

A Year of Care pathway for COPD: problems, pitfalls and solutions from practice

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In May 2005, North East Yorkshire and North Lincolnshire Strategic Health Authority (NEYNL) challenged its PCTs to adopt Professor Degeling's Year of Care model in an attempt to reduce avoidable emergency hospital admissions. One of the PCTs, Hambleton and Richmondshire, attended a workshop presented by Professor Degeling and decided to reduce admissions in three separate areas including chronic obstructive pulmonary disease (COPD). Within 12 months a multidisciplinary, multi-agency project group implemented the first Year of Care pathway in the country for COPD.

This paper analyses this application of the Year of Care concept. The pathway is at an early stage of implementation and many of the problems and solutions described are generic to any disease specific pathway. We will show how the Year of Care concept has been imaginatively and creatively taken up by champions in PCTs because it offers a method for resolving so many of the paradoxes and problems in practice that arise from, and sustain, the current 'silo' approach to performance management, clinical quality and self-management issues. We will also critically discuss the extent to which the Year of Care pathway has been funded, incentivised, clinically agreed, implemented and evaluated and conclude by offering guiding principles, suggestions and solutions for practical implementation.

CONTEXT

At the time of the initiative, Hambleton and Richmondshire PCT (HRPCT) had a population of 116000 almost exclusively rural and relatively affluent. The health indicators show the population to have a longer than average life expectancy and a lower incidence of disease than some of the neighbouring, more industrial areas. Accessibility to services is a major problem, although

utilisation of services appears high. Pockets of significant disadvantage do exist within the area, most notably around the military base in Catterick Garrison and Colburn.

The PCT itself operated three community hospitals. The Friarage Hospital in Northallerton, operated by the South Tees Hospitals NHS Trust, was the area's main provider of general acute services. More specialist services such as cardiothoracic surgery, neurosurgery and radiotherapy were provided at the James Cook University Hospital in Middlesbrough, although some of the population in the south of the area travel to Leeds for these services. A small but significant proportion received their hospital services from hospitals in York, Darlington, Harrogate, Kendal and Lancaster. There were 20 general practices (18 NHS and two military) in the area, ranging from large group practices to a single-handed practice in the Dales.

The PCT had identified over 1250 people on GP registers with COPD in the Hambleton and Richmondshire area. An analysis of local hospital episode statistics carried out by the Centre for Clinical Management Development at the University of Durham showed high numbers of COPD admissions and multiple emergency admissions (i.e. more than one admission in one year). For example, in 2004/05, exacerbation of COPD was among the top 10 reasons for admission, and an estimated 33.39% of bed day savings could be made if the actual rate of multiple emergency admissions was reduced to expected rates. Thus, COPD appeared to be the type of high volume condition that could benefit from systematised care.

The illness is strongly associated with smoking and long-term exposure to coal dust, and is characterised by a progressive loss of lung capacity and associated physical functionality.¹ Medical treatments draw from a limited range of options designed to maximise lung function and the six month period at the end of life is often characterised by multiple unplanned hospital admissions made in response to attacks of severe breathlessness and infection.^{1,2} Despite this gloomy prognosis, sufferers report that gains in quality of life *can* be made in such non-medical treatments as smoking cessation, nutritional interventions, exercise, social support and cognitive therapy to deal with the debilitating panic attacks often associated with breathlessness.

On this basis, GPs were engaged to provide proactive, non-medical management (i.e. focusing on social and psychological factors as well as clinical) and to support patients in self-management. The resultant pathway, implemented in April 2006, goes beyond the usual medical, reactive response to an exacerbation (secondary care focused drugs, stabilisation and discharge) to a proactive, holistic approach in primary and community care with long-term management of the patients to include self-management. The project group is outcome focused and aims to achieve a cost neutral 15% reduction in COPD emergency admissions in 2006/07 and a further 15% in 2007/08.

GUIDING PRINCIPLES

A Project Team was set up and was governed by a number of explicit and implicit principles. First, from its inception, the development of the Year of Care pathway was outcome driven: to reduce COPD unplanned admissions by 30% by March 2008. This clearly measurable outcome helped the team to be focused and enabled it to quantify the cost savings so vital to securing invest-to-save funding. The cost saving was to prove crucial as the financial climate deteriorated (as with all PCTs at this uncertain time). The team distinguished between the measurable *outcome* of reducing emergency COPD admissions and the *process* of using the Year of Care model to achieve this aim. But while the measurable outcome was fewer hospital admissions, it was always understood that this clearly translated into far better quality of care for patients.

