

## ACCEPTED VERSION

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**Best-practice care for people with advanced chronic obstructive pulmonary disease: the potential role of a chronic obstructive pulmonary disease care co-ordinator**  
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**Best practice care for people with advanced COPD: the potential role of a COPD Care Co-ordinator**

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**NEW TITLE: Best practice care for people with advanced COPD: the potential role of a COPD Care Co-ordinator**

**ABSTRACT**

**Objective:** To explore service availability and accessibility for people with advanced COPD and their carers and strategies for improvement, including the potential role of a COPD care co-ordinator, in ensuring best practice care in the Australian context.

**Methods:** This qualitative study used focus groups and interviews with health professionals, carers and consumers to explore gaps and restrictions in services, barriers to access and the functioning of services. Data were analysed deductively.

**Results:** Key themes arising from the data included difficulties around access to care, lack of continuity of care, poor care co-ordination, the need for active disease management as well as supportive care and poor communication. A COPD care co-ordinator was suggested as an effective strategy for ensuring best practice care.

**Conclusions:** People with advanced COPD often have difficulty navigating the acute, primary and community care systems to deal with the multiple services that they may require. Lack of communication between health professionals and services is frequently a significant issue. A COPD care co-ordinator, encompassing advanced nursing skills, could ensure that care is centred on the needs of the person and their carer and that they receive continuing, appropriate and accessible care as they approach the end of their life.

## KEY QUESTION SUMMARY

1. What is known about the topic?

The importance of care co-ordination as a quality care indicator in chronic disease is growing, and the care co-ordinator role as a facilitator of quality care is increasingly being recognised in the UK and US. There is currently little information in the Australian context about how a COPD care co-ordinator role could be implemented, where it could be situated and the level of skill required.

2. What does this paper add?

This paper explores the specific issues in developing a COPD care co-ordinator role and provides a detailed model of care for the introduction of care co-ordinators into the Australian setting.

3. What are the implications for practitioners?

The proposed COPD care co-ordinator role has the potential to improve quality, continuing care for people with advanced COPD. It could facilitate the linkage of multidisciplinary teams across acute, primary and community care settings and promote timely and effective communication. The role would provide a clear point of contact for all practitioners and the opportunity for nurses to develop an advanced practice role in COPD care co-ordination, combining a palliative care approach with a chronic disease management framework.

## BACKGROUND

*Individuals with multiple needs are perhaps least poised to navigate the complex and fragmented health care system, yet are often left to serve as the only link among their various professional care providers<sup>(1),(p2)</sup>*

Chronic Obstructive Pulmonary Disease (COPD) is recognised as being a major global public health problem, with a substantial morbidity and economic burden<sup>(2)</sup>. It is one of the few chronic diseases that is an increasing cause of mortality and morbidity internationally,<sup>(3)</sup> but there is a growing body of local and international evidence demonstrating that the care provided for people with advanced COPD does not meet their needs.<sup>(4-6)</sup> Gardiner et al<sup>(7)</sup> identified the specific needs of people with advanced COPD, highlighting their significant symptom burden, specific needs around education and access to specialist and palliative services as well as the significant issues affecting their families.<sup>(7)</sup> The basis of best practice care for chronic diseases such as COPD is systematic management<sup>(8, 9)</sup> incorporating co-ordinated, multidisciplinary care<sup>(10)</sup> and the integration of care between the acute and primary care sectors where multiple providers may be involved.<sup>(11)</sup> However, there are few current models of care that reflect the key elements of best practice COPD care as summarised by Disler et al<sup>(12)</sup> and which integrate systematic chronic disease management with a palliative approach.<sup>(7)</sup>

