Improving earlier diagnosis and the long term management of COPD: Testing the case for change
NHS Improvement - Lung National Improvement Projects - Improving earlier diagnosis and the long term management of COPD: Testing the case for change

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Introduction

Case for change: the current position for chronic obstructive pulmonary disease in the UK

There are around 835,000 people currently diagnosed with Chronic Obstructive Pulmonary Disease (COPD) in England and an estimated 2,000,000 people with COPD who remain undiagnosed and are living with the disease \(^1\). The majority of these have mild or moderate disease but if they were diagnosed early, they could then take the necessary steps to improve the outcome of their disease and modify its progression. The disease is progressive and cannot be cured, with one person dying every 20 minutes in England and Wales. However, timely and accurate diagnosis, with supportive ongoing management can help modify the impact of the disease, helping people to self-manage more effectively and thereby reducing the need for hospital admission. It is therefore vital that patients receive a quality-assured diagnosis at the earliest opportunity in order to commence appropriate treatment and to slow the progression of the disease for the individual. This can also reduce the impact on carers and on the burden of long term management and its related costs.

The Outcomes Strategy for COPD \(^1\) and Asthma in England and the NCROP Audit \(^2\) identified that there is significant variation across England in the way in which people are referred, diagnosed and treated. There is significant scope to improve the quality and timeliness of diagnosis, treatment and management, including pharmacotherapy, and to organise care in a more integrated way. This would not only improve the quality and efficiency of the service, but also empower patients to manage their own condition.

A reduction in this variation would also increase value for money of services as well as improving outcomes for people with COPD in line with the Quality, Innovation, Productivity and Prevention agenda.

During the first year of project work, NHS Improvement – Lung through the 'Earlier Diagnosis' and 'Managing COPD as a Long Term Condition' national workstreams have focussed on developing services that deliver efficient and high quality care and support for patients suspected to have COPD or living with the disease. This has been achieved through working with and supporting clinical teams to identify, test and implement the changes needed to achieve this level of care and understand the key components that have the greatest impact on the pathway and benefit to patients.

The aim of the earlier diagnosis workstream was to ensure that all people with suspected COPD receive an accurate and quality assured diagnosis sooner and as a result, are placed on the correct treatment pathway. The aim also included ensuring that patients receive appropriate information about their condition and are added to the practice disease register. With the right pathway in place, it was hypothesised that timely and quality assured diagnosis would lead to a reduction in service costs by optimising the treatment pathway for patients and initiating self-management at an earlier stage in the disease progression. Project work included testing service models in both primary and secondary care, understanding and reviewing registers and the development of tools to improve and monitor quality.

The aim of the managing COPD as a long term condition workstream was to explore how supported self-care and regular review can best be delivered in order to improve the outcomes and quality of care offered to patients. The aim also included related work to test the optimisation of health resources towards a reduction in emergency admissions. An important component of the work incorporated medicines management by ensuring all patients with COPD were on the correct treatment in relation to the severity and symptoms of their disease, and were regularly reviewed to help support them to use their medication correctly. Project work included testing ways to develop and implement effective self-care models and ongoing patient review, and to identify the key challenges and solutions for overall long term condition management.

This publication, which is aimed at healthcare professionals, commissioners and other key stakeholders involved in respiratory health, draws together the evidence and learning from the past 12 months and highlights the work undertaken by the project sites within both national workstreams.

Improvement approach

In July 2010, NHS Improvement - Lung invited NHS organisations to work in partnership on projects dedicated to improving the COPD patient pathway and to help address the variation in care that patients receive. Projects plans were submitted from a number of sites including acute trusts, primary care trusts (PCTs) and community organisations.
The primary aims of the projects in the two national workstreams were to:

- Define the patient’s pathway
- Identify and reduce variation in the delivery of care
- Challenge the system and test the components of care that lead to consistent and effective diagnosis and management of the condition
- Identify the success principles that other organisations and teams could learn from and adopt
- Distil the learning to inform future ‘prototyping’ work.

