Evaluation of the Rotherham Breathing Space Programme for Chronic Obstructive Pulmonary Disease

Interim Report March 2008

Introduction

The Rotherham “Breathing Space” initiative is a comprehensive and systematic programme aimed at reducing the burden of chronic obstructive pulmonary disease (COPD) in a high-risk population. The overall aims of the initiative and the major objectives of the evaluation are outlined in the Baseline Evaluation Report produced in April 2008.

This interim report reviews the information available to inform the evaluation to date and reflects on some of the key implications for both the Breathing Space Programme and the evaluation process. It is largely based on analyses and reports produced for the Breathing Space Evaluation to date, in particular, information presented at the Interim Evaluation Conference held at Breathing Space on the 27 Feb 2008. This report should be read in conjunction with the detailed reports and presentations produced for each component of the evaluation and available on the web: (http://www.rotherhampct.nhs.uk/healthprofessionals/breathingspace/evaluation.asp).

Interim Findings from Evaluation 2007/08

1. Primary care audit

This audit was completed in 2006/07 and involved the review of the clinical records of 3217 primary care patients with a diagnosis of COPD from 38 practices (a stratified random sample from a total COPD patient population of 5649). A more detailed notes audit was conducted for a sample of 761 patients. The main findings of the primary care audit have been reported previously. Overall wider variations were found between practices with significant scope to improve the quality of management. Some key issues have been identified by subsequent analyses and from comparison of the audit data with information from the Quality and Outcomes Framework (QOF) for the same practice populations.

Comparison of diagnostic and severity coding and FEV1 results:

A comparison of the results of spirometry tests and the clinical coding of severity was carried out for 1386 patients for whom both are available. This suggests that overall 12% (162/1386) are coded as having COPD despite spirometry results being within normal limits. 25% (346/1386) have a clinical severity recorded which is worse than would be expected on the basis of their spirometry result. Only 5% (76/1386) have a recorded severity less severe than expected from their spirometry result. This suggests a degree of “over-diagnosis” of COPD and of the clinical severity. However we have no indication of the proportion of the primary care population with abnormal lung function in whom COPD has not been diagnosed (or diagnosed but not coded) as the audit only included those with a COPD code on the clinical information system. So the extent of over-diagnosis can be assessed but the extent of under-diagnosis remains unknown.

Comparison of audit and QOF data
A comparison was also made between the audit results and QOF data from a similar period (2006/07) at practice level. This analysis suggests that while most practices performed well on the QOF criteria based on the proportion of COPD patients having had an FEV1 recorded in the previous 15 months, fewer practices performed well on the audit criteria of spirometry performed, and recorded, to the audit standard in the previous year. This suggests that it is not possible to rely wholly on QOF data in making a detailed assessment of the quality of diagnostic testing or monitoring of COPD.

2. Breathing Space activity audit

The initial analysis of activity data, based on referrals to Breathing Space since referrals for assessment and rehabilitation programmes started in May 2007, has identified a number of crucial issues for both the programme and the evaluation.

**Progression rates from referral to rehabilitation programme completion**

Although 828 referrals had been received between May 2007 and January 2008, only 85 patients have so far completed rehabilitation programmes. This is in part because of the time required to develop programmes and then see initial cohorts through the programme. There is also early evidence that a large proportion of the patients referred are regarded as not suitable for further assessment (24% of those referred, 152/643) and a large proportion of those fully assessed decline rehabilitation (22% of those assessed, 98/441). This means that only about 60% of those referred are currently being assessed and enrolled on a rehabilitation programme. There are also issues of capacity with 130 patients currently awaiting a place on a programme, whilst 128 are currently enrolled on programmes.

**Outcomes of assessment**

Comparison of clinical outcomes before and after rehabilitation show clinically and statistically significant improvements. Outcomes compared include exercise capacity and performance (using incremental and endurance shuttle walking test results), quality of life and symptoms (as measured by the CRQ) and anxiety and depression (measured using HAD scores). 41 of 133 smokers referred to the programme have been seen and offered treatments; six are reported as having managed to stop smoking and 13 are recorded as having cut down. It is planned to repeat follow up at six months and 12 months for at least a proportion of rehabilitation programme participants in order to assess whether benefits persist and this information will help inform the development of maintenance rehabilitation programmes.

**Data collection and extraction issues**

A major concern for Breathing Space is the finding that it is extremely difficult to extract raw activity data and clinical data from the clinical information systems currently in use (TPP and STAR systems). Although the TPP system is widely used and can be searched, which may be sufficient for some basic audits, for evaluation and research it will be important to be able to extract anonymised data to another database for statistical manipulation. Although the STAR system does use an Access database, it is not clear that the formatting and coding of data will allow raw data to be extracted. For example, although the SF36 questions are included in the current version of STAR, only recoded, rather than original, variable values and summary scores are recorded.