Whilst there is consensus that care co-ordination is a key element of best practice Chronic Disease Management (CDM) models,<sup>(13-15)</sup> there is little agreement on the most effective processes for actually co-ordinating care. There is a clear distinction between *care* coordination and *service* coordination: service co-ordination is undertaken at a *system* level, whereas care co-ordination is undertaken at an *individual* level (see Box 1). The key components of care co-ordination have been

identified in a number of reviews,<sup>(16, 17)</sup> however the US Agency for Healthcare Research and Quality has identified that there is little clarity around who should be responsible for co-ordinating care, what approaches to care co-ordination were likely to work (e.g. should approaches be generic or disease based) and what strategies would improve care co-ordination (see Table 1).<sup>(10)</sup>

INSERT BOX 1 and TABLE 1 HERE

One care co-ordination strategy for which there is increasing international evidence is the care co-ordinator role, with the UK<sup>(18, 19)</sup> and US<sup>(13, 20)</sup> increasingly using care co-ordinators to ensure best practice care for people with chronic and complex conditions. There is no consensus on the definition of a care co-ordinator,<sup>(21)</sup> although there is increasing evidence about the most effective tasks which a care co-ordinator can undertake.<sup>(22)</sup> Moreover, there are a variety of titles given to the care co-ordinator role including “Case Manager”; “Care Manager”, “Care Co-ordinator” and “System Navigator” incorporating a variety of definitions of these roles, many of which overlap and none of which are consistent.<sup>(22-24)</sup>

Although heart failure and diabetes have been identified as benefiting from a systematic CDM approach (which includes care co-ordination),<sup>(25)</sup> there is international and local evidence that the care provided for people with advanced COPD is neither systematic nor co-ordinated.<sup>(4, 6, 26)</sup> Best practice care for people with advanced COPD should include a multidisciplinary, palliative approach in parallel with active disease management.<sup>(5, 6)</sup> COPD exacerbations are currently managed largely in the acute hospital setting, with care provided by respiratory specialists or general physicians, then referral back to general practitioners (GPs). There has been little co-ordinated community support for people with COPD living at

home. Despite the evidence around care needs, there seems to be little ability to translate this evidence into practice. A care co-ordination framework offers a practical option for integrating both a CDM and palliative approach – identified as a key element of COPD care by the American Thoracic Society<sup>(27)</sup> and in the COPD-X Guidelines.<sup>(28)</sup>

A recent study undertaken in Adelaide, South Australia (SA), examined care provision for people with advanced COPD and explored the views of a wide variety of health professionals on how care could be best provided as people approach the end of their life.<sup>(4)</sup> This research project made a number of recommendations, particularly around the need to markedly improve co-ordination of care. It was suggested that this should encompass improving communication, co-ordinating care across the acute, primary and community sectors, combining supportive and active care, facilitating advance care planning and supporting greater health literacy. The major strategy identified by participants to facilitate care co-ordination was to develop a specific COPD Care Co-ordinator role and this paper explores ~~in detail~~ the options for implementing a COPD care co-ordinator role in the Australian setting.

## METHODS

The ~~study-research~~ reported here was part of a larger study examining the care needs of people with advanced COPD in SA.<sup>(4)</sup> A series of focus groups and interviews with consumers and a variety of health professionals providing care to people with advanced COPD were undertaken. A purposive sampling technique was used to identify key COPD service providers who could supply specific information on who provides services for people with advanced COPD in South Australia, how these services are structured and function, barriers and any other issues associated with

service provision. All participants were identified through the differing networks of the Project Team and encompassed private and public primary and specialist care, medical, nursing and allied health professionals and support groups.

Five focus groups were held with GPs (n=8), respiratory specialist nurses (n=6), palliative care nurses and social workers (n=8), respiratory physicians (n=4) and community palliative care nurses (n=8). Two group sessions were held with a COPD community support group (n=30) and with the respiratory team at a major public hospital (including respiratory specialists, nurses, social workers, registrars and interns) (n=20). Interviews were also undertaken with representatives from a carer support group (n=2) and a community service provider (n=3). Focus groups were held in the workplace of the professional group, or a location nominated by the group.