The figure of 30% was set as a stretch target. The team adopted the philosophy behind the Modernisation Agency's Pursuing Perfection programme that only by setting radical goals would a new radically innovative approach emerge.³ The team did not wish to merely tweak the existing system, but overhaul it. However, neither was the figure plucked from thin air: the data from Durham University had indicated that the observed rates of readmission for COPD in Hambleton and Richmondshire were well over 30% greater than expected rates of readmission.

Second, the pathway had to be cost neutral. At the inauguration of the project, the requirement was to shift resources from secondary to primary care. The recently introduced Payment by Results would allow the savings made from reduced hospital admissions to be invested in primary or community care. The Project Team initially planned a 30% reduction in admissions over two years. However, within two months of the start of the project the economic climate changed: Hambleton and Richmondshire PCT, like so many others, began fighting to prevent a deficit. All investment ceased. The Project's only hope was to make the pathway cost neutral *in one year*.

Third, based on the Project Manager and Clinical Lead attendance at Year of Care workshops run by Pieter Degeling, self-management and a holistic approach to patient care became central to the pathway development. It is very easy to see the impact of non-medical factors on COPD patients, so the emphasis on psychological, social and economic elements within the pathway was always understood. Not only did research evidence back this up (e.g. among older people with COPD, prevalence rates for mild depression are 25% and for major depression reports range from 6% to 42%⁴) but the first hand experience of the specialist respiratory nurses and the practice nurse on the team reinforced the view that people were often admitted to hospital due to factors other than the purely clinical. Once this holistic approach becomes central, a paternalistic model of care is untenable: in other words, unless the person is fully engaged as a co-producer of their own health outcomes, they will

not be able to impact on these psychological, social and economic factors.

Fourth, the Year of Care model posits three stages of care for people with long-term conditions: Stage 1, self-management, Stage 2, care management and Stage 3, case management. In effect each stage has its own Year of Care pathway. Any such stratification has an inherent tension between providing collective equity of access to services and individualised care. While the Project Team acknowledged the need to stratify patients, this was simply to determine the frequency of review and the clinician in charge of their support. Thus patients in Stage 3 would receive reviews by the Specialist Respiratory Outreach Nurses at least every three months whereas those in Stage 1 would receive an annual review by their practice nurse. Stratification was based on the perceived likelihood of an emergency hospital admission, with the aim of providing targeted support to those deemed most at risk.

The team agreed that all patients would have access to the same type of management no matter which stage they were in. All are assessed for all 10 aspects of the management plan (shown in Box 10.1) and their care determined by their need. For example, a patient in Stage 1 may need advice and support for nutrition in just the same way as a patient at Stage 3. It quickly became apparent within the team that a key principle was to systematise the good practice carried out by the specialist nurses, and ensure that all patients, at whatever stage, received the same standard of care. Thus patients who have only mild COPD will receive high quality support which will better enable their self-management and thereby keep them at that stage for much longer.

BOX 10.1 Aspects of the COPD Management Plan

- 1 Carers
 - 2 Drugs
 - 3 Exercise
 - 4 Mental health
 - 5 Nutrition
 - 6 Patient education
 - 7 Physiotherapy
 - 8 Self-management
 - 9 Smoking cessation
 - 10 Social
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Fifth, the primacy of primary care was not only a high priority for the Department of Health but also was a significant part of the PCT's vision. Hambleton and Richmondshire is a very rural area, so providing care closer to a person's home really does make a significant difference. As stated above, the pathway was systematising existing good practice and ensuring that all people with COPD received this from the time of their diagnosis. The GP surgery

was the obvious place to receive this care for all but those whose illness made them housebound.

But the pathway was not developed in isolation from the acute trust. The respiratory consultant and the two specialist respiratory outreach nurses employed by the acute trust were all members of the Project Group and key contributors. Rather than see the development of the pathway as a threat, they were confident that it would reduce the frustration of avoidable hospital admissions, and ensure that their excellent work was not unravelled once patients were discharged.