3. Patient and carer interviews
As well as the in-depth interviews with stakeholders and COPD patients before the programme started, interviews have now been conducted with patients and carers who have experienced the new rehabilitation programmes in order to get early feedback on the patient experience. The patients who consented to interview may not be representative of all patients with COPD or all patients referred to Breathing Space. Most notably, none of the interviewees were current smokers so no feedback was available on the perceived accessibility of the site or rehabilitation programmes to current smokers. Key findings include:

- Patients identified many positive aspects of the new service and were particularly appreciative of the access to both specialist expertise and to opportunities to access peer support and social interaction with other patients.
- Patients felt they had been helped to access support and manage their condition better but did not feel there had been any direct impact on their use of other services.

Further patient and carer interviews are planned to assess whether the benefits of programme participation persist and what factors may influence continued use of the Breathing Space facilities and continued benefit after an initial rehabilitation programme is completed.

4. Burden of Disease and economic modelling

**Burden of Disease study**

The overall impact of COPD on quality of life was assessed by a community survey sent to a sample of 857 primary care patients with CPD coded as mild, moderate and severe disease. Quality of life was measured using the SF36 which asks 36 questions to assess eight different dimensions of quality of life. As expected, physical functioning and physical role dimensions of the SF36 were lower in those with moderate and severe disease. However other dimensions, such as mental and emotional health were not predicted by severity coding and when a single index of overall quality of life (ie a utility value) was calculated for the 388 patients returning completed surveys (139 mild, 135 moderate and 114 severe) the value was 0.57 for those with mild disease, 0.58 for those with moderate disease and 0.56 for those with severe disease (on a scale on which perfect health = 1). Comparison with expected values from UK population samples from the same age groups as Rotherham COPD patients suggests that in every age group quality of life is significantly lower for COPD patients with the absolute difference greatest for younger patients. These findings confirm previous research that suggests that whilst there is certainly scope to improve the quality of life of COPD patients, lung function is not a major predictor of quality of life and therefore rehabilitation can have a significant impact even where it is not possible to delay progression.

**Factors influencing the cost effectiveness of Breathing Space**

The preliminary modelling of incremental cost-effectiveness uses the current overall costs (£2.1 million) and proposed activity (1,168 patients/yr) and assumes that other NHS costs remain unchanged. Under these assumptions, the Breathing Space programme would need to increase quality of life by an average of 20% to achieve a
cost per QALY around £24 000 (ie within the NICE threshold for acceptable cost-effectiveness of £20-30 000/QALY). If a more realistic estimate of expected benefit is assumed to be 5%, this implies four to five fold increase in throughput being required to achieve acceptable cost-effectiveness. These results compare to estimates from traditional hospital-based pulmonary rehabilitation of costs between £2 000 and £8 000/QALY.

It is likely that the throughput and activity levels could be increased and since this is a new programme it is likely to build up activity levels gradually over time. It is also possible that a significant proportion of the costs of maintaining and staffing the Breathing Space building could be offset by other uses, including residential/inpatient use and, potentially, in the longer term, by reducing secondary care costs. Hospital admission and length of stay data is being monitored and comparative data from Doncaster and Barnsley will examined to determine whether it is likely that the programme has have a measurable impact on COPD related admissions.

Summary of key findings and recommendations

- **Primary care audit:** There is clearly potential to improve diagnosis, monitoring and management of COPD in primary care and a repeat audit is planned to assess the extent of improvement in the first year of the Breathing Space programme.

- **Breathing Space activity audit:** Early results suggest measurable clinical improvement for patients completing rehabilitation programmes and further follow up will also whether those gains are maintained. However, about 40% of patients referred either are not offered or do not accept a rehabilitation programme despite a range of different programmes being offered. Current capacity is relatively low whilst programmes are still being developed. A major concern is the quality of information systems which may jeopardise on-going clinical audit and evaluation.

- **Patient and carer interviews:** Initial feedback from patients and carers is generally very positive, but further qualitative follow up is needed to assess the longer term impact of participation in rehabilitation programmes.

- **Burden of Disease and economic modelling:** The impact of COPD on quality of life is significant in every affected age group and not predicted by recorded COPD severity. In order to demonstrate cost-effectiveness, it is likely that some of the costs of the Programme will need to be offset by savings, for example by using the building to provide other functions or by reducing NHS costs elsewhere.

Dr Liddy Goyder

on behalf of the Breathing Space Research and Evaluation Steering Group
Introduction: Robin Carlisle, Deputy DPH, Rotherham PCT
Introduction

- Introduction to the Mini-conference
- Introduction to the Breathing Space Programme
- Introduction to the aims and process of the evaluation project
- Information not discussed elsewhere
- Housekeeping and timetable
Invitees to the event

- Those involved in aspects of the evaluation including ScHARR
- Patients and carers
- Breathing Space staff
- Stakeholders including the Coalfields Regeneration Trust
- Clinicians from primary and secondary care
- Managers from primary and secondary care
- Boehringer-Ingelheim
Aims of the Mini-conference