~~A purposive sampling technique was used, and all participants were identified through the differing networks of the Project Team.~~

An open ended interview schedule was developed based on a literature review and expert opinion, which varied slightly with each health professional/consumer group to ensure relevance. Questions focussed on gaps in services, barriers to access, service restrictions, functioning of services, service co-ordination and suggestions for service improvement. Each focus group/interview took between 60 – 120 minutes and was audio recorded, with notes taken throughout each session.

A deductive analysis was undertaken.<sup>(29)</sup> Each focus group/interview was individually coded, using the questions from the interview schedules as a framework for the analysis and the data were then drawn together to identify key themes. Data



management for coding and analysis was facilitated using NVivo 8 (QSR International Pty Ltd, 2008).

Ethics approval for the project was obtained from the Royal Adelaide Hospital and the University of Adelaide Human Research Ethics Committees.

## RESULTS

The need for continuity of care was stressed by all service provider groups, with a particular emphasis on better co-ordination between acute and primary care services. A number of participants noted that the variety of care providers accessed by people with COPD (such as respiratory specialists, GPs, pulmonary rehabilitation teams, mental health service providers, occupational therapy, Domiciliary Care SA) means there is often no *one* provider who actually knows all of the services that the person is using. A care co-ordinator was suggested as being invaluable in accessing and linking all of these services.

*If there were someone – and I particularly think of the Divisions [of General Practice] in that sense – that their job is to keep on top of all the services and be available (FG 3: GP).*

*we need an integrated service ... there needs to be much more of an interchange of services happening (FG 1: Respiratory Nurse Specialist)*

Focus group participants identified four major themes and three lesser themes (see Table 2). Access to services, particularly access to support for activities of daily living (ADL), respite for carers and age related barriers were all highlighted. Whilst patients referred to specialist palliative care services had priority access to ADL support, patients with chronic diseases such as COPD did not. Palliative care

programs were often more flexible and responsive but did not offer longer term solutions. Participants agreed that referral to specialist palliative care services for all patients with COPD was not appropriate, but input and support from palliative care services was important. They emphasised that the integration of a palliative approach into a CDM framework was essential.

INSERT TABLE 2 HERE

The importance of the role of carers, the fact that this was rarely acknowledged in COPD and the lack of services available to support carers was raised by most groups. The consumer and carer groups clearly identified that there was a lack of information from health service providers about the disease and the availability of services, and they were expected to navigate the complex acute, primary and community systems with minimal assistance:

*Services are there, but only if you go out and find them for yourself.* (Consumer Support Group)

*The system is very complex .....there's so much that's assumed out there about what's available* (Carer Support Organisation)

It was noted that when people with an acute exacerbation of COPD were admitted to hospital, there was often limited knowledge of their past history or treatments and on discharge there was little follow up communication with the GP. The issue of poor communication was a consistent theme raised by all participants and was closely linked to care co-ordination. Participants also identified communication between health professionals and patients as a major theme and it was suggested that a care co-ordinator could facilitate communication, including discussions around advance

care planning. GPs emphasised that the role of a care co-ordinator should be as a facilitator of services, not as a gate-keeper.

Participants in this study clearly identified the need for a co-ordinator to function across the primary, acute and community sectors to provide specialised as well as generalist support. The importance of being able to ensure a palliative approach, whilst still providing specific disease-related care was emphasised, hence specialised COPD knowledge was seen as an important aspect of the role. Box 2 outlines the COPD care co-ordinator tasks ~~as~~ identified through the COPD Project.<sup>(4)</sup>

INSERT BOX 2 HERE

## DISCUSSION

It is increasingly clear that a best practice model of care for people with advanced COPD should be patient-centred and based on CDM principles; reflect a palliative approach at all phases of the illness; support people in navigating the acute health care and community support systems and that care co-ordination is a key strategy for ensuring this.<sup>(4, 7, 12)</sup> Whilst the COPD project identified a number of strategies required to improve care for advanced COPD, a COPD care co-ordinator was considered to be a key facilitator for ensuring and supporting their implementation.