Focus was also given to improving the patient’s experience and outcomes along with removing duplication and waste from the pathway or specific processes through different ways of working and service redesign. Productivity gains achieved by sites were measured to identify the impact of the work.

During the ‘testing’ phase of the programme, project teams have explored the reality of making this happen by taking stock of current practice and understanding the process of implementation to ensure patients receive optimal care in a challenging environment. The project sites adopted a systematic approach to quality improvement to ensure that any changes implemented were thoroughly tested and measured. Prior to commencing the work, the project sites were required to establish their service baseline through analysis of local data and to understand the variation in services.

Once the project teams were established, a period of analysis followed to allow teams to understand the patient pathway. This also helped dispel any assumptions about the process, its challenges and the solutions. Potential solutions were tested using the model for improvement and plan-do-study-act (PDSA) cycles with ongoing measurement to evaluate the impact of the interventions and refine where appropriate.

**Common challenges and solutions**

Clinical teams at all sites have been focussed on specific aims which have included:

- Identifying the current state of practice and any gaps, duplication, waste or opportunities to improve the quality of care
- Increasing the number of patients whose treatment is optimised by identifying the right patients, providing appropriate information and support, and ensuring they are on the right treatment path
- Identifying ways to ensure that their systems for diagnosis and management are consistent and effective.

Whilst each project site has worked on a different part of the diagnosis and management pathway, a number of themes have emerged across all sites:

- Although clinicians understand the components of optimal COPD care, there is widespread variation in practice in the way in which diagnosis and management are provided. This includes aspects such as spirometry, support for self care and optimising treatment
- There appears to be extensive variation in the quality of spirometry being undertaken and interpreted, along with the quality of information being collected. This includes the accuracy of COPD registers.
- Taking time to understand what is happening in the current system and identifying who is doing what may mean that change can occur more quickly, safely and reliably without the need for additional resources
- Significant variation across primary care may not be immediately apparent. Identifying low prevalence, high admission rates and prescribing performance can help target efforts for improvement
- Consistent recording of data across the practice team is essential to allow stratification, monitoring of deterioration and impact of changes in care, and highlights any increasing frequency of exacerbations early in order to initiate targeted intervention where appropriate
- Data is essential for improvement. There is plenty of it available but it is important to identify what is most useful and how best to present it. Targeting patients or practices with high resource use can help towards demonstrating benefits more quickly
- There can be a significant impact on admissions by targeting moderate COPD patients and increasing their confidence in self management, while ensuring work is undertaken to correctly identified patients’ severity in the first instance
• Where there are no formal systems in place for risk stratification, it is still possible to start the improvement process by exploring which patients account for the greatest use of resources – for example, appointments, accident and emergency attendances, admissions or medicines. Using the Pareto principle – the principle that 20% of people or problems may account for 80% of resources – can help target effort more effectively
• It is important to work together to improve the management of COPD by both gaining common agreement with stakeholders, and developing integrated and consistent approaches to patient pathway management
• Good management and self-care support requires 30–60 minutes and a patient-led approach. Patients with more than one long term condition (LTC) may benefit from a holistic assessment and review, which may also reduce total demand for healthcare resources over any twelve month period. Shorter appointments may mean there is little time to listen to the patient and establish their needs and may lead to repeat appointments
• Inhaler technique is a key area for improvement in the management of COPD. Many patients do not maintain the correct technique and many staff may not be demonstrating correctly. There is evidence of the cost effectiveness of using trainer devices to improve technique, and regular checking can ensure patients receive the maximum benefit from their medication
• People are motivated by different things. Taking time to find out what will motivate someone to change behaviour will lead to an increased chance of helping them
• Teams may have concerns about the practicalities of offering longer appointments, including the impact of patients not attending. Group sessions for review or patient education can limit the impact on resources and may enhance the patient experience
• Taking time with patients to explore how the care they receive affects their health or their ability to self-manage, using a tool such as the COPD Assessment Test (CAT) or similar, can lead to improved outcomes and overall experience
• Providing patients with information, advice and contact names and numbers can result in improved management along with earlier recognition of and action on symptoms, thereby reducing the need for emergency care and admission
• Providers should systematically address the way they work to find consistent and sustainable pathways that deliver proactive and holistic care.