- Highlight emerging themes - from the ongoing evaluation
- Brief presentations - covering the scope of the evaluation
- First interim evaluation report - the presentations will form the basis of this report
- Feedback on the evaluation - from the delegates

http://www.rotherhampct.nhs.uk/healthprofessionals/breathingspace/evaluation.asp
Breathing Space Programme

- Open since May 2007, current focus on assessment and multi-disciplinary rehabilitation for patients with COPD
- By 1 Feb 2008 around 650 people had initial assessments for outpatient rehabilitation (12% of the number of people known to have COPD)
- Very few residential stays
- New business case for residential stays being prepared but not the subject of this mini-conference
# Components of the evaluation

**Target population:**

All 5600 people with COPD, their carers and undiagnosed COPD cases

<table>
<thead>
<tr>
<th>Component</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Qualitative research</td>
<td>Patients, carers and stakeholders’ views before &amp; after Breathing Space</td>
</tr>
<tr>
<td>Outcomes</td>
<td>For patients and carers going through programme</td>
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<tr>
<td>Impact</td>
<td>- Primary care before &amp; after audit</td>
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<tr>
<td></td>
<td>- Smoking</td>
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<td></td>
<td>- Prescribing costs</td>
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<td></td>
<td>- Secondary care services</td>
</tr>
<tr>
<td>Comparisons</td>
<td>With other health communities</td>
</tr>
<tr>
<td>Modelling</td>
<td>Whole system cost effectiveness</td>
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</tbody>
</table>
The Evaluation Timetable

<table>
<thead>
<tr>
<th>Report</th>
<th>Date</th>
</tr>
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<tbody>
<tr>
<td>Baseline</td>
<td>April 2007</td>
</tr>
<tr>
<td>First interim</td>
<td>April 2008</td>
</tr>
<tr>
<td>Second interim</td>
<td>December 2008 (mini-conference in October)</td>
</tr>
<tr>
<td>Final</td>
<td>July 2009</td>
</tr>
</tbody>
</table>
Information not discussed elsewhere

- Comparison with other health communities
- Secondary care impact
COPD: Reported QoF prevalence
April 2005 – March 2006

COPD Definition: ICD10 Primary diagnosis code in range J40-J44

Source: NHS Comparators
COPD: All Admissions
April 2006 – March 2007

COPD Definition: ICD10 Primary diagnosis code in range J40-J44

Source: NHS Comparators
COPD: Admissions per 100 patients on QoF register
April 2005 – March 2006

COPD Definition: ICD10 Primary diagnosis code in range J40-J44

Primary Care Trust

Source: NHS Comparators
Adam Dowling (PCT FACT) produces a series of secondary care trend charts with pre and post Breathing Space data these cover:

- All medical admissions
- Respiratory admissions
- COPD admissions, length of stay and re-admissions
- COPD tariff costs
Rotherham COPD admissions
By month, all providers

Actual data April 2005 to September 2007

Predicted data April 2007 to March 2009
Messages from the 2006-7 COPD audit

Mark Strong
Clinical Lecturer in Public Health
ScHARR
University of Sheffield
Method

Audit conducted autumn-winter 2006/7
3217 sets of notes in 38 practices
   (stratified random sample from n=5649)
1 in 5 notes (n=761): more detailed audit
Standards from NICE, BTS and PCT
# Method

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patients diagnosed as COPD should have had spirometry.</td>
<td>100%</td>
</tr>
<tr>
<td>(NICE COPD Guidelines 2004)</td>
<td></td>
</tr>
<tr>
<td>2. Patients should have spirometry every 12 months.</td>
<td>80%</td>
</tr>
<tr>
<td>(NICE COPD Guidelines 2004)</td>
<td></td>
</tr>
<tr>
<td>3. Spirometry results should be recorded on the COPD template</td>
<td>100%</td>
</tr>
<tr>
<td>(PCT standard)</td>
<td></td>
</tr>
<tr>
<td>4. Airflow obstruction is defined as FEV1 &lt; 80% predicted AND FEV1/FVC &lt;</td>
<td>100%</td>
</tr>
<tr>
<td>0.7.</td>
<td></td>
</tr>
<tr>
<td>(NICE COPD Guidelines 2004)</td>
<td></td>
</tr>
<tr>
<td>5. COPD patients should be categorised as Mild, Moderate or Severe in</td>
<td>100%</td>
</tr>
<tr>
<td>accordance with NICE Guidance. (Mild FEV1 50-80% predicted, Moderate</td>
<td></td>
</tr>
<tr>
<td>FEV1 30-49% predicted, Severe FEV1 &lt; 30% predicted.</td>
<td></td>
</tr>
<tr>
<td>(NICE COPD Guidelines 2004)</td>
<td></td>
</tr>
<tr>
<td>6. COPD patients should not have a normal spirometry.</td>
<td>100%</td>
</tr>
<tr>
<td>(NICE COPD Guidelines 2004)</td>
<td></td>
</tr>
<tr>
<td>7. Current smokers should be offered smoking cessation.</td>
<td>100%</td>
</tr>
<tr>
<td>(NICE COPD Guidelines 2004)</td>
<td></td>
</tr>
<tr>
<td>1 in 5 Audit</td>
<td></td>
</tr>
<tr>
<td>8. There is evidence that spirometry has been carried out to BTS</td>
<td>100%</td>
</tr>
<tr>
<td>standards (3 consistent readings of which 2 are within 5%).</td>
<td></td>
</tr>
<tr>
<td>(BTS Spirometry in Practice 2005)</td>
<td></td>
</tr>
<tr>
<td>9. COPD patients categorised as Moderate or Severe should have a self</td>
<td>50%</td>
</tr>
<tr>
<td>management plan that includes steroids and antibiotics if appropriate.</td>
<td></td>
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<td>(NICE COPD Guidelines 2004)</td>
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<tr>
<td>10. COPD exacerbations should be Read Coded as COPD exacerbation.</td>
<td>100%</td>
</tr>
<tr>
<td>Emiss/Vision: H3122 or H3y1.</td>
<td></td>
</tr>
<tr>
<td>TPP: H3122 or Xa351 or H3y0 or X101i</td>
<td></td>
</tr>
<tr>
<td>(PCT Standard)</td>
<td></td>
</tr>
<tr>
<td>11. Patients with Moderate or Severe airways obstruction should be</td>
<td>90%</td>
</tr>
<tr>
<td>assessed for O₂ using pulse oximetry.</td>
<td></td>
</tr>
<tr>
<td>(NICE COPD Guidelines 2004)</td>
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</tr>
</tbody>
</table>
Results - age

