about their unmet needs and the difficulties they faced with remarkable congruence. (Table 3)

The outstanding findings from this research are the consistent and recurring messages that came from all three studies. The Expert Panel and professional focus groups echoed

~~the findings from patients and carers about their unmet needs and the difficulties they faced. Despite the clinicians representing a range of disciplines and all the health care sectors, the assessment of unmet need and the issues identified were remarkably congruent.~~

~~This project demonstrated that the needs of people with COPD are not being met. Care for people with advanced COPD has been focused in the acute care setting with some community support, but this has been shown to be inadequate in meeting Care was found to be fragmented, episodic and reactive and did not meet the day-to-day and palliative care needs of these people with COPD.~~

~~Three key aspects were identified that would improve the care of people with advanced COPD and these should be reflected in all health policy and service provision.~~

~~Firstly, the focus of service provision should be on assisting people to live at home. This will require a revision of eligibility criteria for access to community services (e.g. age limitation and performance status) as well as increased recognition of, and support for, carers.~~

~~Secondly, the model of care for people with advanced COPD should be based on the chronic care model, incorporating regular and systematic review, multidisciplinary team care, with coordinated and continuing care. The model must include timely and accurate communication with people with advanced COPD and between all care providers to achieve quality care in a multidisciplinary environment. This research clearly demonstrated the absence of a co-ordinated pathway for support, the inclusion of people with COPD in the chronic disease management model and the integration of a palliative approach at all phases of the illness. These three aspects should be reflected in all health policy and service provision.~~

Care co-ordination is pivotal to any new model of care and should occur across hospitals, community and home. The care co-ordination role should be pro-active, supporting as much independence as possible through education and assistance with problem solving, but also incorporating the skills and capacity to intervene with more specific assistance when needed.

Thirdly, a key principle of the care model should be the integration of a palliative approach at all phases of the illness. This would foster a person-centred approach, focussing on symptom management and emotional and psychological support, as well as allowing continuing COPD interventions. ~~The model of care must have a palliative approach as a core principle. This must include timely and accurate communication with people with advanced COPD and between all care providers to achieve quality care in a multidisciplinary environment.~~ Health professionals in all areas of chronic disease management require education in palliative care principles and practice.

COPD guidelines and health professional education should emphasise the vulnerability of people with advanced COPD, the symptom burden, in particular dyspnoea and fatigue, the many losses including changes in role, the impact on relationships experienced by people with this chronic illness and the need for sensitivity and compassion. ~~There needs to be a strong focus on psychological assessment and where necessary, improved access to psychological support.~~

A series of recommendations were developed from the data. (Table 4) Whilst all the recommendations from this study are grounded in the data from the participants, it is important to note that they are also in line with current health policy and proposed health reforms in Australia.<sup>18-22</sup> ~~The NHMRC note that “Palliative care should not be confined to ‘end-of-life’ care”<sup>18-p2</sup> and the recommendations from this project mirror~~

~~the ethical principles and values outlined by the NHMRC.<sup>18</sup> State and national policies and guidelines around chronic disease emphasise the importance of a chronic disease management approach and the development of co-ordinated and integrated care for chronic diseases such as COPD. The 2006 National Chronic Disease Strategy<sup>19</sup> and current health reforms such as the National Health and Hospital Reform Commission (NHHRC) Report,<sup>20</sup> Medicare Locals<sup>21</sup> and particularly the National Primary Health Care Strategy<sup>22</sup> reiterate their importance. The National Health and Hospitals Reform Commission recommendations had a specific focus on caring for people at the end-of-life, urging expansion of access to palliative care services, support for advance care planning and workforce education in this area.<sup>20</sup>~~

~~Palliative Care Australia (PCA), the peak body for palliative care in Australia, suggests that seamless, well co-ordinated care is vital for best practice care at the end-of-life. PCA and emphasises the importance of care that is person- and carer-focused, and has made a series of recommendations about incorporating a patient-centred focus into health care systems and practice.<sup>23</sup> There are also national statements endorsing the importance of patient-centred care,<sup>24</sup> support for carers of people with chronic disease<sup>25</sup> and for Advance Care Directives,<sup>27</sup> all of which are strongly endorsed by the National Palliative Care Strategy.<sup>28</sup> The Australian Commission on Quality and Safety in Healthcare<sup>24</sup> has developed a comprehensive blueprint for the introduction of patient-centred care, which was endorsed by the Council of Australian Governments in August 2011. The importance of carers for people with chronic disease has recently been recognised at a national level in the National Carer Strategy.<sup>25</sup> This holistic approach basing care on patient and carer and family needs is a core element of a palliative approach.<sup>26</sup> The NHHRC recommendations had a specific focus on caring for people at~~