If Australia is to consider implementing a care co-ordinator model for people with COPD (or any other chronic disease), a number of issues need to be addressed, particularly around the scope of the role, funding (including the development of new and innovative business models), skills and location. A care co-ordinator could facilitate the implementation of comprehensive and continuing care, provide direct

clinical care as required, support the patient through ongoing education and assist them to navigate the system and act as a patient advocate.<sup>(21)</sup>

A central tenet of the care co-ordinator role is a commitment to a patient (or person)-centred care approach. Internationally, patient-centred care is increasingly recognised as a key element of quality health care.<sup>(30)</sup> The Australian Commission on Quality and Safety in Health Care (ACQSHC) has identified co-ordination of care, clear communication and the provision of information as core elements of patient-centred care.<sup>(31)</sup> (See Box 1) For COPD, with its uncertain trajectory, care should be dictated by needs and symptoms rather than age or prognosis and a patient-centred approach such as this requires a different, more flexible funding model, with a focus on quality of care rather than cost containment.

The importance of co-ordinating care across the acute, primary and community sectors was identified as key to ensuring effective care.<sup>(22, 32)</sup> Primary care has been seen as the most appropriate setting for CDM and care co-ordination in the US<sup>(22)</sup> and UK.<sup>(13)</sup> In Australia, both the National Health and Hospitals Reform Commission<sup>(33)</sup> and the National Primary Health Care Strategy<sup>(34)</sup> focused on the importance of the primary care setting for CDM. General practice has been nominated as the focus of care co-ordination, with specific funding initiatives to support care co-ordination at a practice level (Enhanced Primary Care Items, General Practice Management Plans etc).<sup>(35)</sup> However, this raises a number of difficulties, as it assumes that people with COPD are accessing primary care and that primary care practices can spend the time required with complex patients.<sup>(22)</sup> In Australia, the issues associated with general practice (and practice nurses in particular) taking on the role of care co-ordinator include: the heterogeneity of the

general practice setting, a lack of funding, no clear definition of practice boundaries between nurses and GPs and a lack of knowledge and skills in specific aspects of care co-ordination.<sup>(35)</sup> GPs in the COPD study recognised that general practice was not structured or funded to support the time required to co-ordinate care for people with advanced, complex disease: *the last 5% of your income takes up 95% of your stress* (GP Focus Group).

However, the biggest barrier for the placement of care co-ordinators in general practice in Australia lies in funding mechanisms. Care co-ordinators must work across the primary, acute and community sectors, but each of these sectors has different funding sources. General practice is funded federally, whilst hospitals and community health services are state funded. A number of states have provided funding for specific CDM programs in general practice – e.g. the GP Plus Health Strategy in SA<sup>(36)</sup> and Connecting Care in New South Wales,<sup>(37)</sup> but hospitals themselves are generally reluctant to fund any program that is not directly related to hospital avoidance.<sup>(35)</sup> Funding is also a major barrier to practice nurses taking on a care co-ordination role.<sup>(38)</sup> Although specific funding for some practice nurse activities has been introduced through Medicare (e.g. development of care plans), care co-ordination for complex patients is not supported.<sup>(35)</sup> Thus, whilst practice nurses may be able to effectively co-ordinate the care of people with chronic disease in the earlier stages of the disease using care planning processes, once the chronic disease becomes advanced and more complex, this becomes increasingly difficult. Whilst practice nurses have a broad generalist knowledge, evidence from the US and the UK suggests that there needs to be specialist knowledge as well as generalist care to effectively co-ordinate care in advanced disease.<sup>(20, 22, 32)</sup>

People with advanced COPD can be overwhelmed by the variety of health professionals and community services with whom they engage.<sup>(4,7)</sup> Care co-ordinators therefore need knowledge of how general practice and the acute sector function and require links with other key support services in the health and community sectors. Knowledge of the differing organisational cultures of these care settings is also vital to be able to navigate them and access services. It is essential that care co-ordinators are trusted by both the acute and primary care sectors, if continuing co-ordinated care is to become a reality.