Males

Females

n=1675 (52%)

n=1542 (48%)
Results – smoking

Smoking prevalence

Smoking prevalence (%)
Results - spirometry

Spirometry

Percentage achievement

Spirometry ever

Spirometry last yr
Results - spirometry

3 readings (2 within 5%)

Achievement (%)
Results - diagnosis

Mild, moderate or severe

Diagnosis

- Spiro not normal
- Categorised

- Percentage recorded
- Percentage achievement

- Mild
- Moderate
- Severe
## Results - diagnosis

<table>
<thead>
<tr>
<th>Categorised as</th>
<th>Normal &gt;80%</th>
<th>Mild 50-80%</th>
<th>Moderate 30-50%</th>
<th>Severe &lt;30%</th>
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<tr>
<td>Mild</td>
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<td>470</td>
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<tr>
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Cohen’s kappa = 0.34 (0.30 – 0.38)
## Results - diagnosis

**FEV1 (% predicted) result**

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*Note: The table shows the number of cases for each category.*

*Cohen’s kappa = 0.34 (0.30 – 0.38)*
## Results - diagnosis

### FEV1 (% predicted) result

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*Tendency to over-diagnose*
Results - other

Management plans, READ codes and Pulse Ox assessments
QOF…

33 points in QOF for COPD
Each point worth ~ £125 (on average)
38 practices = 1254 pts available
Achievement = 1184.8 pts (94.5%)
Approx £184,000 in Rotherham (06-07)
QOF FEV1 in last 15m vs audit spirometry in last year
QOF spirometry achievement vs audit quality of spirometry
Conclusion

Variability in achievement against standards
- across criteria
- across practices within each criterion

Suggestion of over-diagnosis

QOF vs audit findings
- QOF score may not reflect “quality”
Conclusion

Variability in achievement against standards
- across criteria
- across practices within each criterion

Suggestion of over-diagnosis

QOF vs audit findings
- QOF score may not reflect "quality"

m.strong@sheffield.ac.uk
Angela Burnett and Gail South
The Patient Pathway

Referral

Clinic 1 Nurse assessment

Clinic 2 Rehabilitation assessment

Traditional Rehabilitation Programmes
- HIP
- LIP
- ADL

Discharge

Follow up Review (6 months and 1 yr)

Clinic 1 follow up
- Oxygen Clinic
- Referral elsewhere

Discharge

Individual Programme
- Home Programme
- Other referral out

Maintenance
Initial Clinic 1 Assessment

• Full history
• Investigations e.g. CXR, PFTs, ECG, Echo
• Confirm diagnosis of COPD
• Treatment e.g. inhaled medication, oxygen
• Refer to MDT for rehab assessment
• Refer to chest physicians
• Refer back to GP
Clinic 2 Rehabilitation Assessment

- Seen by Physiotherapist and Occupational Therapist
- Complete relevant walking tests and other assessment measures
- Establish current level of activity and limiting factors
- Identify any individual needs e.g. equipment or social support
- Discuss with patient (and carer) rehabilitation aims
- Joint decision made as to most appropriate rehabilitation plan
Referrals to Breathing Space?