~~the end of life, recommending expansion of access to palliative care services, support for advance care planning and workforce education in this area.<sup>20</sup> The Australian Government has developed a National Framework for Advance Care Directives<sup>27</sup> which is strongly endorsed by the National Palliative Care Strategy.<sup>28</sup>~~

**Future role of specialist palliative care services:** Palliative care services have led the way with their broad ranging, multidisciplinary, flexible approach, and will need to continue to lead in embedding a palliative approach in a chronic disease management model. The role of specialist palliative care services will be vital in providing education, consultation, advice and support for respiratory and other clinicians to continue to care for people they may have known for considerable periods of time. Referral to a specialist palliative care service may not be necessary for all people with advanced COPD but the interface between specialist palliative care and other clinicians will continue to be important in the model of care. The skills to discuss issues such as the desired extent of intervention and to sensitively raise end of life conversations are core skills of palliative care clinicians, however they are not perceived as necessary for many other health professionals. Other members of the treatment team for people with COPD need to be supported to develop confident communication skills. A clear finding of this research was that advance care planning discussions were often initiated around the time of an acute exacerbation when both people with COPD and their carers were stressed. This was not appropriate as people could not think clearly, did not have the time to consider the issues and it was too late for many of the planning aspects.

## Conclusion

The findings of this research reflect both the international evidence and the Australian context and demonstrate clearly that the health care system must change if it is to provide best-practice care for people with advanced COPD and their carers. Neither respiratory nor palliative care services alone can adequately support people with COPD. There is a need for a flexible model of care that assists these people to navigate the acute health care and community support systems, that is patient-centred, and is coordinated across the primary, acute and community sectors. The integration of a multidisciplinary palliative approach within a chronic disease management strategy, as well as the recognition that active disease management and palliation are complementary, not mutually exclusive, will be central for the best care for people living with advanced COPD.

### Acknowledgments

This research was funded by the National Health and Medical Research Council, Australia, Study No. 519359. We wish to acknowledge the other investigators, A/Prof Alan Crockett PSM, Dr Ral Antic, and Prof Debbie Kralik, and the support given by Dr Kerry Hancock and Ms Janet Taylor. In particular we wish to thank the people with COPD and their carers who gave of their time and energy, and the many clinicians who also freely gave of their time to improve the care of people living with COPD.

For Peer Review



## References

1. Australian Institute of Health and Welfare. Chronic diseases mortality. Canberra: AIHW; 2008 [5/2/10]; Available from: [http://www.aihw.gov.au/cdarf/data\\_pages/mortality/index.cfm](http://www.aihw.gov.au/cdarf/data_pages/mortality/index.cfm).
2. Buist A, McBurnie M, Vollmer W, Gillespie , Burney S, Mannino D, et al. International variation in the prevalence of COPD (The BOLD Study): a population-based prevalence study. *Lancet*. 2007;**370**(9589):741-50.
3. Access Economics. Economic impact of COPD and cost effective solutions: The Australian Lung Foundation 2008.
4. Pinnock H, Kendall M, Murray S, Worth A, Levack P, Porter M, et al. Living and dying with severe Chronic Obstructive Pulmonary Disease: multiperspective, longitudinal qualitative study. *BMJ*. 2011;**342**:d142:doi:10.1136/bmj.d142.
5. Gardiner C, Gott M, Payne S, Small N, Barnes S, Halpin D, et al. Exploring the care needs of patients with advanced COPD: An overview of the literature. *Respir Med*. 2010;**104**(2):159-65.
6. Edmonds P, Karisen S, Khan S, Addington Hall J. A Comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliat Med*. 2001;**15**(4):287-95.
7. Murray S. & Sheikh A. Care for all at the end of life. *BMJ*. 2008;**336**:958-9.