Project Outcomes: Emerging Success Principles from Project Learning

Through problem solving and a systematic approach to improvement, all teams worked through a number of challenges in order to achieve their project aims. Across the sites, a number of success principles have been identified that represents improvement opportunities towards effective service provision in the diagnosis and management of COPD:

• Defining and gaining a good understanding of the whole pathway of care supported by robust data to demonstrate current processes, performance and variation is essential when embarking on improvement work. This allowed organisations to identify priorities for change and also to benchmark themselves with others locally and nationally
• Issues and challenges viewed in isolation without due consideration to the whole patient pathway were less likely to lead to sustainable improvements in care provision
• Effective working relied on the commitment of teams in primary, secondary and community care to improve communication across the patient pathway. Integrated working helped to build positive relationships with health care professionals, departments and organisations, and improve the critical interface between these organisations
• Access to and effective use of data through collaboration between clinical and managerial staff enabled the project teams to better understand the patient pathway and demonstrate the impact of any change. The routine collection and review of data was important in implementing sustainable improvements and understanding outcomes of any service improvements.

• Identifying the key levers and drivers in the system by integrating local and national priorities into the work such as Quality, Innovation, Productivity and Prevention (QIPP) raised the profile and priority of the project work with decision makers and helped to achieve improved engagement from senior management teams.

• There was a need to identify and understand the gaps, duplication and waste in the patient pathway in order to make best use of available resources. It was essential to work and communicate with colleagues, commissioners and other stakeholders in service provision in order to maximise these resources and to ensure a consistent and co-ordinated approach to care.

Many of the issues and challenges met by the project teams were similar to those faced in other specialities and several of the success principles have been demonstrated to be effective in other disciplines. It was important for sites to recognise areas where common principles and practice meant that learning could be transferred across specialities.

Future ‘prototyping’ work

In the forthcoming year of project work sites will be building on the learning from the ‘testing’ phase of work. Sites will be refining the components attributed to the emerging care models and success principles that demonstrated the greatest impact on the patient pathway during the past year. The prototyping work will define the chronic care model for patients with COPD, representing an efficient and high quality care model that reflects not only best practice, but also demonstrates examples of practical approaches towards sustainable implementation. The evidence and learning from the diagnosis workstream will inform its scoping work prior to commencing the prototyping phase.

Earlier diagnosis workstream

Using national data currently available, a national scoping exercise will be undertaken to determine the current diagnostic pathways for patients with suspected COPD. This will also define the optimum pathway and identify best practice case study examples. Following analysis, service gaps between the ‘current’ state and ‘future’ state pathways, common themes and principles, challenges and potential solutions will be pulled together in order to inform future priorities for improvement and prototype work.

In summary, the key aims of the scoping work will be to identify:

• Sustainable and innovative service models (including direct access to secondary care, GP provision and secondary care provision)
• Models to support earlier diagnosis and improved primary care access
• Models to support diagnosis of all severities and associated conditions
• Service models that support diagnosis across the whole pathway (for COPD, Asthma, Home Oxygen and Sleep Apnoea)
• Opportunities for diagnostic bundle approaches
• Workforce skills and competency requirements.

Managing COPD as a long term condition workstream

It is known that patients who understand what to do in the event of an exacerbation are more confident to seek help earlier and can avoid admissions, while regular medication reviews and inhaler technique checks can help reduce waste in prescribing. It is also acknowledged that while it is critical to have access to tools like plans, reviews and templates to help patients manage their condition, effective management needs to be underpinned by a set of skills, an approach and an infrastructure that will allow delivery. These components can be considered as:

• The resources that patients need
• What professionals need to do
• The infrastructure that needs to be in place to facilitate to delivery.