### **A proposed model for the care co-ordinator role in advanced COPD.**

#### *Scope of the Role*

The COPD study identified a number of aspects that any advanced COPD care co-ordinator role should encompass (see Box 2) and these tasks are reflected in the national and international literature.<sup>(21, 22, 38-40)</sup> A COPD care co-ordinator should be pro-active, supporting as much independence as possible through education and assistance with problem solving, but also have the skills and capacity to intervene with more specific assistance when needed. ~~Such a~~This advanced practice role should combine the skills of a palliative approach, with those specific to COPD, e.g. management of dyspnoea, oxygen therapy. Table 3 outlines the specific skills required of a COPD care co-ordinator, based on the domains of practice outlined in the Australian literature.<sup>(4,21,41,42)</sup>

INSERT TABLE 3 HERE

#### *Location of Care Co-ordinators*

Because COPD care co-ordinators would be required to have knowledge of, and earn the trust of, the acute, primary and community care sectors, their location is vital

in ensuring they are seen as “honest brokers”. Cross boundary communication has been identified as a key failure in attempts to co-ordinate care<sup>(43)</sup> and in order to integrate care across boundaries, an “intermediate” care setting, where both specialist and generalist nurses are based, with close links into the acute and primary care sectors is required. An intermediate setting facilitates information transfer and provides flexibility, allowing referral of patients between generalist and specialist nurses and the acute and primary care settings. Wiese et al.<sup>(44)</sup> note that the newly developed Medicare Locals are charged with facilitating the co-ordination of care through linking GPs more closely, not only with other Primary Health Care (PHC) services, but also with hospitals through the links with Local Hospital Networks, thus providing a possible “intermediate” care location, an appropriate location for a COPD Care Co-ordinator. ~~The Medicare Local could act as an “intermediate” care setting, where both specialist and generalist nurses are based, with close links into the acute and primary care sectors.~~ An intermediate setting provides flexibility, allowing referral of patients between generalist and specialist nurses and the acute and primary care settings. ~~Consideration of clinical and administrative governance is also an important issue.~~

#### *Funding COPD Care Co-ordinators*

Funding care co-ordinators provides an ongoing challenge. Whilst community care packages, transitional care packages, enhanced primary care items and state funded CDM programs provide funding for some (but not all) of the required care, they will not fund co-ordinator positions. ~~It may be that, as the care co-ordinator role has the potential to contribute significantly to Medicare Local and Local Hospital Network outcomes, the positions are jointly funded through these two groups.~~ Medicare Locals will potentially hold the funds for service integration, and so new business

models which incorporate funding for care co-ordinators across the Medicare Local and Local Hospital Network could be developed.<sup>(45)</sup> It should be noted that any funding mechanisms must allow the co-ordinator to access and activate required services in the same way as, for example, palliative care professionals are able to access such services.

~~Although it has been suggested that~~ Whilst specialist knowledge is required for effective COPD care co-ordination,<sup>(4, 32)</sup> much day to day care could be provided by generalist care co-ordinators. ~~As~~ funding specialist nurse co-ordinators for the growing numbers of people with a variety of chronic and complex advanced diseases could be a barrier to service provision, so it may be more feasible to provide a small number of specialist care co-ordinators for diseases such as COPD and heart failure who act as consultants to more generalist care co-ordinators, working closely with palliative care services and primary care,

### Limitations of the Study

This study was undertaken in one state of Australia, and so the results may not be transferable to other states where health system structures may differ. A wide range of health professionals participated in the focus groups and interviews, and so it is likely that their views reflect the views of many health professionals working with people approaching the end of their life, but the results cannot be generalised to all health professionals. ~~Although COPD care co-ordinators were identified by both patients and health professionals as a key strategy for improving end of life care, and have therefore been the focus of this discussion, a number of other strategies and recommendations were also identified in this study.~~<sup>(4)</sup> It is recognised that no one strategy will address the many issues confronting people with advanced COPD, but a



~~care co-ordinator can help to address a number of significant issues raised through this research.~~

