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

Second Interim Report February 2009

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 Breathing Space building opened for outpatient rehabilitation in May 2007 and for inpatient provision in October 2008. A number of national developments in health policy, including World Class Commissioning, have implications for the future development of the Breathing Space model. The anticipated publication of the National Service Framework for COPD (http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/COPD/index.htm) later this year is likely to ensure that both prevention of COPD and improving the quality of life of COPD patients has a higher priority nationally, increasing interest in the innovative, whole system, community-based Breathing Space approach.

The overall aims of the initiative and the major objectives of the evaluation are outlined in the Baseline Evaluation Report produced in April 2007. Initial evaluation findings were presented at the Interim Evaluation Conference held at Breathing Space on the 27 Feb 2008 and summarised in the first interim report.(http://www.rotherhampct.nhs.uk/healthprofessionals/breathingspace/Mini%20Conference/Interim%20Report%20March%202008.doc).

This second interim report reviews and summarises 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 based on analyses and reports produced for the Breathing Space Evaluation to date and information presented at the Conference held at Oak House, Rotherham on 28 January 2009. 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 2008/09

A. BENEFITS: What measurable change in COPD care and outcomes has been achieved since the opening of Breathing Space?

1. Changes in primary care

The COPD primary care audit has been repeated in 2008 in all but one Rotherham general practice. The original audit in 2006 showed that, despite practices achieving relatively high scores in the Quality and Outcomes Framework measures, when audit standards were based on NICE clinical guidelines there was significant scope for improvements in both diagnosis and management. The repeat audit showed improvements on a range of audit criteria, with scope still for further improvements, both in accuracy of diagnosis and in adherence to prescribing guidelines.

Primary care activity – Annual mean contact rates for a retrospective cohort have remained stable (7.4 in 2006; 8.0 in 2007; 8.0 in 2008) and mean exacerbation rates

slightly increased over time (1.1 in 2006, 1.2 in 2007; 1.3 in 2008). This is not unexpected as COPD is a progressive condition.

Prevalence – Initially the overall prevalence of COPD cases reduced from 2005 to 2006 (at the time of the first primary care audit), presumably as misdiagnosed individuals were detected by the audit and increased awareness of spirometry-based diagnostic criteria led to some individuals being removed from registers. Subsequently prevalence has increased from 5600 to 6000, presumably due to increased diagnostic awareness, and is expected to increase further as some practices are now offering spirometry to all smokers who have been smoking for 20 years or more to raise awareness and improve detection (funded as a Locally Enhanced Service).

Smoking – Audit data suggested a third of COPD patients still smoke (36.1% in 2006; 33.4% in 2008). This reduction equates to approximately 150 fewer smokers with COPD in Rotherham.

Changes in hospital admissions

Routine data on COPD admission rates allow analysis of trends and comparison with Barnsley and Doncaster rates. Data to August 2008 does suggest some downward trend in admissions and a measurable impact may be expected once more recent data showing the impact of opening the beds at Breathing Space can be obtained.

Changes in prescribing

Changes in prescribing largely reflect changes in prescribing guidance and product availability. Changes in management, with an increase in use of inhaled antimuscarinics and corresponding decrease in prescribing of nebulised anti-muscarinics may be related to the Breathing Space programme changing prescribing practice. Otherwise, increases in prescribing, and overall respiratory prescribing costs largely follows regional and national trends. Whilst inhaled steroid use has increased, relative costs have not increased as much, suggesting more cost-effective prescribing. Increases in mucolytic use reflects changes in guidance and is likely to be cost-effective in the specific patient groups who can benefit.

Major national changes in the way oxygen is provided make it difficult to make direct comparison. Costs have increased six-fold (from £20 000 to 120 000 per quarter) but overall it is likely that patients who can benefit from oxygen are better assessed and given a wider choice of options, including ambulatory oxygen. These changes are largely due to the new national procurement system.

2. Impact of assessment and rehabilitation at Breathing Space

Comparison of clinical outcomes before and after rehabilitation show clinically and statistically significant improvements. Whilst walking measures (ISWT) and disease specific quality of life measures (CRQ-SR) show improvement, it is particularly relevant for assessing the cost effectiveness of rehabilitation that the generic quality of life measure (SF36v2) shows significant differences on all dimensions except general health.

Whilst initial measures were available for 585 patients, post-rehab measures were only available for 314. 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 to date six month follow-up is available for 129 patients.

A patient satisfaction questionnaire completed after rehabilitation yielded very positive responses: 98% enjoyed the programme; 80% felt their quality of life had improved; 85% felt their health had improved. Internal Breathing Space feedback from patients has been almost entirely positive, with only one complaint, which led to a system change.

B. COSTS: What do we know about the costs of Breathing Space activity?

The financial analysis of activity and cost data, based on completed rehabilitation episodes and in-patient episodes may not reflect actual activity simply because the data systems are not capturing all contacts with patients and carers receiving assessment and rehabilitation.

Inpatient activity – With a capacity of 140 bed days/week, mean occupancy has been 81 bed days/week (range between 48 and 127 bed days/week). This represents a mean occupancy rate of 58%. The true cost per night is estimated at £409 (whilst relative cost at acute trust is £364) although this could be reduced by increasing occupancy

Rehabilitation activity – This is measured as "rehab packages" and a capacity of 16 packages/week has been assumed. In the first 8 weeks, 83 packages were recorded suggesting operation at 65% of expected activity levels. Subsequent activity data was apparently not available, although the System One activity report data suggests 349 completed episodes by January 2009 ie in 20 months since Breathing Space opened averaging 4/week or 25% of assumed capacity.