For patients to be effectively supported to self care and for professionals to deliver chronic disease management successfully each of these components needs to be in place. The challenge now is to identify how best to implement this consistently, reliably and cost effectively. Further work is also required to identify the essential elements and most effective means to put these into practice, including:

• Planning for early intervention in the event of exacerbation
• Medicines management and good inhaler technique
• Adequate time for regular review that encompasses what is important to both the clinician and the patient/carer and supports self management
• Skills to deliver support, education and treatment.

As a result the workstream will now focus on demonstrating how to improve management and self care for people with COPD to reduce admissions, optimise medicines use and enhance patient experience by prototyping:

• The optimal time and components of an effective review from both patient and clinician perspective
• Practical ways of implementing this and delivering it within existing resources
• How to optimise medicines use and the impact of doing so on cost, experience and use of other health care resources
• The key components that need to be in place for patients to be able to effectively self-manage and the benefits of doing so.

This will allow the production of a model that demonstrates what needs to be in place for care to be delivered effectively and how to implement it, to ensure that every minute of contact is used to maximum effect, every time.

In summary, the key aims of prototype project sites will be to:

• Define the exemplar model of care
• Demonstrate an integrated care model to identify and manage acute episodes/exacerbation
• Demonstrate an approach to improving other condition management

• Ensure a supportive self management approach to care that incorporates a regular structured review
• Ensure a medicines management and review approach that optimises treatment.

It is the aspiration of the national programme to deliver a QIPP reduction in emergency admissions by 20%, a reduction in readmissions at 30 days by 20% and reduction in prescription spend by 10% to which effective diagnosis and management can contribute. In addition, the workstream will continue to identify the key components of care that improve the overall patients’ experience and outcomes, and further develop the learning and key success principles that support effective commissioning of respiratory services in England.

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Introduction

Project summary
Historically, most patients referred to the secondary care consultant-led respiratory clinic via Choose and Book received detailed pulmonary function testing prior to their appointment with the consultant. However, an audit highlighted that 30% of referrals did not require intervention and were immediately discharged back to the GP as these patients could have been diagnosed and managed in primary care (estimated saving of £10,000).

This led to the introduction of a direct access service to provide full pulmonary function testing for those GPs who required support diagnosing and managing their respiratory patients in primary care.

The new service provided detailed pulmonary function testing (spirometry, static lung volumes, gas transfer +/- reversibility testing) for all referred patients. Where there is diagnostic certainty, the patients receive information from the physiologist about the outcome of their test and a British Lung Foundation (BLF) leaflet; where this certainty does not exist, patients receive more general information about lung health, based upon leaflets from the BLF. GPs receive fully interpreted Pulmonary Function Tests, with chest physician guidance as necessary. Depending on the outcome of the tests, patients no longer automatically see the consultant respiratory physician, although advice may be given to refer the patient in to the respiratory clinic where deemed appropriate.

Project aim
• Improve the accuracy of diagnosis, especially chronic obstructive pulmonary disease (COPD), in primary care
• Ensure all patients are on the appropriate management pathways with appropriately identified patients being managed in primary care, resulting in:
  • Earlier access to smoking cessation
  • Improved access to COPD respiratory nurse specialists
  • Earlier access to pulmonary rehabilitation services
• Appropriate referrals into the hospital respiratory clinics for specialist guidance (a reduction in unnecessary referrals for patients who can be managed in primary care)
• To create a measurable effect on GPs’ decision to refer a patient to hospital clinics with the aim to reduce referrals by 25%.

Highlights and achievements
Reduction in unnecessary consultant appointments by 78% for those patients referred in to the service:
• Saving of £144 per patient who does not require a consultant appointment
• Reduction in waiting times – from eight weeks to one week
• 32% of patients have had their diagnosis changed following detailed Pulmonary Function Tests:
  • 15% classified as restrictive by GP were normal
  • 15% classified as obstructive by GP were normal
  • 69% classified as normal by the P were obstructive
  • 54% of patients referred needed to be added to the practice COPD disease register and 7% needed to be removed to the register
• Out of the total GP referrals which were classified as obstructive, 32% of patients had their Global Initiative for Chronic Obstructive Lung Disease (GOLD) disease severity changed:
  • 43% maintained their severity as classified by GP spirometry
  • 20% changed by one GOLD stage
  • 38% changed by two GOLD stages.