- 828 referrals May 07 – Jan 08
- 643 first contacts
- 441 Rehabilitation Assessments completed
- 85 Completed outpatient rehabilitation programmes
- 128 patients currently undertaking programmes (31 of which currently on-hold)
- 130 patients awaiting place in programmes
- Length of referral to 1\textsuperscript{st} contact: currently $< 4$ weeks
- From March 08 - 128 Rehab places (per week of 2 sessions)
- In addition to flexible maintenance class sessions (early am and later pm)
In other words

- 152 patients (26%) were not suitable for clinic 2 referral

Reasons?
- Not COPD
- DNA
- Declined

Further 98 patients (22%) attend Clinic 2 but decline rehabilitation
Initial Suggested Criteria for the Rehabilitation Programmes:

Higher Intensity Programme (HIP)
- Breathlessness major limiting factor
- Minimal or no co morbid history limiting ability to exercise
- More traditional gym based pulmonary rehabilitation (but individual!)

Lower Intensity Programme (LIP)
- Presence of other limiting factors to exercise (co morbidities)
- Higher risk or those requiring more supervision (e.g. cardiac or desaturation)
- Increased supervision and/or increased modification of exercise

Activities of Daily Living (ADL) Programme
- Functional exercised based
- Individually goal directed related to ADL’s
- Increased level of psychosocial support

Home Programme and Individual Rehabilitation programmes
# Review of patient characteristics from Clinic 2 Rehabilitation Assessments (n = 416)

<table>
<thead>
<tr>
<th></th>
<th>HIP</th>
<th>LIP</th>
<th>ADL</th>
<th>IND</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number</strong></td>
<td>158 (38%)</td>
<td>109 (26%)</td>
<td>118 (28%)</td>
<td>31 (8%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>85M/73F</td>
<td>56M/53F</td>
<td>52M/66F</td>
<td>12M/19F</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>67 (8) *</td>
<td>69 (9)</td>
<td>72 (9)</td>
<td>73 (13)</td>
</tr>
<tr>
<td><strong>FEV₁ % p</strong></td>
<td>47 (15)</td>
<td>44 (16)</td>
<td>45 (14)</td>
<td>38 (13) *</td>
</tr>
<tr>
<td><strong>FEV₁/FVC</strong></td>
<td>49 (14)</td>
<td>48 (13)</td>
<td>50 (14)</td>
<td>49 (13)</td>
</tr>
<tr>
<td><strong>MRC SCORE</strong></td>
<td>2.8 (0.8)</td>
<td>3.4 (0.8)</td>
<td>4.1 (0.9) *</td>
<td>3.7 (1)</td>
</tr>
<tr>
<td><strong>ISWT (M)</strong></td>
<td>259 (128) *</td>
<td>109 (63) *</td>
<td>56 (39) *</td>
<td>-</td>
</tr>
</tbody>
</table>

* p < 0.05
Outcomes so far for patients completing programmes (HIP and LIP)  (n = 74)

- Exercise capacity (Incremental Shuttle Walking Test- ISWT)
- Exercise performance (Endurance Shuttle Walking Test - ESWT)
- Health status measure – QoL  (Chronic Respiratory Questionnaire – Self Reported – CRQ-SR)
- Anxiety and depression scores – (Hospital Anxiety and Depression Scale – HAD)
Outcomes 1: Exercise capacity
Incremental Shuttle Walking Test Results (n = 74)

Metres

p < 0.01

PRE REHAB

POST REHAB

0
50
100
150
200
250
300

300
275
250
225
200
175
150
125
100
75
50
25
0

PRE REHAB

POST REHAB
Outcomes 1: Exercise Performance
Endurance Shuttle Walking Test Results (n = 69)

![Graph showing pre and post rehab results with a p-value of < 0.01](image)
Outcomes 2: Quality of Life Results
CRQ (n = 69)

![Bar graph showing outcomes with p < 0.01]

- Dyspnoea
- Fatigue
- Emotion
- Mastery
Outcomes 3: Anxiety and Depression
HAD Scores (n = 68)

p < 0.01
Outcomes 4: Patient satisfaction
What you enjoyed most

“What I have learned from this programme is that the word chronic does not mean terminal……the programme has had a profound effect on my outlook towards my health problem, and has made me realise that there are many more people around that are far worse than I am”

“Being together as a group, all having the same problem but being able to have a laugh about it as well as discussing problems raised by it”

“Really relaxing and feel so at home, the staff really care”

“Knowing there is someone I can contact should I feel the need to. The patience and understanding of all the staff and the kindness shown to all the patients”

“Meeting with other with the same condition, talking with staff about things I was worried about . Confidence I can get help if I required it”
Outcomes 4: Patient satisfaction

What do you feel could be better

“Nothing. Could have been fewer forms to fill in”

“increase to 50 weeks”

“bit more equipment”

“sometimes difficult to get a turn on equipment – could do with more equipment”

“Have softer seats while you are exercising”
Conclusions of these Results so far.....

• Patients completing the traditional evidence based programmes (HIP and LIP) at BreathingSpace gain improvements in exercise capacity, improved quality of life and reduced anxiety and depression

• Patients enjoy attending BreathingSpace and value the support of staff and other patients

Some Future considerations .....