8. Boyd K, Murray S. Recognising and managing key transitions in end of life care. *BMJ*. 2010;**341**:649-52.
9. McKenzie D, Abramson M, Crockett A, Glasgow N, Jenkins S, McDonald C, et al. The COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease 2011. 2011.
10. Kendall M, Murray S, Carduff E, Worth A, Harris F, Lloyd A, et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ*. 2009;**339**:196-9.
11. Pauwels R, Buist A, Ma P, Jenkins C, Hurd S. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: National Heart, Lung, and Blood Institute and World Health Organization Global Initiative for Chronic Obstructive Lung Disease (GOLD): executive summary. *Respir Care*. 2001;**46**:798-825.
12. Abernethy A, Shelby-James T, Fazekas B, Woods D, Currow D. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice. *BMC Palliat Care*. 2005;**4**(7).
13. Bestall J, Paul E, Garrod R, Garnham R, Jones P, Wedzicha. Usefulness of the Medical Research Council (MRC) dyspnoea scale as a measure of disability in patients with chronic obstructive pulmonary disease. *Thorax*. 1999;**54**:581-586.
14. The Gold Standards Framework. SCR7 Alternative assessments: Quality of Life. Birmingham: National GSF Centre; 2011 [January 2011]; Available from: <http://www.goldstandardsframework.nhs.uk/TheGSFToolkit/ToolsandTemplates>

15. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;**3**(2):77-101.
16. Strauss A, Corbin J. Basics of Qualitative Research. 2nd ed. Thousand Oaks: Sage; 1998.
17. Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ*. 2000;**320** :114.
18. National Health and Medical Research Council. An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions. Canberra: National Health and Medical Research Council 2011.
19. National Health Priority Action Council (NHPAC). Health Priorities: National Chronic Disease Strategy. Canberra: Australian Government Department of Health and Ageing 2006.
20. National Health and Hospitals Reform Commission. A Healthier Future for All Australians. Final Report. Canberra: Australian Government; 2009.
21. Australian Government. Medicare Locals – Discussion Paper on Governance and Functions. Canberra: Department of Health and Ageing; 2010.
22. Department of Health and Ageing. Building a 21st Century Primary Health Care System: A Draft of Australia's First National Primary Health Care Strategy. Canberra: Government of Australia 2009.
23. Palliative Care Australia. Health System Reform and Care at the End of Life: A Guidance Document. Canberra: Palliative Care Australia; 2010.

24. Australian Commission on Quality and Safety in Health Care. Patient-centred care: improving quality and safety through partnerships with patients and consumers. Sydney: ACQSHC 2011.
25. Government of Australia. National Carer Strategy. Canberra: Commonwealth of Australia 2011.
26. WHO. WHO Definition of Palliative Care. Geneva: WHO; 2010 [cited 2010 22/1/2010]; Available from: <http://www.who.int/cancer/palliative/definition/en/>
27. The Clinical Technical and Ethical Principal Committee. A National Framework for Advance Care Directives. Consultation Draft. Canberra: Australian Health Ministers' Advisory Council, 2010.
28. Commonwealth of Australia. National Palliative Care Strategy 2010. Canberra: Commonwealth of Australia; 2010.

**Table 1: Study 1 Participant demographic information and scores for MMRC, AKPS, QoL at interviews 1 & 2.**

<u>Participant</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5*</u>	<u>6*</u>	<u>7</u>	<u>8</u>	<u>9</u>	<u>10</u>	<u>11</u>	<u>12</u>	<u>13</u>	<u>14</u>	<u>15</u>
<u>Location</u>	<u>M</u>	<u>M</u>	<u>M</u>	<u>M</u>	<u>M</u>	<u>SR</u>	<u>M</u>	<u>M</u>	<u>M</u>	<u>R</u>	<u>R</u>	<u>R</u>	<u>R</u>	<u>R</u>	<u>R</u>
<u>Age</u>	<u>74</u>	<u>79</u>	<u>75</u>	<u>64</u>	<u>60</u>	<u>54</u>	<u>60</u>	<u>79</u>	<u>79</u>	<u>67</u>	<u>72</u>	<u>65</u>	<u>67</u>	<u>61</u>	<u>53</u>
<u>Gender</u>	<u>M</u>	<u>F</u>	<u>F</u>	<u>F</u>	<u>M</u>	<u>M</u>	<u>M</u>	<u>M</u>	<u>F</u>	<u>M</u>	<u>F</u>	<u>M</u>	<u>M</u>	<u>F</u>	<u>M</u>
<u>Lived alone</u>	<u>✓</u>		<u>✓</u>	<u>✓</u>	<u>✓</u>		<u>✓</u>		<u>✓</u>				<u>✓</u>		
<u>Lived with</u>		<u>P/C</u>				<u>P/C</u>		<u>P</u>		<u>P</u>	<u>P</u>	<u>P</u>		<u>P</u>	<u>C</u>
<u>MMRC Interview 1</u>	<u>1</u>	<u>3</u>	<u>3</u>	<u>3</u>	<u>3</u>	<u>4</u>	<u>3</u>	<u>4</u>	<u>4</u>	<u>4</u>	<u>3</u>	<u>3</u>	<u>2</u>	<u>3</u>	<u>3</u>
<u>MMRC Interview 2</u>	<u>1</u>	<u>3</u>	<u>3</u>	<u>N/A</u>	<u>4</u>	<u>4</u>	<u>4</u>	<u>X</u>	<u>4</u>	<u>4</u>	<u>3</u>	<u>3</u>	<u>3</u>	<u>4</u>	<u>3</u>
<u>AKPS Interview 1</u>	<u>70</u>	<u>50</u>	<u>70</u>	<u>70</u>	<u>50</u>	<u>50</u>	<u>60</u>	<u>50</u>	<u>60</u>	<u>50</u>	<u>60</u>	<u>60</u>	<u>70</u>	<u>60</u>	<u>60</u>
<u>AKPS Interview 2</u>	<u>70</u>	<u>50</u>	<u>60</u>	<u>50</u>	<u>50</u>	<u>40</u>	<u>50</u>	<u>X</u>	<u>40</u>	<u>50</u>	<u>60</u>	<u>60</u>	<u>60</u>	<u>60</u>	<u>60</u>
<u>QoL Interview 1</u>	<u>1</u>	<u>3</u>	<u>2</u>	<u>4</u>	<u>4</u>	<u>3</u>	<u>4</u>	<u>4</u>	<u>3</u>	<u>4</u>	<u>2</u>	<u>2</u>	<u>1</u>	<u>4</u>	<u>2</u>