Learning
• Meaningful patient engagement presents valuable insights into a current service provision. Patient engagement was highly beneficial resulting in a direct impact on the project: improvements included the way in which the patient invitation letters are structured and written along with the information leaflets that are given out to patients at the time of their tests
• GP engagement can be challenging. Use data to target high volume referrers. Only providing written information about a new service does not instigate a change in referral patterns. Newsletters, emails and letters have a limited effect. Building relationships and using personal mediums of communication like face-to-face meetings can have a positive effect.

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The introduction of direct access pulmonary function testing to support primary care in accurately diagnosing and managing respiratory patients, while reducing waiting times for clinic appointments and reducing costs.
Case studies

North East, North Central London and Essex Health Innovation and Education Cluster (NECLES HIEC) have been working with nine practices in Walthamstow West Primary Care Commissioning Group with support from GlaxoSmithKline UK to quantify the region of error in the diagnosis of COPD and the recording of information on disease registers.

Project summary
North East, North Central London and Essex Health Innovation and Education Cluster (NECLES HIEC) have been working with nine practices in Walthamstow West Primary Care Commissioning Group with support from GlaxoSmithKline UK to quantify the region of error in the diagnosis of COPD and the recording of information on disease registers.

Project aim
• Quantify the region of error in diagnosis of COPD, by understanding the proportion of patients with an incorrect diagnosis (following National Institute for Health and Clinical Excellence (NICE) 2010 guidelines for confirming COPD diagnosis)
• Quantify the variation between practices
• Establish a comprehensive and accurate disease registers that capture all elements of the diagnostic and severity assessment, enabling healthcare professionals to take a proactive approach to the identification and management of people with COPD, in line with the NICE COPD guideline 2010
• Reduction in waste, improved productivity and quality of services provided locally, by reducing inappropriate administration of medicines
• Prevent inappropriate treatment due to inaccurate diagnosis or incorrect assessment of severity.

Quality of COPD diagnosis measures at practice level

Highlights and achievements
• A baseline from the practices was extracted using GSK POINTS tool along with a list of COPD patients on each disease register
• Any patient without a recorded spirometry result or with an FEV1/Ratio recorded ≥0.7 was invited for a review with the respiratory nurse specialist – using NICE COPD 2010 guidelines. The review was based on and included a full patient history and spirometry with reversibility testing
• Following a clinical review, the practice registers were updated and the GP informed. If any medication changes were necessary, the patient notes were also updated along with dialogue with the GP
• Up to 36% of records on the registers had no documented spirometry which would suggest that spirometry has not been performed or the result had not been documented on the register
• Between 3% and 100% of records in the nine surgeries had incomplete spirometry results which could indicate that these patients have not had a validated diagnosis and that there is the possibility that these patients are not being treated effectively
• 18% to 100% of records in the nine practices did not document ‘percentage of predicted FEV1’ to assess severity of the disease and monitor disease progression over time
• Between 21% and 47% of records had a ‘FEV1/FVC ratio ≥ 0.7’ which could indicate that the patient does not suffer from COPD and there is an issue with poor technique or interpretation of spirometry results
• Four out of the nine practices had 60% or more patients with a dual diagnosis of asthma
• Evidence from the practices confirmed that patients on both COPD and Asthma registers receive two reviews which is costly to the health service and confusing to patients
• Results following a review with the respiratory nurse specialist to confirm diagnosis highlighted 50% of patients had a confirmed diagnosis of COPD and 50% did not have COPD.