• What benefits will be observed in the more disabled population (e.g. ADL) and those not accessing the traditional programmes?
• How long are these benefits sustained for?
• What is the role of Maintenance Programmes?
• What are the other impacts and results from BreathingSpace?
Outcomes 5: secondary care contact

4 requests for information

9 referrals to Respiratory Physicians (1.5%)

- 2 referrals for lung transplant consideration
- 2 for rapid access clinic - ? lung cancer
- 2 with suspected Sleep apnoea
- 1 with Bronchiectasis
- 1 with Restrictive pattern
- 1 with undiagnosed breathlessness
Outcomes: others

Issues:

1) TPP not fit for purpose for research

2) STAR not fit for purpose for BS research?

3) Excel spreadsheet probably fit for purpose but requires double entry of data
Outcomes: Sampling Strategy

• TPP search under “BMI” (seemed like something most people would have recorded)

• N=463

• Sorted by NHS number

• Initial 90 ascending order NHS no. patients analysed
Outcomes: Data Collection

• Outcome variables
  – Age
  – Sex
  – MRC
  – Pack years
  – FEV1
  – FVC
  – FEV1/FVC ratio
  – BMI
Demographics

• Age
  – Median age 74 years
  – Range 40-90

• Sex
  – Female 57%!!!
Smoking Status

• Data available on 80 patients (89%)

• Mean pack years 36.3
  (range 0-140)

• 22.5% patients have pack year total <10
  (and would be ineligible for inclusion in any COPD trial!!)
Smoking Status

- Of patients with pack years Hx <10
  - 2 normal spirometry
  - 11 obstructive spirometry!!
  - 1 restrictive spirometry
  - 2 mixed obstructive/restrictive picture
  - 2 patients with no recorded data

- i.e. significant prevalence of airflow obstruction in non or light smokers
  (occupational causes very likely?)
Smoking Cessation

- 133 smokers
- 41 patients seen (22%)

<table>
<thead>
<tr>
<th></th>
<th>NRT</th>
<th>Champix</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quit</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Decreased</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Ongoing</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Drop out</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>30</td>
<td>11</td>
</tr>
</tbody>
</table>
Symptoms: MRC

- Data from TPP available on 73/90 patients (76%)
  - MRC 1: 2 (2.7%)
  - MRC 2: 9 (12.3%)
  - MRC 3: 39 (53.4%)
  - MRC 4: 17 (23.3%)
  - MRC 5: 6 (8.2%)

- Appropriate level of symptoms to consider rehabilitation in 85% cases
Physiology: FEV1/FVC ratio

• Data available on 76/90 patients (84%)
  • Median ratio: 52
  • Range: 28-87

• 17% (n=15) patients had ratio >70%
  (i.e. not fulfilling diagnosis of COPD!!!)

• Of these patients 10 had spirometry that would
  be classified as “normal” and 5 as “restrictive”
Physiology: FEV1 (%predicted)

- Data available on 76/90 patients (84%)

- Median value: 74% pred.
- Range: 25-123

- 12% (n=9) patients had FEV1 >80% pred! (i.e. not even classifiable as mild COPD)

- Of these patients 6 had FEV1/FVC ratio >70%
- Of the 3 with ratios <70% the FVC was 106, 99 and 136% predicted!
475 patients assessed May 2007 - Jan 2008. 75 dietetic referrals during this period.

<table>
<thead>
<tr>
<th>Support</th>
<th>Weight reduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI &lt;20</td>
<td>No. referred (%)</td>
</tr>
<tr>
<td>55 (11.6)</td>
<td>35 (7.3)</td>
</tr>
</tbody>
</table>
• 243 men (median age 68, range 45-94) and 232 women (median age 69, range 39-91) were assessed at BreathingSpace between May 2007- Jan 2008.

<table>
<thead>
<tr>
<th>BMI</th>
<th>Number</th>
<th>%</th>
<th>Pop %</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;20</td>
<td>33</td>
<td>14.2</td>
<td>7</td>
</tr>
<tr>
<td>20-25</td>
<td>48</td>
<td>20.7</td>
<td>39.3</td>
</tr>
<tr>
<td>25-30</td>
<td>68</td>
<td>29.3</td>
<td>32.8</td>
</tr>
<tr>
<td>&gt;30</td>
<td>83</td>
<td>35.8</td>
<td>20.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BMI</th>
<th>Number</th>
<th>%</th>
<th>Pop %</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;20</td>
<td>22</td>
<td>9.1</td>
<td>4.5</td>
</tr>
<tr>
<td>20-25</td>
<td>66</td>
<td>27.1</td>
<td>32.4</td>
</tr>
<tr>
<td>25-30</td>
<td>86</td>
<td>35.4</td>
<td>44.2</td>
</tr>
<tr>
<td>&gt;30</td>
<td>69</td>
<td>28.4</td>
<td>18.9</td>
</tr>
</tbody>
</table>
Any other possible conclusions??

• Not really!! But..............................................

• There is a lot of “not COPD” around in the clinics (so change those READ codes!)

• There is also quite a bit of “non-smoking” COPD around

• There is a lot of symptomatic disease, especially in women! (so may not be as much occupational disease as we thought!!!)
Any other definite conclusions??