## CONCLUSION

COPD has a major impact on individuals and families and affects all aspects of life, including financial, emotional, mental and physical. People with advanced COPD are often unable to navigate the acute health and community systems to deal with the multiple services ~~that~~ they ~~may~~ require, and the lack of communication between health services is frequently a significant issue for them. ~~With such an unpredictable course, the needs of people with COPD may continue for many years. Services such as palliative care and home support cannot be actually or de facto conditional on prognosis, but rather access should be based on physical and symptom needs, lest COPD sufferers continue to be disadvantaged. Care co-ordinators have been demonstrated to support person-centred care and the development of a COPD care co-ordinator role would ensure that people with advanced COPD receive continuing, appropriate and accessible care as they approach the end of their life.~~

~~There are currently no funding mechanisms for such a role, hence there are both policy and service provision implications for the adoption of such a strategy at state and national level. However, ~~t~~his research has demonstrated that a COPD care co-ordinator ~~there are practical and effective strategies that could significantly improve the quality of life of people with COPD and their families. could effectively combine a palliative approach with disease management and so significantly improve the quality of life of people with COPD and their families.~~ ~~With disease progression, a palliative approach, combined with management of the disease provides the most appropriate care model. A care co-ordinator can ensure that care is centred on the needs of the~~~~

~~person and their carer and ensure people with advanced COPD receive continuing, appropriate and accessible care as they approach the end of their life.~~

Although COPD care co-ordinators were identified by both patients and health professionals as a key strategy for improving end-of-life care, and have therefore been the focus of this discussion, a number of other strategies and recommendations were also identified in this study.<sup>(4)</sup> It is recognised that no one strategy will address the many issues confronting people with advanced COPD, and further research is required in this area, ~~but~~ however, a care co-ordinator can help to address a number of significant issues raised through this research.

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**BOX 1. Definitions**

**Service co-ordination:** “places consumers at the centre of service delivery, to ensure that they have access to the services they need, opportunities for early intervention, health promotion and improved health and care outcomes. Service Co-ordination enables organisations to remain independent of each other, while working in a cohesive and coordinated way to give consumers a seamless and integrated response.”<sup>(462)(p1)</sup>

**Care co-ordination** is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.<sup>(9)(p5)</sup>

**Case management** often refers to a limited set of episodic services assisting patients and families in navigating the health care and social service systems with cost reduction as its primary goal. In contrast, care management is a broad set of longer-term services that includes medical management and assistance in navigating the system, with both quality enhancement and cost reduction as goals. Care management requires the involvement of professionals with clinical training, usually registered nurses (RNs).<sup>(22)(p4)</sup>

**Patient-centred care:** is health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. The widely accepted dimensions of patient-centred care are respect, emotional support, physical comfort, information and communication, continuity and transition, care co-ordination, involvement of family and carers and access to care.<sup>(31)(p1)</sup>

**BOX 2: COPD care co-ordinator tasks identified by the COPD Project<sup>(4)</sup>**

- Assistance for people to navigate the acute health care and community support systems
- Support for a patient-centred model of care
- Support and facilitation of a palliative approach. *(A palliative approach is a term that has been used to describe care that aims to improve the quality of life for individuals with an eventually fatal condition, and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, psychological, social, cultural and spiritual needs)*<sup>(45)(p11)</sup>
- Ensuring timely, comprehensive and appropriate communication between all service providers providing care for the person with COPD
- Co-ordination of care across the primary, acute and community care sectors
- Undertaking an active program of health literacy improvement including patient education on COPD, self management, the health care system etc
- Self management support -as required
- Encouragement and facilitation for attendance at pulmonary rehabilitation programs

