Cheshire and Wirral Partnership NHS
NHS Foundation Trust

Document level: Clinical Service Unit (CSU)
Code: CC1
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Guide for end of life care for patients with chronic obstructive pulmonary disease

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Type of document	Guidance
Target audience	All community staff
Document purpose	To outline guidelines for end of life care for people with Chronic Obstructive Pulmonary Disease (COPD)

Document consultation	COPD Specialist Team	
Approving meeting	Patient Safety and Effectiveness Sub Committee	16-Jun-11
Ratification	Document Quality Group (DQG)	8-Sep-11
Original issue date	Sep-11	
Implementation date	Sep-11	

CWP documents to be read in conjunction with	HR6	Trust-wide learning and development requirements including the training needs analysis (TNA)

Training requirements	There **are no** specific training requirements for this document.

Financial resource implications	Yes - For 2011/12, this guidances supports the delivery of Commissioning for Quality Innovation payment framework monies totalling £45,612.

Equality Impact Assessment (EIA)

Initial assessment	Yes/No	Comments
Does this document affect one group less or more favourably than another on the basis of:		
• Race	No	
• Ethnic origins (including gypsies and travellers)	No	
• Nationality	No	
• Gender	No	
• Culture	No	
• Religion or belief	No	
• Sexual orientation including lesbian, gay and bisexual people	No	
• Age	No	
• Disability - learning disabilities, physical disability, sensory impairment and mental health problems	No	
Is there any evidence that some groups are affected differently?	No	
If you have identified potential discrimination, are there any exceptions valid, legal and/or justifiable?		
N/A		
Is the impact of the document likely to be negative?	No	
• If so can the impact be avoided?	No	
• What alternatives are there to achieving the document without the impact?	No	
• Can we reduce the impact by taking different action?	No	

Where an adverse or negative impact on equality group(s) has been identified during the initial screening process a full EIA assessment should be conducted.

If you have identified a potential discriminatory impact of this procedural document, please refer it to the human resource department together with any suggestions as to the action required to avoid / reduce this impact.

For advice in respect of answering the above questions, please contact the human resource department.

Was a full impact assessment required?	No	
What is the level of impact?	Low	

Monitoring compliance with the processes outlined within this document

Is this document linked to the NHS litigation authority (NHSLA) risk management standards assessment?	No NB - The standards in bold above are those standards which are assessed at the level 2 and 3 NHSLA accreditation.

Who is responsible for undertaking the monitoring?	COPD team and COPD CQUIN leads.
How are they going to monitor the document?	Quantitative and qualitative data - BODE variables and outcome measures.
What are they going to monitor within the document?	The COPD team and COPD CQUIN leads will monitor the BODE variables and outcome measures and the agreed CQUIN targets during the CQUIN monitoring period.
Where will the results be reviewed?	The results of the monitoring will be reviewed by the CCWC CQUIN Group and the Patient Safety and Effectivenss Sub Committee
When will this be monitored and how often?	The results will be monitored monthly within the service, with quarterly reports to the Patient Safety and Effectiveness Sub Committee, and the CCWC CQUIN Group/ quality contract meetings [during the CQUIN monitoring period].
If deficiencies are identified how will these be dealt with?	Actions will be identified by the COPD team on a monthly basis where there are deficiencies, which will be monitored through the Patient Safety and Effectiveness Sub Committee and CCWC CQUIN Group.
Who and where will the findings be communicated to?	BODE variables and outcome measures - Patient Safety and Effectieveness Sub Committee and CCWC CQUIN Group. Quarterly reports on progress and completion of CQUIN milestones - quality contract meetings and via the quarterly Quality Report to to Patient Safety and Effectiveness Sub Committee, Quality Committee and Board of Directors.
How does learning occur?	Variance in relation to the BODE measures and learning from outcome measurement will be shared with service governance groups and result in actions being identified by the COPD team, subsequently monitored through the Patient Safety and Effectiveness Sub Committee and CCWC CQUIN Group.
How are the board of directors assured?	The Board is assured via direct receipt of the quarterly Quality Report in relation to the CQUIN milestones. The Board delgates oversight of risks associated with compliance with clinical standards to the Patient Safety and Effectiveness Sub Committee. Any strategic risks associated with the clinical standards outlined in the clinical guidelines would be escalated via the corporate risk register process.

Document change history

Changes made with rationale and impact on practice
1.

External references

References
1. Bode index for COPD (Celli et al., 2004) N Engl J Med 2004;350:1005–12.
2. British Lung foundationhttp://www.lunguk.org/you-and-your-lungs/conditions-and-diseases/copd
3. End of life pathway (Cheshire and Wirral Partnership NHS Foundation Trust, 2010)

Content

1. Introduction

For 2011/12, the Trust has agreed the following goal as part of the Commissioning for Quality Improvement (CQUIN) target:

Use of the BODE index as a composite marker of disease to identify patients with Chronic Obstructive Pulmonary Disease (COPD) who are at a stage in their care when palliative care should be considered (Celli BR, N Engl J Med 2004)

The Trust's COPD specialist team have developed these clinical guidelines on the implementation, monitoring and reporting of the BODE index to help support best, end of life practice for those patients with COPD. The components of the BODE index - FEV1, MMRC and BMI - are already included on initial assessment of new patients; this document sets out their correlation and scoring.

