

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

Summary Report December 2009

Introduction

The Rotherham “Breathing Space” initiative is a comprehensive programme developed to reduce 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.

Over the last two years, a comprehensive evaluation of the developing programme has been undertaken, with oversight from the Research and Evaluation Steering Group, in order to assess the impact of Breathing Space for patients, carers and the wider community.

A number of national developments in health policy, including World Class Commissioning, have had implications for the future development of the Breathing Space model. The anticipated publication of the national COPD Strategy (expected to be out for consultation in early 2010) is likely to ensure that improving the quality of life of COPD patients and their carers has a high priority nationally and will entail widespread 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 in February 2008 and summarised in the first interim report. A second interim report reviewed the information available in January 2009. All three evaluation reports and the associated documentation are in the public domain (<http://www.rotherhampct.nhs.uk/healthprofessionals/breathingspace/evaluation.asp>).

This report covers the five original success criteria and considers the extent to which they have been shown to have been met. Since a very wide range of data has been collected and analysed for the evaluation of Breathing Space, this report, rather than attempting to be exhaustive, highlights the main findings which directly address whether Breathing Space has achieved its original five success criteria.

Success Criterion 1: The Breathing Space Programme offers substantially improved care for patients with chronic respiratory disease and their carers in Rotherham.

Primary care quality - A comprehensive primary care audit was undertaken in 2006/07 and repeated in 2008 in all but one Rotherham general practice. The original audit 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.

Completeness and accuracy of diagnosis – Initially the overall prevalence of COPD cases reduced from 2005 to 2006 (at the time of the first primary care audit), 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, which will largely be due to increased diagnostic awareness. Where practices are offering spirometry to all smokers who have been smoking for 20 years or more to raise awareness and improve detection it is likely to increase further.

Reduction in smoking prevalence – Primary care audit data suggests a third of COPD patients still smoke (36.1% in 2006; 33.4% in 2008). There have been 113 direct referrals from Breathing Space to smoking cessation services that have all set quit dates (and 14 other referrals that mention Breathing Space) but only 29 recorded as having quit at four weeks. This suggested that although smokers are accessing the programme (26% of attendees are recorded as smokers), the direct impact at Breathing Space on referrals to formal smoking cessation services and on quit rates is modest. A follow up telephone survey with a random selection of patients found that all 38 smokers interviewed had been offered support to stop smoking and whilst seven of the smokers said they had managed to stop, two ex-smokers reported starting smoking again, highlighting a potential need for support both to quit and to avoid relapse. Extrapolating from this self-report data, a net reduction of 5 smokers per 100 COPD patients could imply approximately 70 additional people stopping smoking in association with attending Breathing Space.

Prescribing quality - Changes in prescribing data 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.

Provision of Oxygen therapy - Changes in the way oxygen is provided due to the new national procurement system make it difficult to make direct comparison or to credit Breathing Space alone with the significant improvements that have occurred in both the quality of initial assessment and choice of options, including ambulatory oxygen, given to patients. It is important that in any new service specification there is clarity about responsibilities for oxygen assessments across the Rotherham Health Community and that this reflects both the considerable additional commissioning requirements that have emerged for oxygen assessment since Breathing Space opened but also the potential for efficiency savings in this area.

Overall, it is possible to say that the primary care data and prescribing data both demonstrate that there have been some improvement in quality since the baseline audits and that there remains scope for further improvement.

Success Criterion 2: The programme delivers improved outcomes for chronic respiratory disease patients and carers who have direct contact with the Breathing Space Programme.

Total activity delivered – A total of 1430 patients have attended Breathing Space between May 2007 and October 2009 (1311 as outpatients, 340 as inpatients – ie 221 seen as both inpatients and out-patients). 608 patients completed 14 or more rehabilitation sessions (compared to performance target of 800), 239 completed 8-13 sessions and 508 completed less than 8 sessions. The main reasons for

discontinuing are health-related rather than due to programme organisation, content or accessibility.

The total number of admissions (episodes) is 749 ie an average of 2.2 admissions per patients. Average bed-occupancy was 69% (compared to a performance target of 85%) with 749 admissions and average length of stay of 5.2 days (Target 5 days). The time taken for staff to be recruited and services to be established, and the prolonged delays in opening the Breathing Space beds means that total activity is lower than originally predicted.