Learning
• A standardised register which incorporates the requirements for Quality Outcomes Framework (QOF) and NICE diagnosis and management is required to drive up quality
• Variation occurs in the patient information collected on the practice templates. This occurrence is due to different software companies (EMIS, VISION etc) and variations within each version of the software
• Education and training for practice staff is imperative to the quality of COPD diagnosis and the recording of information. Both individual and group education and training session are required ensure all new diagnoses are quality assured and the correct information is added to the COPD register
• A standardised register would assist learning for healthcare professionals who are new to COPD
• Collecting data is time consuming but important to understand the current reality and the variation in clinical practice so that action can be taken to improve quality and patient care.

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Imperial College Healthcare NHS Trust and Central London Community Healthcare NHS Trust

An integrated respiratory team can make significant improvements across the entire COPD patient pathway

**Project summary**
A consultant led integrated respiratory team in Hammersmith and Fulham (H&F), working across Imperial College Healthcare NHS Trust (ICHT) and Central London Community Healthcare NHS Trust (CLCH) has been working to improve the quality of services for patients with COPD and other long term respiratory conditions.

The project was part of a broader review to reconfigure and re-commission services to deliver an integrated COPD patient pathway, supported by the primary care trust and local stakeholders. The project was commenced after a gap analysis showed that H&F had among the worst outcomes for COPD patients in London, with high admissions costing over £1m per year and an estimated 5,000 patients with as yet undiagnosed COPD.

Service developments have included specialist support to primary care delivering quality assured spirometry, workplace based training and quality reviews; community based pulmonary rehabilitation; a COPD discharge bundle with community follow-up; and community clinics.

**Project aim**
- To review practice disease registers and support primary care clinicians to confidently diagnose and manage respiratory patients
- Ensure all reviews include quality assured spirometry to confirm diagnosis, with an assessment of disease severity, and patients receive written information about their diagnosis
- To support patients to self manage
- To facilitate NICE standard pharmacological and non pharmacological management of COPD and asthma
- To support patients post discharge after acute exacerbation
- To improve communication and joint working by clinicians looking after COPD patients in primary, secondary and community teams.

**Highlights and achievements**
- Improvements across the patient pathway have led to a reduction of admissions by 19% and readmissions by 66%
- Reduction in first and follow up outpatient appointments equating to approximately £170k savings
- Reduction in the proportion of patients presenting with an acute exacerbation of COPD who do not have a previous GP diagnosis
- 145 patients have had a quality review with a respiratory specialist as a result of which:
  - Quality of recording of FEV1, exacerbations and breathlessness have improved in line with National Institute for Health and Clinical Excellence (NICE) quality standards in a practice audit exercise
  - 30% additional referrals to smoking cessation advice were made
  - 41% of patients received rescue medication packs
  - 23% of patients were referred to pulmonary rehabilitation
  - 44% of patients underwent changes to prescribed pharmacotherapy
  - 5% of patients had their diagnosis changed from Asthma to COPD.
- A real time ‘COPD Report’ tool has been developed in liaison with Public Health to capture patient and practice level data on COPD care and outcomes and to monitor progress of the pathway.

**Learning**
- Shared aims and joint working across primary, secondary and community care, with engagement of commissioners is critical to the success of an integrated service
- Changing traditional patterns of working is challenging and takes time to implement
- Data is crucially important; robust timely data is difficult to obtain and clinicians need to take ownership and responsibility for it
- Managing change can be slow and difficult. Communication throughout the process is vital
- Implementation of the chronic care model in COPD pathway can deliver improved outcomes. Working across traditional boundaries to deliver an integrated pathway is one way to achieve these outcomes and deliver value for money.