QoL Interview 2      1      3      2      N/A      4      4      3      X      3      4      2      3      2      4      1

\* Referred to a specialist palliative care service

MMRC      Modified Medical Research Council Dyspnoea Scale      M      metropolitan

AKPS      Australia-modified Karnofsky Performance Status Scale      SR      semi-rural

QoL      Quality of Life Measure      R      regional country

P      Partner      C      Adult child

M      Male      F      Female

X      Deceased      N/A      Missing data

**Table 1: Study 3 Focus group participants.**

	Type of Session	No. of Participants
1. Respiratory nurses (from the Respiratory Nurses Special Interest Group)	Focus Group	6
2. Palliative care service representatives (Social workers/nurses from specialist palliative care services throughout Adelaide)	Focus Group	8
3. General Practitioners	Focus Group	8
4. Respiratory physicians (from private practice)	Focus Group	4
5. Royal District Nursing Service SA	Focus Group	8
6. Carers SA	Interview	2
7. Domiciliary Care SA	Interview	3
8. Public hospital respiratory team (including physicians, doctors in training, nurses)	Group Session	Approx. 20
9. Consumer support group (people with COPD and their carers)	Group Session	Approx. 30

**Table 2: Study 2 and 3 participants.**

	<u>Study 2</u>		<u>Study 3</u>		
	<u>Panel 1 (n=6)</u>	<u>Panel 2 (n=7)</u>	<u>5 Focus groups (n)</u>	<u>2 Interviews (n)</u>	<u>2 Group Sessions (n)</u>
<u>Respiratory specialist physician</u>	<u>3</u>	<u>2</u>	<u>4 (from private practice)</u>		
<u>Palliative medicine physician</u>	<u>1</u>	<u>1</u>			
<u>General practitioner(s)</u>	<u>1</u>	<u>1</u>	<u>8</u>		
<u>Respiratory scientist/academic</u>	<u>1</u>	<u>-</u>			
<u>Respiratory nurse specialists</u>	<u>-</u>	<u>2</u>	<u>6</u>		
<u>Palliative care specialist nurse(s)</u>	<u>-</u>	<u>1</u>	<u>8</u> <u>(plus social workers)</u>		
<u>Royal District Nursing Service SA</u>			<u>8</u>		
<u>Carers SA</u>				<u>2</u>	



Domiciliary Care SA

3

Public hospital respiratory team (including physicians, doctors in training, nurses)

Approx. 20

Consumer support group (people with COPD and their carers)