With regards to outpatient rehabilitation current activity at Breathing Space is considerably more complex than the simple care pathways envisaged in the original business case. A large proportion of people are accessing the unit for a variety of short or 'incomplete' episodes (such as one off assessments or oxygen assessment) and comparatively few people seen for initial assessment are undertaking a full 16 session rehabilitation sessions as originally envisaged. With regards to inpatients initially the majority of admissions were for people who were first admitted to RNHSFT and then transferred. Now 50% of admissions are coming directly to Breathing Space.

Improvements in quality of life, disease specific outcome measures and exercise capacity for patients who complete pulmonary rehabilitation – Data is available for 427 patients who completed outcome assessment both pre-rehabilitation and post-rehabilitation. This shows statistically and clinically significant improvements in their exercise tolerance (walking distance) and respiratory symptoms (including breathlessness and fatigue) assessed by a disease specific health status measure. Improvements in anxiety and depression scores were relatively small but still statistically significant and were the benefits that were most sustained over time after the completion of rehabilitation programmes. The generic quality of life measures (SF-36 and SF-16 analysed to produce a single preference based quality of life utility measure) again showed small but statistically significant improvements which were not maintained over time, suggesting that it was the mental health benefits, rather than physical improvements, that are maintained over time. Overall outcomes were comparable to those found in clinical trials of rehabilitation despite the differences in case mix and issues with the timing of data collection. Fewer patients had data on longer term follow-up and overall this data showed a gradual loss of improvement with some long term improvement for all outcomes except overall quality of life. Improvements in anxiety and depression were best maintained. These results suggest that patients who complete rehabilitation and have continued contact with Breathing Space do see benefits which persist for up to 12 months, despite having a chronic and progressive condition. It is not possible to draw any inference about patients who do not complete rehabilitation or attend for reviews, as they are likely to have worse health (and potentially poorer outcomes from rehabilitation) than those who do attend. Those that did not complete rehabilitation reported either that this was because of worsening health or because of other family or social commitments making attendance impossible.

Experience of patients and carers – Information on the views of service users is available from the follow-up interviews conducted with eight patients and five carers and from the patient satisfaction returns from 176 in-patients, 455 out-patients and 28 carers. There is considerable consistency between the survey returns and in-depth interview analysis in identifying the patients' interactions with the staff and with other patients as what they most value about Breathing Space, followed by the exercise facilities provided and the building itself. Survey findings also confirm the quantitative findings around the impact on physical, mental and social wellbeing of patients. For example from the outpatient survey: 83% agreed that their health had improved, 77%

that they were physically fitter and 79% that their quality of life had improved. 96% agreed or strongly agreed that they had learnt more about their condition. 62% of carers agreed that assessment had helped to identify needs and 74% agreed that they felt supported. Fewer reported a direct impact on their health (27%) or wellbeing (50%) or social activities (31%). 78% felt they had a better understanding of when and where to seek help which would be associated with feeling supported and 64% identified other benefits from contact with Breathing Space. These included carers reporting a positive impact on their relationship with the patient or a better understanding of their condition.

Equity of access to Breathing Space – The Equity audit examined whether patients attending Breathing Space were largely representative of the total population of COPD patients in Rotherham. It demonstrated that overall they are and, although there are significant differences in referral rates between general practices, all Rotherham practices have patients accessing Breathing Space.

Overall there was less activity to October 2009 than originally planned, but those patients who completed rehabilitation programmes did show statistically significant improvement in their symptoms and quality of life post-rehabilitation and the results appear to be largely of the same magnitude as observed in clinical trials.

Success Criterion 3: Rotherham Health and Social Care Community will have successfully managed the changes in costs and resources needed to ensure the long-term sustainability of the programme

The total cost of Breathing Space is £3,023,633, including £1,305,399 for outpatient services and £1,585,275 for in-patients, with £132,884 research and evaluation costs. This compares with the current total cost of secondary care provision at Rotherham Foundation Trust for respiratory disease of £6,025,740 (including £1,596,340 specifically for COPD admissions and £421,776 for respiratory medicine out-patients appointments). There will also be a material sum of activity and costs buried within General Medicine Outpatients which relate to Respiratory conditions, however because of established coding methods it is not possible to separately identify this data.

It has not been feasible to calculate a “cost per Quality Adjusted Life Year gained” for Breathing Space as a whole as originally intended. This is mainly because of the degree of uncertainty about quantifiable impacts in terms of reduced secondary care or primary care contacts (which could be a major contributor to making the service cost-effective) and because it is difficult to quantify all the impact of the diverse services provided by Breathing Space (such as carer benefits and end-of-life-care and improved assessment and diagnosis) as QALYs

Improvements in the quality of primary care and improved self-care and symptoms for patients completing the rehabilitation programme could both be expected to produce a downward trend in demand for hospital admission (and total bed-days) for acute exacerbations for COPD. The successful opening of the Breathing Space beds for acute, respite and end-of-life admissions would also be expected to reduce pressure on hospital admissions.