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Example of the GP practice reports and progress made

**PRACTICE A**

**PRACTICE B**

**PRACTICE C**

Number of admissions by patients who are on and not on the GP COPD disease register

<table>
<thead>
<tr>
<th>COPD (DZ21 A-K) Spells by current GP registers, FY 2009/10 to date</th>
</tr>
</thead>
<tbody>
<tr>
<td>FY 2009/10</td>
</tr>
<tr>
<td>Patient on GP condition register</td>
</tr>
</tbody>
</table>

- Patient on GP condition register
- Patient not on GP condition register
London Community Healthcare NHS Trust and Hammersmith and Fulham Primary Care Trust
Using an innovative data warehouse development to improve respiratory services

Project summary
In all quality improvement projects, access to data is a crucial part of identifying the areas for improvement and for monitoring progress.

An integrated respiratory team in Hammersmith and Fulham working across Imperial College Healthcare NHS Trust and Central London Community Healthcare NHS Trust started their improvement project by working with local GP practices. Using the GlaxoSmithKline POINTS (GSK) audit tool to assess the quality of chronic obstructive pulmonary disease (COPD) management in their area, a respiratory specialist team worked with practices to review COPD and asthma patients to deliver workplace based training aimed at primary care clinicians. Data from enhanced COPD and asthma reviews was entered on read code linked templates and progress was followed up with a second audit.

Significant improvements were made to reduce the variation between practices and improve the quality of diagnosis and management. To sustain the improvement in the area, a multidisciplinary team from Central London Community Healthcare NHS Trust, Hammersmith and Fulham Primary Care Trust (PCT) and General Practice initiated a project to build a near a real-time audit tool.

The tool can baseline and monitor information recorded on practice computer systems, monitor out patient appointments, admissions and re-admissions, along with highlighting those admissions coded as COPD or asthma who are not on the GP practice disease register. This then generates a local ‘COPD’ or ‘asthma’ report at patient, practice or Primary Care Trust (PCT) level as required which also can track improvements over time. A key component of this is measuring compliance with locally agreed and National Institute for Health and Clinical Excellence (NICE) standard care, rather than Quality Outcomes Framework (QOF) targets, and focusing on important data such as smoking prevalence in the respiratory population.

Project aim
• Improve joint working across primary, secondary and community care to deliver and monitor an integrated pathway
• Improve the collection and analysis of primary and secondary care data to support local services and the decision making processes
• Improve monitoring of the local integrated COPD pathway, through monthly monitoring across primary care and secondary care
• Improve local monitoring of asthma patients
• Provide greater feedback on admissions data to local GP practices
• Create useful performance measures to support clinicians and managers in the area.

Data extraction and matching process
A multidisciplinary team made up of an integrated care consultant, primary and community clinicians, public health specialists and commissioners built the warehouse based on primary and secondary care read codes relevant to COPD and asthma. The 30 practices in NHS Hammersmith and Fulham agreed to share a generic monthly extract of data from their practice systems to the PCT.

• Data is automatically extracted from GP practices and aggregated by Apollo Software
• The data is then downloaded from Apollo and linked into the PCT data warehouse
• The data warehouse combines individual patient level data from Secondary Uses Service (SUS), the local RIO database and the extract from primary care, matching patients on NHS number
• An innovative, interactive document is produced for viewing and sharing the data, using Tableau software. Tableau software provides an intuitive dashboard style interface that enables practices to have an overview of the key measures for their practice, and click into the detail for patient level information if they require
• This data is shared with practices and the integrated respiratory team to facilitate appropriate intervention and monitor progress.

Highlights and achievements
• This innovative approach enables the PCT to access and merge the data from the local acute services and general practices to provide a whole system picture of the care received by COPD and asthma patients in the area
• Data is collected on compliance with locally agreed and NICE standards of care as opposed to QOF targets (e.g. stop smoking support, pulmonary rehabilitation referrals etc)
• The architecture of the data warehouse is owned by the PCT and is available for other healthcare providers to use and implement in their local area. No additional software is required as the warehouse is based on the commonly used Microsoft SQL database
• The database structure and definitions of the read code extractions are available to share with other PCTs or clinical commissioning groups
• The extracts from Apollo software are automated for the practices and the PCT. No further user input is required once the extract is set up
• Matching the data from GP practices to secondary care allows for some useful measures to be calculated. For example, each month the PCT reviews the COPD and asthma patients who have had an admission for their respiratory condition who do not have a diagnosis in Primary Care and are not on the practice disease register
• The practice list data is refreshed monthly, compared to the previous annual QOF practice list which the practice received
• Practices receive admissions and re-admissions data on a monthly basis
• The data is obtained from the practices each month providing a timely update on performance unlike annual data sources such as QOF
• The tableau interface provides a tailored approach depending on the audience’s requirements; it can output to a pdf or word document, or using the tableau browser interface. This enables practices to drill-down to the individual patient level data
• Transferability – current work has piloted reports for COPD and asthma. The same data warehouse could be used for other disease areas.