Finally, while the motto 'the best is the enemy of the good' was not often spoken, the team was happy to accept that a less than perfect pathway was better than no pathway at all. There was a shared agreement that the pathway would be operationalised when it was deemed to be 'good enough' and that it would then be improved from feedback which was only attainable from usage. The collection of variance data has not yet been systematised; however, feedback is obtained at training sessions and at regular one-to-one meetings between the new community respiratory nurse and practice nurses. Furthermore, because the pathway was not seen as an 'all or nothing' affair, aspects of it were implemented early as quick gains; for example, reminding GPs of the correct drugs to use for exacerbations.

PROJECT MANAGEMENT

In May 2005 the PCT's Modernisation Manager proposed to the PCT's Professional Executive Committee (PEC) the development of three Year of Care pathways, one of which was COPD. In June a presentation was made to the PCT's Respiratory Local Implementation Team (LIT) and it was agreed that the Year of Care project should become the main focus of the LIT, and that the LIT should re-form as a specific Project Team. This group's first meeting was in July 2005.

From inception, the team was accountable and reported to the Long Term Conditions Steering Group, the PEC and the Modernisation Delivery Group to ensure widespread understanding of and involvement in the project. The Project Team was set up to include representation from all key stakeholders. These included representatives of service users, primary, secondary and community care, the ambulance trust, social services and the voluntary sector. The Team's Chair and clinical lead was a GP and member of the PEC. The patient representative who was initially involved felt she could not contribute adequately and asked a colleague from the PPI Forum to take her place: her input was very useful (although limited due to illness) particularly in challenging the jargon-ridden language of the team.

The team explicitly utilised a project management methodology. At the initial meeting a Project Initiation Document (PID) was agreed setting out the team membership, the aim and scope of the project. Key milestones and the

accountability and reporting arrangements were also agreed. The PID acted as a contract that provided focus for the team.

In the early stages of the project, four sub-groups worked on (1) data and costings, (2) drugs and diagnostics, (3) support, and (4) self-management. Each reported to the full team every month. However, as work progressed the issues were so cross-cutting that this structure ended, although sub-group leads retained responsibilities for their areas.

The pathway was launched in April 2006 at an educational event attended by 60 delegates with 17 out of 18 GP surgeries being represented by both a GP and a practice nurse. The GPs' involvement was secured with a Local Enhanced Service (LES) that recognised the additional work they would need to undertake beyond their nGMS contract. At the launch, GP and practice nurse COPD leads from each practice were given an A4 Pathway File. These were also circulated to district nurse case managers, nursing home staff, physiotherapists and others. The files consisted of clear advice on diagnosis and assessment, the flowcharts for all the management plans, a flowchart for COPD palliative care, plus selected examples of patient literature with re-ordering details. Follow-up educational sessions were held in autumn 2006.

PATHWAY DEVELOPMENT

The Project Manager's initial plan was to benchmark best practice, process map the existing service and then to identify the ideal local service specification. However, just prior to the planned process mapping session in October 2005, the Clinical Lead attended a Year of Care Workshop and became so enthused that he sketched out an outline Year of Care pathway, arguing that process mapping the existing services would not contribute a great deal because the project was not setting out to tweak what existed but to implement something completely new. Yet there is a paradox here: the pathway would be systematising existing local best practice, and yet the approach was innovative. The novelty of the approach was fourfold.

- 1 All patients diagnosed with COPD would receive the same proactive support, even if their condition was still mild.
- 2 Primary care would deliver this support, using acute care clinicians as 'knowledge nodes'.
- 3 The focus would be on the provision of targeted self-management support that was intended to enable people with COPD to self-manage in a way that gave them greater choice and improve their quality of life.
- 4 Simple written guidelines were collaboratively produced for all parts of the pathway which enabled the systematisation and made transparent the contributions of each stakeholder at each stage of the pathway, including that of the person with COPD.

The outline pathway was so well received by the team that it only changed

slightly in the ensuing months. At that meeting in October, the main framework of the stratification model and the elements of the management plans were discussed and agreed.

The Clinical Lead wrote to his GP colleagues at regular intervals in the early days of the project to raise the profile of COPD. The secondary care team informed the team that patients were frequently admitted after being given inadequate medication to prevent an exacerbation worsening. Thus one letter to GPs included detailed advice on the correct medical treatment of exacerbations. GP practices were also sent details of the number of admissions as a proportion of their list size and COPD register size: this encouraged one practice to analyse its admissions and to give feedback to the team that most of their admissions occurred out of hours. Thus out of hours doctors were given education about the correct treatment of exacerbations.