Approx. 30

For Peer Review

**Table 2: Participant demographic information and scores for MMRC, AKPS, QoL at interviews 1 & 2.**

Participant	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Location	M	M	M	M	M	SR	M	M	M	R	R	R	R	R	R
Age	74	79	75	64	60	54	60	79	79	67	72	65	67	61	53
Gender	M	F	F	F	M	M	M	M	F	M	F	M	M	F	M
Lived-alone	✓		✓	✓	✓		✓		✓				✓		
Lived-with		P/G				P/G		P		P	P	P		P	G
MMRC-Interview-1	1	3	3	3	3	4	3	4	4	4	3	3	2	3	3
MMRC-Interview-2	1	3	3	N/A	4	4	4	X	4	4	3	3	3	4	3
AKPS-Interview-1	70	50	70	70	50	50	60	50	60	50	60	60	70	60	60
AKPS-Interview-2	70	50	60	50	50	40	50	X	40	50	60	60	60	60	60
QoL-Interview-1	1	3	2	4	4	3	4	4	3	4	2	2	1	4	2

---

QoL-Interview-2      1      3      2      N/A      4      4      3      X      3      4      2      3      2      4      1

---

MMRC — Modified Medical Research Council Dyspnoea Scale      M — metropolitan

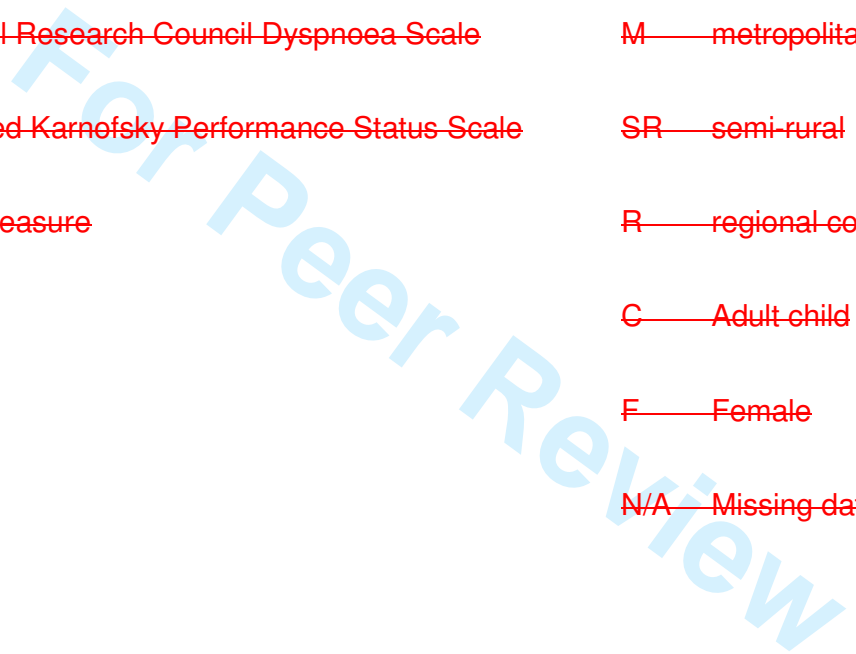
AKPS — Australia-modified Karnofsky Performance Status Scale      SR — semi-rural

QoL — Quality of Life Measure      R — regional country

P — Partner      C — Adult child

M — Male      F — Female

X — Deceased      N/A — Missing data



**Table 3: Comparison of themes from different studies.**

Study 1	Study 2	Study 3
<b>Nature of COPD</b>		
<ul style="list-style-type: none"> <li><i>Limited understanding of COPD, particularly its progressive and terminal nature</i></li> </ul>	<ul style="list-style-type: none"> <li><i>Difficulty defining end-of-life in COPD</i></li> </ul>	<ul style="list-style-type: none"> <li><i>Recognition of unclear trajectory and length of time involved.</i></li> <li><i>Chronic disease context emphasised</i></li> </ul>
<b>Impact of COPD:</b>		

- 
- *Physical limitations due to breathlessness*
  - *Difficulties with ADLs*
  - *High levels of anxiety/panic*
  - *Social Isolation*
  - *Importance of ADL support*
  - *Transport a major issue.*
  - *High level of needs of people with COPD especially the need for ADL support at home*
  - *Anxiety and depression major problems*
  - *Need for spiritual support*

#### **Access to Community Services**

- 
- *Uncertainty re access and entitlement to community services.*
  - *Age barriers to gaining services*
  - *Limited involvement of Palliative Care services*
  - *Difficulty in accessing GP, specialist, and hospital appointments and medications*
  - *Pulmonary rehabilitation access very limited and often too late*
  - *Use of Palliative Care referrals to expedite access to community services*
  - *Difficulty in timing of referrals based on uncertain prognosis.*
  - *Concern re possible number of referrals*
  - *Need for diverse range of health workers to meet needs of people with COPD.*
  - *Need for guidelines/ checklist approach.*
  - *Need for home visits*
  - *Age under 65 a major barrier to services.*
  - *Access to ACAT assessment limited*
  - *Palliative care input valued, but current model does not support the fluctuating need for services*
  - *Difficulty accessing hospital admissions by GPs*
  - *Home visiting important*