2. Definitions

COPD or chronic obstructive pulmonary disease, it is a progressive disease that makes it hard to breathe. COPD can cause coughing that produces large amounts of mucus, wheezing, shortness of breath, chest tightness, and other symptoms. Cigarette smoking is the leading cause of COPD. Most people who have COPD smoke or used to smoke. Long-term exposure to other lung irritants, such as air pollution, chemical fumes, or dust, also may contribute to COPD. (British Lung Foundation 2011)

BODE is a multi-dimensional index designed to assess clinical risk in people with COPD and can help predict COPD mortality i.e. how long people will live after diagnosis.
It includes 4 variables into a single score:

B - Body mass
O - Obstruction of airflow measured by forced expiratory volume FEV
D - Dyspnoea measured by MRC scale
E - Exercise capacity measured by a 6 minute walk

Each component is graded and a score out of 10 is obtained. The higher the score the greater risk of mortality is indicated.

The BODE index

Variable	Points on BODE index			
	0	1	2	3
FEV1 (% predicted)	≥65	50-64	36-49	≤35
6-Minute Walk Test (metres)	≥350	250-349	150-249	≤149
MMRC Dyspnea Scale	0-1	2	3	4
Body Mass Index	>21	≤21		

6 minute walking test - measures the distance, in metres, a patient can walk quickly on a flat, hard surface in 6 minutes and reflects an individual's ability to perform daily physical activities.

Body Mass - Body mass index (BMI) is a measure of body fat based on height and weight that applies to adult men and women.

FEV (forced expiratory volume) - the maximal amount of air the patient can forcefully exhale in one second. It is then converted to a percentage of normal as predicted based on height, weight, and race. FEV1 is a marker for the degree of obstruction:

- FEV1 greater 80% of predicted = normal
- FEV1 60% to 79% of predicted = Mild obstruction
- FEV1 40% to 59% of predicted = Moderate obstruction
- FEV1 less than 40% of predicted = Severe obstruction

MMCR (Modified Medical Research Council) Dyspnoea Scale - uses a simple grading system to assess a patient's level of dyspnoea. Dyspnoea is shortness of breath. It can be defined as air hunger, or the sensation of having the urge to breathe:

Grade	Description of breathlessness
0	I only get breathless with strenuous exercise.
1	I get short of breath when hurrying on level ground or walking up a slight hill.
2	On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace.
3	I stop for breath after walking about 100 yards or after a few minutes on level ground.
4	I am too breathless to leave the house or I am breathless when dressing.

3. Procedure

The COPD team will use the modified BODE index as per appendix 1. It should be acknowledged that the majority of patients referred to the Community COPD service do not have the physical ability to complete the 6 minute walking test component of the index and also it is advised that this test is not undertaken at home in the absence of proper medical supervision, so the majority of patients will score 3 for this competent. The MMRC will be used as an indicator to the level of exercise patients can complete.

The COPD team will complete the assessment at point of referral and at 6 monthly review assessments of existing and new patients. Note:

a. The FEV is completed at the GP surgery or hospital, as a non portable Spirometer is used and so accuracy of the score will depend on when the last test was undertaken, prior to referral. The GP or Consultant should include the % score in referral documentation. With disease progression, the ability of patients to attend external appointments to undergo this test decreases.
b. MMRC is already used as part of the initial assessment.

4. Pathway

Appendix 1

5. Monitoring

Monitoring will be as per the monitoring compliance section of the clinical guidelines, which includes arrangements for specific monitoring during the CQUIN reporting period.

The BODE score will be recorded using Digital pens, which will then enable reports correlating BODE score, preferred place of care (PPOC), date PPOC discussion occurred, deaths and place of death. Prior to use of digital pens, a paper scoring sheet will be completed and information entered at a later date.

Analysis of the scores will be completed by CCWC CQUIN leads during the CQUIN reporting period, thereafter the COPD team, to determine if there is a correlation between high scores and timing of PPOC discussion and then death, which would then give a clearer understanding of how and if the BODE index could be used as a marker for palliative care. The lower scores will be compared as to whether they are the patients referred to pulmonary rehabilitation.

Monthly data will be collected and a report will be compiled quarterly to include the report on the scores and the outcome for patients and milestone targets during the CQUIN reporting period.

6. Duties and Responsibilities

6.1 Chief Executive

The Chief Executive has overall responsibility to ensure that appropriate clinical standards are in place within the Trust and that contractual obligations are met.

6.2 Medical Director

The Medical Director has responsibility for clinical standards within the Trust and is the lead for the CQUIN schedule of the Trust's contracts.

6.3 Director of Nursing, Therapies and Patient Partnership

The Director of Nursing, Therapies and Patient Partnership has responsibility for nursing standards, learning and development within the Trust and is the lead executive for this document.

6.4 Quality Committee (QC)

The Quality Committee is the overarching committee responsible for clinical quality and risk within the Trust's governance structure and will therefore review any strategic risks associated with variance against the standards set out in clinical guidelines, escalating risks/ recommendations to the Board of Directors.

The quality committee will receive the quarterly quality report which provides an update on progress with the milestones set out in the Trust's CQUIN schemes.

6.5 Patient Safety and Effectiveness Sub Committee (PSESC)

Patient Safety and Effectiveness Sub Committee is responsible for the approval of clinical guidelines and oversight of their monitoring, elevating issues as necessary to the QC.

6.6 COPD team

The COPD team will complete the BODE index and score for all new patients and at 6 month review; they will enter the score on a paper system initially and then on to Oracle.

The COPD team will follow the pathway to determine how patients are managed as the disease progresses. The team will monitor scores and outcomes for patients.

6.7 CCWC COPD CQUIN leads

The CCWC COPD CQUIN leads will meet monthly during the CQUIN reporting period to ensure that scores are being entered as required and will correlate results. They will ensure that milestones are on target and will inform the PSESC of any issues relating to compliance with the CQUIN scheme.

Appendix 1 - Chronic Obstructive Pulmonary Disease decision making pathway