Routine data on COPD admission rates do allow analysis of trends and comparison with Barnsley and Doncaster rates and there is some evidence for a downward trend in admissions although it remains too soon to demonstrate a significant impact.

The original business case for Breathing Space was based on a significant reduction in admissions and length of stay for COPD and so it will be very important to consider whether the theoretical reduction in admissions (based on evidence for

improvements in primary care and for the effective delivery of the rehabilitation programme to a high proportion of patients at risk of admission discussed above) can be expected can be translated into real cost savings across the COPD patient pathway.

Success Criterion 4: The programme will deliver improved outcomes for chronic respiratory disease patients and carers at population level

It could be argued that it is too soon to expect to be able to measure improved outcomes at population level but that these improved outcomes could be imputed from the proportion of Rotherham COPD patients known to have benefited from assessment or from completed rehabilitation programmes or admission at Breathing Space (ie 1430 patients or approximately a quarter of all Rotherham residents with COPD) and from the proportion of general practices that have measurable improvements in quality of care reported in the primary care audit.

Success Criterion 5: The changes in the whole system costs for chronic respiratory disease in Rotherham provide value for money for the outcomes that have been achieved

It has been widely recognised that developing major new facilities and new services has significant set-up costs. There is also evidence from the qualitative evaluation that Breathing Space has developed a very high quality service which is hugely appreciated by a, previously relatively neglected, patient group. However it is also recognised that any new commissioning specification would have to pay very close attention to ensuring and maximising value for money.

In terms of delivering outpatient rehabilitation and respite care, Breathing Space is likely to be more expensive than other facilities because of the standard of provision in terms of specialist facilities and specialist staff. In terms of providing beds for acute admissions for exacerbations, Breathing Space may be more comparable to other in-patient facilities.

This implies that if Breathing Space is to be considered value-for-money, it will be necessary to consider whether to take account of the less tangible and difficult to quantify benefits of the service. There are a range of services currently being delivered to meet current needs including end-of-life care (which was specifically excluded from the original business case) and oxygen assessments (which would need to be commissioned elsewhere if they were not being done by Breathing Space). These include both the specialist and high quality nature of provision, which is highlighted by patients and carers and the wide range of other activities and impacts which relate to Breathing Space's status as a nationally-recognised centre of excellence and innovation in COPD rehabilitation. These include the delivery of training to a wide range of health professionals and profile-raising activities through national and international disseminations of lessons learnt through the development and evaluation of Breathing Space.

Conclusions

The challenges involved in both developing and operationalising the Breathing Space model of care and in attempting to measure the impact of a new programme should not be underestimated. A number of important lessons have been learnt during this process. In particular, the commissioners under-estimated the management challenges of starting from scratch a completely new model of service and the length of time that would be taken for any system wide benefits to become apparent. Two

issues have been particularly challenging, the delay in opening the inpatient unit due to infection control issues and opening the new unit at the same time as introducing across community services a completely new IT system. The evolving nature of the Breathing Space programme over the past two years, means that it is difficult to predict the future impact, based on activity and outcomes measured during the development of new services. It is also too soon to be able to quantify the impact in terms of medium and long term savings in primary and secondary care costs due to the adoption of Breathing Space community-based model.

However, since there is a relatively robust evidence-base from randomised controlled trials and systematic reviews for the overall cost-effectiveness of pulmonary rehabilitation, largely through reducing hospital bed-days, it would still appear reasonable for future commissioning decisions to take account of the potential for investment in pulmonary rehabilitation, supporting self-care and integrated care pathways to reduce secondary care costs as well as improving the quality of life of both patients and carers.

In considering the overall value-for-money offered by Breathing Space, it would be important to acknowledge the very wide scope for benefits to patients, carers and the wider community. These can be delivered through a range of different activities, including not only formal rehabilitation programmes and acute or respite admission but also through the much wider range of assessment and supportive activities that Breathing Space is now developing.

As a result of the learning from Breathing Space, Rotherham as a health community may be uniquely well placed to re-commission respiratory services from October 2010 in line with the priorities of the national strategy for COPD.

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on behalf of the Breathing Space Research and Evaluation Steering Group