• And it is really really really really difficult extracting useful data from our current sources!!
Interim Evaluation Mini-conference
27 February 2008
Hannah Jordan, PH Specialist Trainee Rotherham PCT
Qualitative stakeholder, patient and carer interviews

Dr Hannah Jordan
Public Health
Rotherham PCT
What are the interviews for?

- **Stakeholders**: expectations, hopes and concerns
- **Patients and carers (before Breathing Space opened)**: living with COPD, using health services
- **Patients and carers (after Breathing Space opened)**: living with COPD, using Breathing Space
Why use qualitative interviews?

‘Open’ questions and statements allow people to talk around a subject, and bring up issues that may not be uncovered by direct questioning
How do the interviews work?

• We decided on some questions
• We talked
• Everything was recorded
• Everything was transcribed
What did people expect from Breathing Space?
What did people think about the care they were already getting as COPD patients?
Is Breathing Space helping patients and their carers to make useful changes in their lives?
How satisfied are patients and carers with the way the programmes at Breathing Space are delivered?
Analysing the interviews

• Framework analysis
  – We looked at everything that had been said in the interviews and collected together comments around each of our questions
  – We began to draw some conclusions
Stakeholders

• COPD has been largely ignored
• Services for people with COPD are lacking
• Breathing Space – ‘righting the wrongs’, presenting Rotherham in a positive light
  Dr: “there isn’t a comparable clinical area where there is such a big disease burden that has had such little attention in terms of things like National Service Frameworks and policy”
• Breathing Space as a pilot others can learn from
• But…
  • May be difficult to secure funding
  • Must be effective
  • Partnership working takes work
  • Might there be problems with being ‘smoke free’?
  • Will the staffing mix work?
“there isn’t a comparable clinical area where there is such a big disease burden that has had such little attention in terms of things like National Service Frameworks and policy
Stakeholders

• New opportunities

• Threats to success

• Putting Rotherham ‘on the map’

Follow up interviews at the end of 2008 – have attitudes changed, reasons for success, problems and learning…
Patients and carers (before Breathing Space)

• Experience of living with COPD
  – Understood that there is no ‘cure’
  – Want to achieve personal goals
  – Often find it difficult to get out and about
  – Feel there is a lack of understanding of COPD
  – Don’t want to criticise current care, but recognise limitations

  Patient: “I get on well with my doctor although … for the past couple of years he’s been too busy … he’s a good doctor, but he hasn’t got the time, that’s the point”
Patients and carers (before Breathing Space)

- Positive feelings about Breathing Space
  - Centre of excellence
  - Provision of information and expertise
  - May help people to access care
  - May help people manage their COPD better
  - May provide peer support, information and social interaction all in one place
Patients and carers
(after Breathing Space)

• Positive things
  – The staff, the staff, the staff
  – The other patients
  – Confidence in managing breathlessness
  – Being cared for by experts
  – Not being judged
  – Being valued
  – The building
Carer: “up to going to Breathing Space X was under the impression nobody cared, nobody asked her how she were… she says nobody’s bothered about us who’s got COPD”
Patients and carers
(after Breathing Space)

• Negative things
  – Virtually nothing…
  – Maybe a bit more equipment in the gym?
  – One worrying case of not having understood what Breathing Space was
  – no real change in use of other health services
  – No impact on smoking – everyone had already given up!
What do we do with the information?

- The information from the interviews will be fed back into the decision making process of how we provide care for COPD in future.
- Qualitative information is an important addition to quantitative data.
Interim Evaluation Mini-conference
27 February 2008
Malcolm Whitfield, Professor, ScHARR
Breathing Space
(Burden of illness)

Dr Malcolm Whitfield - Director
Health Policy & Management (ScHARR)
University of Sheffield

m.whitfield@sheffield.ac.uk
The Problem - Prevalence

In Rotherham around 5800 people are identified with COPD on GP Quality and Outcome Framework registers – this is about 1.7 times the national average prevalence.
The Problem – The effect

### UK Population Norms for EQ-5D from Kind

<table>
<thead>
<tr>
<th>Age Groups</th>
<th>count</th>
<th>mean QoL</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-44</td>
<td>256</td>
<td>0.91</td>
<td>0.17</td>
</tr>
<tr>
<td>45-54</td>
<td>221</td>
<td>0.84</td>
<td>0.27</td>
</tr>
<tr>
<td>55-64</td>
<td>196</td>
<td>0.78</td>
<td>0.28</td>
</tr>
<tr>
<td>65-74</td>
<td>228</td>
<td>0.78</td>
<td>0.28</td>
</tr>
<tr>
<td>75+</td>
<td>108</td>
<td>0.75</td>
<td>0.28</td>
</tr>
</tbody>
</table>