**TABLE 1: Possible range of care co-ordination tasks\***

Care Co-ordination Tasks	Common features of possible interventions to support co-ordination activities
<p><b>1. Assess patient</b> <i>Determine likely co-ordination challenges</i></p>	<p><b>Information systems</b> <i>Electronic medical record; personal health record; continuity of care record, decision support; population identification for intervention.</i></p>
<p><b>2. Develop care plan</b> <i>Plan for co-ordination challenges and organise separate care plans if required</i></p>	<p><b>Tools</b> <i>Patient education, standard protocols, evidence-based guidelines, self-management program, clinician education on co-ordination skills, routine reporting/feedback.</i></p>
<p><b>3. Identify participants in care and specify roles</b> <i>Specify who is primarily responsible for co-ordination</i></p>	<p><b>Techniques to mitigate interface issues</b> <i>Multidisciplinary teams for specialty and primary care interface; case manager or patient navigators to network and connect between medical and social services; collaborative practice model to connect different settings or levels of care; medical home model to support information exchange at interfaces.</i></p>
<p><b>4. Communicate to patients and all other participants</b> <i>Ensure information exchange across care interfaces</i></p>	<p><b>System re-design</b> <i>Paying clinicians for time spent co-ordinating care; changes that reduce access barriers including system fragmentation, patient financial barriers - lack of insurance, underinsurance, physical barriers - distance from treatment facilities.</i></p>
<p><b>5. Execute care plan</b> <i>Implement co-ordination interventions</i></p>	
<p><b>6. Monitor and adjust care / evaluate health outcomes</b> <i>Monitor for and address co-ordination failures</i></p>	

\* Adapted from McDonald K, Sundaram V, Bravata D, Lewis R, Lin N, Kraft S, et al. <sup>(9)(p6)</sup>

**TABLE 2: Data analysis – codes and themes**

<p style="text-align: center;"><b>Initial Codes</b> <i>(derived from review of all transcripts from health professional and consumer focus groups and interviews)</i></p>	<p style="text-align: center;"><b>Major Themes</b></p>
<ul style="list-style-type: none"> <li>• Access to palliative care               <ul style="list-style-type: none"> <li>- The capacity of palliative care services to address chronic disease needs</li> <li>- Referral processes</li> </ul> </li> <li>• Access to hospital care               <ul style="list-style-type: none"> <li>- Patients accessing hospitals</li> <li>- Issues around GP access to admitting COPD patients</li> </ul> </li> <li>• Age related access issues (especially for &lt;65 yrs)</li> <li>• Continuity of care / care co-ordination               <ul style="list-style-type: none"> <li>- Lack of shared medical records</li> <li>- No single care co-ordinator with knowledge of all the care particular patient is receiving</li> <li>- Lack of care planning</li> </ul> </li> <li>• “Working the System”               <ul style="list-style-type: none"> <li>- Getting access to ADL support through palliative care</li> </ul> </li> <li>• The importance of community based services</li> <li>• COPD patients may not appear as disabled as they actually are</li> <li>• Transport (including access to disabled parking)               <ul style="list-style-type: none"> <li>- Maintaining independence</li> </ul> </li> </ul>	<p style="text-align: center;"><b>Access to community services</b></p>
<ul style="list-style-type: none"> <li>• The importance of ADL support</li> <li>• Financial Implications               <ul style="list-style-type: none"> <li>- Disability often starts early so people can't work</li> <li>- Carers also have to stop working</li> </ul> </li> <li>• Advance Care Directives               <ul style="list-style-type: none"> <li>- Very few completed</li> <li>- A lack of clarity about whose responsibility it is to have the discussions</li> </ul> </li> <li>• Invisibility of the disease / blame / stigma</li> </ul>	<p style="text-align: center;"><b>Impact of the trajectory of COPD</b></p>
<ul style="list-style-type: none"> <li>• Lack of recognition of the importance of the role</li> <li>• Respite Care</li> </ul>	<p style="text-align: center;"><b>Carers</b></p>
<ul style="list-style-type: none"> <li>• Communication between health service providers and people with COPD</li> <li>• Communication between health services</li> </ul>	<p style="text-align: center;"><b>The importance of communication</b></p>
	<p style="text-align: center;"><b>Lesser Themes</b></p>
<ul style="list-style-type: none"> <li>• Cost (both of oxygen and electricity)</li> <li>• Outreach support</li> <li>• Social isolation</li> <li>• Fear of running out of oxygen when outside the home</li> </ul>	<p style="text-align: center;"><b>Home oxygen</b></p>
<ul style="list-style-type: none"> <li>• Depression</li> <li>• Anxiety associated with breathlessness</li> <li>• Mental health related hospitalisations</li> </ul>	<p style="text-align: center;"><b>Mental health</b></p>
<ul style="list-style-type: none"> <li>• The impact of the loss of personal independence</li> <li>• Grief issues</li> <li>• Coping with impending death</li> </ul>	<p style="text-align: center;"><b>Spiritual and emotional wellbeing</b></p>