Overall it appears that the cost per episode is considerably higher than comparable costs in the acute trust (Rotherham Foundation Trust) but it is unclear how these costs relate to the actual costs of running the programme. It appears that these figures assume that all costs (a total of £2.2 million in 2008/09) relate to admissions and rehabilitation packages. They do not appear to take any account of the much wider range of activities provided by the Breathing Space programme staff or other uses of the Breathing Space building.

C. OTHER KEY ISSUES: What are the views of key stakeholders?

In order to follow up changes in the views of stakeholders 18 months after the opening of Breathing Space, stakeholders were re-interviewed in 2008.

1. Stakeholders interview findings

Whilst confirming that overall attitudes to Breathing Space are highly positive amongst all types of stakeholders, these in-depth interviews raised some important concerns that will need to be addressed if the overall aims of the programme are to be seen to be achieved. Whilst at an organisational level the impact on partnership working within Rotherham was seen as very positive and many of the early concerns had not been realised, there were clearly tensions created by the attempt to create a less clinical, community orientated and inclusive model of rehabilitation which entails a very major change in culture and ways of working, particularly for those whose previous experience is of more traditional specialist services. There were concerns expressed that this change has not be wholly successfully achieved to date.

2. Issues raised at the mini conference

Some of the tensions and concerns reflected in the qualitative interview findings, were confirmed during discussion amongst conference attendees. Some specific issues were also highlighted by the summary of economic issues.

Making the best possible use of Breathing Space resources – This issue was raised by interviewees specifically in relation to the use of the building, but may also relate to use of staff and other resources in ways that maximises the impact on quality of life for as many COPD patients and their carers as possible, rather than the minority who currently benefit from the existing rehabilitation programme.

Patients who do not attend or who drop out from rehabilitation – Concern about the equity of access to Breathing Space for all COPD patients (and potentially for patients with other chronic lung or heart disease) was raised. There was also concern about the high number of people who are seen for initial assessment but do not start, or who start but do not complete, a rehabilitation programme

Data collection and extraction issues - A major concern remains the finding that it is extremely difficult to extract raw activity data and clinical data from the clinical information systems currently in use and the assertion that this data is significantly incomplete (TPP and STAR systems). The view was expressed by several people that it is unrealistic to expect patients to complete so many questionnaire instruments and to complete them more than once.

Implications of findings

Concerns were expressed relating both to whether the Breathing Space programme could be shown to be cost-effective and whether, even if it was cost-effective, the impact could be adequately captured by the evaluation. Some of the suggestions arising from the conference presentations and subsequent discussion are presented here, although they by no means represent an exhaustive list of possible actions.

A. How can the cost effectiveness of Breathing Space be improved?

Given the complexity of the Breathing Space model, the range of activities undertaken and the wide range of direct and indirect effects, both identifying all the potential benefits and then attempting to quantify them represent a major challenge. There are a number of areas of potential benefit that currently may not be appropriately captured.

i. Education and training for Breathing Space staff and local Rotherham health professionals. These will have an indirect impact on improving COPD management and patients' quality of life. Provision of education programmes for a wider audience could impact on COPD management regionally and nationally.

ii. Interventions to support carers, benefits advice, provision of therapy (occupational therapy, physiotherapy) and referral to other services

iii. Expert patient programmes and other patient led activity (formal Breathe-Easi Group and informal peer support and social interaction between Breathing Space patients)

iv. Impact of all Breathing Space activities on quality of life of carers and other family members as well as patients

v. Impact of employment and training for Breathing Space staff

There are two main options which may both be worth pursuing:

1. To use qualitative interviews to capture the range of ways in which these activities lead to tangible benefits both for individuals and the wider community
2. To attempt to quantify benefit though wider use of survey instruments to quantify change in quality of life for a much wider group than individuals completing rehabilitation programmes. Use of SF16 (rather than the longer SF36) might make this more feasible, whilst still allowing benefits to be converted into Quality Adjusted Life Years (QALYs) for the purposes of the economic evaluation.

B. How can the cost effectiveness of Breathing Space be better measured?

The preliminary modelling of incremental cost-effectiveness used the original overall costs (£2.1 million) and proposed activity (1,168 patients/yr) and assumed 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).

It is still likely that the throughput and activity levels could be increased. 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 both primary and secondary care costs as set out in the summary of economic issues.

Summary of key findings and recommendations

The achievements of the Breathing Space programme to date and the very positive feedback received from patients, carers and stakeholders have been widely acknowledged. A number of areas have been identified where it may be possible to both increase the impact of the programme and a number of opportunities identified to ensure that the wider impacts are captured by the evaluation. In particular:

1. Identifying a range of acceptable and feasible ways of working, particularly around increased flexibility in eligibility criteria which would **maximise use of resources** by increasing admissions/bed occupancy and increasing delivery of rehabilitation packages
2. **Identify additional activities**, other than admissions and rehabilitation packages, that can be used of **offset building and staff costs**.
3. **Identify potential savings**, arising from Breathing Space programme activities, even where those savings may not be directly realised (eg use of facilities by patient groups, improving primary care management through audit and education)
4. **Ensure the wider benefits and cost savings related to Breathing Space, as well as the direct impact of completed rehabilitation programmes, are as fully documented as possible and, where possible, quantified**. This may require both additional qualitative research with staff, patients and carers and additional collection of quality of life data from patients and carers using SF16.

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