## Care Coordination

- 
- *Fragmentation of care*
  - *Lack of co-ordination between hospital and community care*
  - *Important role for education and self- management*
  - *Need for new co-ordinated model and access to services*
  - *Call for change in health policy to support care co-ordination*
  - *Co-ordination requires knowledge of both respiratory and palliative aspects of care*
  - *Need for continuity and care co-ordination*
  - *Co-ordination could improve management of exacerbations*
  - *Links to chronic disease management processes important*
  - *Co-ordination requires knowledge of both respiratory and palliative aspects of care*

---

### **Communication**

- *Difficulty communicating with health professionals*
  - *The importance of communication*
  - *Communication between services lacking*
  - *Consumer / health professional communication very poor*
-

### Impact on Carers

- *Lack of respite care*
- *Burden for carers and lack of support acknowledged*
- *Lack of respite care*

### Advance Care Planning

- *minimal conversations about future wishes*
- *resuscitation conversations only in emergency situations*
- *support for the idea of ACP*
- *Palliative Care staff skilled in end-of-life conversations*
- *ICU should not be site for ACP*
- *Need for respiratory examples in ACP guidelines*
- *Uncertainty about timing*
- *ACP supported but not done.*
- *Uncertainty about whose role to raise ACP*
- *Concerns re impact on optimism*

### Role of smoking

- *Support for campaigns to stop*
- *Judgmental attitudes noted*



- 
- smoking*
  - *Negative attitudes of doctors re smokers*
  - *Lack of sympathy for 'self-inflicted' condition*

---

**Home oxygen**

---

- *physical and social limitations*
- *anxiety re supply and equipment*
- *cost and rebate issues*
- *Role of outreach nurses emphasized*
- *Oxygen use contributes to social isolation*
- *Cost an issue*

**Table 4: Recommendations for change.**

- 
1. COPD guidelines should emphasise the symptom burden of COPD and its devastating impact on patients' lives.
  2. Care should be patient-centred, dictated by needs and symptoms.
    - a. A palliative approach should be a core principle of COPD care.
    - b. Access to activities of daily living (ADL) support is central to COPD care.
    - c. Eligibility to access services should not be restricted by age or performance status alone.
    - d. A stronger focus on psychological assessment and support is needed.
    - e. Advance care planning should be available to all, together with skilled assistance to make and document these decisions.
    - f. Bereavement risk should be assessed and intervention provided as required.
  3. Any model of care must incorporate care co-ordination across hospital, community and home.
    - a. The interface between specialist palliative care services, respiratory specialists and general practice needs clearer definition.
    - b. Planning for contingencies and access to 24 hour advice are required.
    - c. Access to pulmonary rehabilitation programmes should be a priority.
    - d. Smoking prevention and cessation programmes need ongoing support.
    - e. Increasing health literacy should be a priority.
  4. The importance of informal care givers must be acknowledged, and access to respite increased.
-

**Table 4: Recommendations for change.**

- ~~1. COPD guidelines should emphasise the symptom burden of COPD and its devastating impact on patients' lives.~~
- ~~2. Care should be patient-centred, dictated by needs and symptoms.~~
- ~~3. A palliative approach should be a core principle of COPD care.~~
- ~~4. Age and performance status restrictions should be removed from eligibility criteria to access services.~~
- ~~5. Access to activities of daily living (ADL) support is core to COPD care.~~
- ~~6. A stronger focus on psychological assessment and support is needed.~~
- ~~7. Any model of care must incorporate care co-ordination across hospital, community and home.~~
- ~~8. Planning for contingencies and access to 24 hour advice are required.~~
- ~~9. The interface between specialist palliative care services, respiratory specialists and general practice needs clearer definition.~~
- ~~10. Advance care planning should be available to all, together with skilled assistance to make and document these decisions.~~
- ~~11. Bereavement risk should be assessed and intervention provided as required.~~
- ~~12. The importance of informal care givers must be acknowledged, and access to respite increased.~~
- ~~13. Access to pulmonary rehabilitation programmes should be a priority.~~
- ~~14. Smoking prevention and cessation programmes need ongoing support.~~
- ~~15. Increasing health literacy should be a priority.~~