**TABLE 3. Domains of practice/skills for a care co-ordinator for people with advanced Chronic Obstructive Pulmonary Disease\***

<b>Service model</b>	<ul style="list-style-type: none"> <li>Nursing consultant / clinician (direct expert clinical care)</li> <li>Broad based service profile including focused clinical service</li> </ul>
<b>Role parameters/ practice domains</b>	<b>Direct Comprehensive Care</b>
	<ul style="list-style-type: none"> <li>Builds active partnerships with the patient and carer(s) to support independence and behaviour change through education and risk factor management along the course of the disease, assisting with symptom management, problem solving, developing advance care and respite plans and plans for physical and psychosocial support, linking of required services and flexibility to increase availability at end of life</li> </ul>
	<ul style="list-style-type: none"> <li>Advocates and negotiates for the patient and carer(s) within the system, providing ongoing support for negotiating the complexities of the health care/service system</li> </ul>
	<ul style="list-style-type: none"> <li>Assesses the needs of the patient and carer(s) in a timely manner and provides expertise to intervene with more specific assistance as required</li> </ul>
	<ul style="list-style-type: none"> <li>Ensures effective communication pathways to all relevant clinicians and service providers regarding the treatment / care plan to ensure that care is delivered to meet the needs of the patient and their carer(s)</li> </ul>
	<ul style="list-style-type: none"> <li>Ensures ongoing referral across all health sectors, transition and discharge planning involving the patient and collaborating with relevant members of the multidisciplinary team</li> </ul>
	<b>System Support</b>
	<ul style="list-style-type: none"> <li>Facilitates optimal progression of the patient's journey through the health care system including access to multiple IT systems for data management</li> </ul>
	<ul style="list-style-type: none"> <li>Facilitates pro-active care provisions rather than <b>reactive</b> episodic <b>care</b>, taking into account the changing needs of people with COPD</li> </ul>
	<ul style="list-style-type: none"> <li>Provides flexible services across primary, acute and community sectors <ul style="list-style-type: none"> <li>Provides a single point of access for the patient into the health care service system</li> <li>Provides continuity for the patient within the complex health care system</li> <li>Integrates a palliative approach within a chronic disease framework for managing care at end of life</li> <li>Monitors for and addresses co-ordination failures and provides regular patient surveillance if required</li> <li>Facilitates services (is not a gatekeeper to deny services)</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>Actively mentors and provides advanced information to patients and communities to promote wellness and prevent morbidity</li> <li>Facilitates students in the specialty area</li> </ul>
	<b>Skills / Knowledge</b>
<ul style="list-style-type: none"> <li>Demonstrates advanced knowledge of management of patients with COPD</li> <li>Demonstrates advanced knowledge that informs care co-ordination, care delivery, and guidance to others, as relevant to a specific patient population</li> <li>Demonstrates high level communication and negotiation skills with a range of people, from family members to doctors and specialists</li> <li>Demonstrates knowledge and understanding of general practice, the acute sector, and community services (including eligibility criteria)</li> <li>Demonstrates knowledge of, and experience with, the variety of patient care IT systems</li> </ul>	

\* Adapted from Nutt & Hungerford<sup>(21)</sup> and SA Department of Health.<sup>(42)</sup>