### COPD utilities by age group and gender.

<table>
<thead>
<tr>
<th>Age Groups</th>
<th>count</th>
<th>mean QoL</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-44</td>
<td>2</td>
<td>0.42</td>
<td>0.17</td>
</tr>
<tr>
<td>45-54</td>
<td>8</td>
<td>0.60</td>
<td>0.18</td>
</tr>
<tr>
<td>55-64</td>
<td>43</td>
<td>0.51</td>
<td>0.14</td>
</tr>
<tr>
<td>65-74</td>
<td>68</td>
<td>0.61</td>
<td>0.12</td>
</tr>
<tr>
<td>75+</td>
<td>63</td>
<td>0.57</td>
<td>0.13</td>
</tr>
</tbody>
</table>

### Difference

<table>
<thead>
<tr>
<th>Age group</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-44</td>
<td>0.50</td>
<td>0.36</td>
</tr>
<tr>
<td>45-54</td>
<td>0.24</td>
<td>0.31</td>
</tr>
<tr>
<td>55-64</td>
<td>0.27</td>
<td>0.23</td>
</tr>
<tr>
<td>65-74</td>
<td>0.17</td>
<td>0.20</td>
</tr>
<tr>
<td>75+</td>
<td>0.18</td>
<td>0.16</td>
</tr>
</tbody>
</table>
The Problem - Treatment

- Smoking cessation is the only intervention proved to slow the decline of COPD
- Pneumococcal and influenza vaccination can reduce in deaths by 30-40% in the elderly
- Long term oxygen therapy can prolong survival in patients with low oxygen saturation
- Pulmonary rehabilitation can improve quality of life and reduce hospital stays
- Long acting bronchodilators and inhaled corticosteroids can reduce exacerbations in some patients
The Problem - Cost

- The breathing space service costs over £2.1 million per annum
### Incremental cost effectiveness

#### Incremental Cost per QALY if you treat 1,168 patients

<table>
<thead>
<tr>
<th>Target increase in QoL</th>
<th>QoL gain</th>
<th>Cost/QALY (£) (20% of Patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5%</td>
<td>12.21</td>
<td>98260</td>
</tr>
<tr>
<td>6%</td>
<td>14.66</td>
<td>81883</td>
</tr>
<tr>
<td>7%</td>
<td>17.10</td>
<td>70186</td>
</tr>
<tr>
<td>8%</td>
<td>19.54</td>
<td>61412</td>
</tr>
<tr>
<td>9%</td>
<td>21.98</td>
<td>54589</td>
</tr>
<tr>
<td>10%</td>
<td>24.43</td>
<td>49130</td>
</tr>
<tr>
<td>11%</td>
<td>26.87</td>
<td>44664</td>
</tr>
<tr>
<td>12%</td>
<td>29.31</td>
<td>40942</td>
</tr>
<tr>
<td>13%</td>
<td>31.75</td>
<td>37792</td>
</tr>
<tr>
<td>14%</td>
<td>34.20</td>
<td>35093</td>
</tr>
<tr>
<td>15%</td>
<td>36.64</td>
<td>32753</td>
</tr>
<tr>
<td>16%</td>
<td>39.08</td>
<td>30706</td>
</tr>
<tr>
<td>17%</td>
<td>41.52</td>
<td>28900</td>
</tr>
<tr>
<td>18%</td>
<td>43.97</td>
<td>27294</td>
</tr>
<tr>
<td>19%</td>
<td>46.41</td>
<td>25858</td>
</tr>
<tr>
<td>20%</td>
<td>48.85</td>
<td>24565</td>
</tr>
</tbody>
</table>

PR = £2K – £8K  NICE = £20K – £30K
Incremental cost effectiveness

Cost-effectiveness of QoL percentage gain

Cost/QALY (£)

Cost/QALY (20% of Pats)

Cost/QALY (30% of Pats)

Cost/QALY (40% of Pats)
Incremental cost effectiveness

Regression model

\[ y = 0.0394x^{-1.0048} \]

\[ R^2 = 0.998 \]

Regression model of numbers of patients treated and the QoL gain at a willingness to pay of £24k
The Strategy – Throughput

- If we assume that the Breathing Space programme will improve mean quality of life in the total COPD population, closing the gap between the current level and the average population scores by around 5%. At this stage in the analysis we are estimating that the Breathing Space Centre would have to treat five times more people than currently planned to achieve a cost effectiveness ratio at £24k per QALY.
The Strategy - QoL Gain

• Similarly if we assume the Breathing Space will treat the 1000 patients currently planned the service would have to improve the mean quality of life of all COPD patients to reduce the gap with the average population by 20% to achieve a cost effectiveness ratio at £24k per QALY.
The Strategy – Cost offset

• Neither of the above scenarios are likely. In any case even if they were achieved the cost per quality adjusted life year would still be between 12 and 3 times higher than the cost normally attributed to pulmonary rehabilitation delivered in another way.
The Strategy – Cost offset

- The assumption is that the cost of the Breathing Space Centre remains at around £2.1 million.
- More efficient use of the building
- Streamlining of the operational policy
- Capturing all activity and all QoL gain
- Apportionment of costs to other functions i.e. research, training, meeting NICE guidance
- Accurately capture other utilisation data hospital admissions, GP visits etc