The pathway details the ideal care any patient with COPD should receive in primary and community care in any year. This includes diagnosis, assessment and stratification, management and review. All patients, independent of the stratification, are given an assessment and subsequent management plan covering the areas shown in Table 8.1. The pathway documentation gives simple flowcharts to enable clinicians to follow systematised mini-pathways for all these areas. Some of these mini-pathways are generic and have been included in a Heart Failure Year of Care Pathway that is being developed along the same lines.

The development of the pathway also entailed collaboration with colleagues in social services, voluntary carers' groups, mental health, palliative care, public health, dietetics and physiotherapy. The aim of this collaboration was to establish what best practice was in order to document it to ensure its systematisation across the whole PCT.

FUNDING AND COMMISSIONING

It was clear that the implementation of the new pathway would not be successful without some additional investment in primary and community care, an investment to be financed from the savings produced by the reduction in admissions. A simple formula was used to calculate the potential savings: the number of spells in the preceding year for the relevant HRGs was multiplied by the predicted percentage reduction (15%) to give an absolute number of predicted admissions saved. This figure was then multiplied by the tariff price for the HRGs to give a total saving.

The project team decided on four main priorities for the new investment.

- 1 A Local Enhanced Service (LES) payment for GPs to incentivise and compensate them for the additional workload (the payment was based on attendance at the educational launch event (April 2006), attainment of specified Quality and Outcomes Framework targets related to the pathway, and a reduction in admissions of 15% in each locality).

- 2 A full-time community respiratory nurse (from August 2006) to support the practices and district nurses in the implementation of the pathway.
- 3 Some part-time community physiotherapy support.
- 4 Equipment: nebulisers for long-term loan and pulse oximeters for the out of hours teams.

The PCT's Board and Finance Committee had to be persuaded of the benefits of the pathway, both in terms of patient care and of cost. While the Board gave the go-ahead for the pathway in March 2006, the Finance Committee was less happy with the perceived risk. The financial climate had changed from the time of the project's inception; the focus now was on the short-term financial goal of breaking even. Further lobbying was undertaken and a cash flow forecast written to enable close performance management of the financial aspects of the pathway. The Finance Committee was due to make its decision on the morning of the launch of the pathway (with 60 delegates present). Fortunately, the decision was positive, perhaps influenced by the fact that the PCT's Chief Executive and Chair – both members of the Finance Committee – were due to attend the launch later that same day.

KEY SUCCESS FACTORS

It is too early at the time of writing to report other than impressionistically on the clinical and other patient outcomes of the use of the Year of Care pathway. The project is subject to continuing performance management; thus, unplanned admissions are being recorded monthly but the normal significant monthly variance in admissions means that conclusions cannot be drawn for several months. However, figures for the first eight months of 2006–07 show at least 10 fewer admissions than in the same period in 2005–06 using a limited set of ICD codes: these in themselves have generated a saving of over £20 000. As part of the evaluation of the project, feedback is being sought from service users on their views on the improved service. At the time of writing, all those asked to comment have rated the new service as excellent. However, the novelty of such a multidisciplinary project is significant; it is thus worth reflecting on the factors that contributed to its successful implementation.

First, the project had a clinical champion who had passion and enthusiasm for the concept and a desire to improve practice. Furthermore, as a much respected GP, PEC member and GP vocational training tutor, he had the credibility, wisdom and experience to effect change among his colleagues.

Second, the specialist respiratory outreach nurses who were employed by the acute trust were very open to the Year of Care concept, and were valuable members of the project team. Rather than feeling threatened by the project's drive to shift emphasis to primary and community care, they appreciated its value to patients and the positive role they could play in this development, and they worked to break down some of the traditional barriers between secondary

and primary care. One of the nurses had previous experience in primary care, which gave her understanding of the role of the practice nurse and thus the benefits they could offer; it also provided insight into the pressures they face – often a lack of time and autonomy.

Third, the wide stakeholder involvement in the project team smoothed the way for implementation. While links with operational managers could have been better, the involvement of key clinical opinion leaders was invaluable. GP engagement was critical for the success of the pathway as the main focus was to be the active management and review of patients in primary care. The setting up of Locality Commissioning Groups (LCGs) in early 2006 gave a useful forum to present the project to GPs, and the LCGs effectively sponsored the project through the PCT's Local Delivery Plan process.

Fourth, the development and implementation of the pathway in such a relatively short time was due in part to the allocation of a project manager to the project. The benefit of this was not only some dedicated time (on average 7–10 hours per week) but also the utilisation of a project management methodology. This avoided some of the pitfalls of committee work and focused on the achievement of milestones and outcomes. The project manager acted as facilitator to the clinicians on the team, providing encouragement as well as practical support, underpinned by assured confidence that the team would achieve its goals. The team members responded well to this, and an energy and momentum was created in which everyone worked hard to ensure that they did not let the others down.

Finally, the effective implementation of the pathway depended on the training and education of those who will deliver it. This was not imposed but shared and led by the clinical champion using a variety of media: letters, e-mails and events. An initial educational event in April was followed up in September, with the latter bringing the pathway to the wider multidisciplinary teams (including district nurses, physiotherapists and community psychiatric nurses).

CHALLENGES AND SOLUTIONS

The main challenge was securing the funding for the project during a time of significant financial difficulty for the PCT. As we have seen, in the end the case had to rest robustly on the project being cost neutral in one year. The whole pathway could not be prospectively costed and commissioned before implementation because of the lack of clear financial data on separate elements of primary and community care. Only the new elements of the pathway were costed and commissioned. However, as the pathway is fully operationalised, audit data will be collected to enable an understanding of the proportions of patients accessing each part of the pathway. This retrospective costing will enable future prospective commissioning.

An information challenge was provided by the poor quality of the admissions data from the acute trust. The HRG data on which the predictions were based

required 'cleaning' to remove duplications and other erroneous entries. This enabled a realistic number – and hence cost – of saved admissions to be calculated. However, performance management of the pathway has to be undertaken with raw data: therefore savings have to be shown by the reduction in the *number* of admissions and not the *percentage* reduction. A key task now is to obtain clinical Read Codes to enable the recording of the stratification of patients on GPs' clinical IT systems. The existing codes only allow the recording of the clinical severity of the condition. Once obtained and practices have coded all the patients on their registers, it will be possible to perform data analysis to understand the proportions of patients accessing different aspects of the pathway. This will then form the basis for prospective commissioning.

A systematised approach to the stratification of patients also proved challenging. Initially the team tried to include all the factors that seemed to affect the likelihood of an exacerbation resulting in an admission. They also endeavoured to completely standardise the process. A realisation that only the frequency of review would be affected by the stratification enabled a solution: only factors that could be improved by increased review frequency needed to be included in the process. The outcome provides a simple model that acknowledges the need for clinical judgement.

Improving both the self-management process and outcomes for people with COPD was another key challenge not least as it was linked to the need for other professionals (especially ambulance and out of hours staff) to access information about the patients' normal condition and their normal and stand-by medication. A Self-Management Plan was produced for patients to keep at home. This told patients how to recognise and react to the early signs of an exacerbation and when to take stand-by medication. Information was produced about the general effects of the disease and also how to deal with the cold of winter or the heat of summer. Also a holistic approach was emphasised because often patients' self-management is thwarted by depression. Clinicians required improved skills in motivational interviewing and this factor is addressed in our educational sessions.

CONCLUSIONS

The challenge laid down by the strategic health authority to adopt the Year of Care model is one that could easily be ignored, given the local climate of financial concerns and organisational change, coupled with wider concerns about the future for acute services and professional silos. And yet key people working in Hambleton and Richmondshire PCT had the vision to recognise an opportunity to improve the level of control, visibility and influence that clinicians have over the process of delivering good quality patient-centred care, thereby addressing the barriers to improving the patient experience that so often conspire against us.

The development of a Year of Care for people with COPD has taken time.

resources, multidisciplinary cooperation and, above all, an understanding of the importance of non-medical, non-acute aspects of patient care. The financial gains of this process will be proven later in the year; there is no doubt that the net effect will be so much more than a drop in avoidable admissions. The value to individual patients is immeasurable; the value to the wider community and for staff working within the organisations is a cultural change which enables the enactment of co-production. This is surely why we joined the NHS in the first place: to care for people in ways that take into account their lives, experiences and ability to make their own decisions. At a time when clinicians often feel exhausted by exhortations to improve the 'patient' experience, this case study shows that collective, multidisciplinary, planned action can indeed make a positive difference.

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We pay special tribute here to the late Dr Bruce Davies, the Project Group's Clinical Lead, who was so instrumental in the development of our COPD Year of Care pathway. Bruce contributed his amazing knowledge and enthusiasm with characteristic wit and humility, and was supportive and encouraging of all team members.

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