Learning
• There is a cost associated with extracting data using Apollo, which is low when considered on a per extract basis, but may limit implementation in larger PCTs over longer periods
• The reports are dependent on the quality of coded data. The data extracted is very useful, but data coding issues can sometimes report unexpected results, which require local investigation
• Risk stratification has been difficult from the initial extracts due to an incorrect level of read code data, but there are plans to fix this in future extracts.

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Example of COPD and asthma reports produced for GP practices
Case studies

NHS Hammersmith & Fulham - GP COPD Audit Tool - Baseline Report
Page Three - COPD in Practice in the last 12 months

Number of COPD Patients
SAMPLE 218

No. of COPD Patients with an Annual Review in the last 12 months
SAMPLE 78

No. of COPD Patients with Clinical Indicators recorded in the last 12 months

<table>
<thead>
<tr>
<th>Indicator</th>
<th>N/A</th>
<th>SAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exacerbation</td>
<td>54.51%</td>
<td>83</td>
</tr>
<tr>
<td>FEV1/FVC</td>
<td>36.21%</td>
<td>92</td>
</tr>
<tr>
<td>PVC</td>
<td>41.89%</td>
<td>46</td>
</tr>
<tr>
<td>MRC Score</td>
<td>76.50%</td>
<td>87</td>
</tr>
<tr>
<td>Immerse Technique</td>
<td>72.41%</td>
<td>84</td>
</tr>
<tr>
<td>O2 Saturation</td>
<td>23.29%</td>
<td>27</td>
</tr>
</tbody>
</table>

No. of COPD Patients with a Body Mass Index recorded in the last 12 months
SAMPLE 78

No. of COPD Patients with a Self Management Plan recorded in the last 12 months

No. of COPD Patients Referred/Attended Pulmonary Rehabilitation recorded in the last 12 months
SAMPLE 10

NHS Hammersmith & Fulham - GP COPD Audit Tool - Baseline Report
Page Four - High Risk COPD Patients & NICE Guidance

Number of COPD Patients
SAMPLE 218

High Risk Patients with COPD
SAMPLE 7

Calculating Predictive Modelling (CPM) refers to the identification of individuals who are at risk of a future emergency admission to hospital within 12 months ahead. The Hammersmith & Fulham model is based on a Kings Fund formula that combines body plethysmography (e.g. age, sex, chronic illnesses, medication) with other measures to calculate the risk for each individual patient. The effective use of the CPM can be made available to practice. This score is determined for the entire period which results in the list of individuals with the scores ranging from 0 to 100.

Patients with a risk score greater than 50 are deemed as very high risk of emergency admission within the last 12 months and the case should be reviewed as a way of preventing unplanned emergency hospital admissions in the near future. The NICE score is often used as a guide to risk assessment. However, given that these models are continuous, these are relatively arbitrary cut-off points.

NHS Indicator
Gender
Age
Details removed from sample
Details removed from sample

Initial Therapy

NICE Guidance

Continuous inhaled therapy in COPD is not normally recommended.

Some patients with severe COPD may need maintenance oral prednisolone. Treatment cannot be stopped without an exacerbation. Keep the dose as low as possible, monitor for osteoporosis, and offer prophylaxis.

Therapy:
Offer only short courses of oral corticosteroids to people who cannot use inhaled therapy.

Therapy can also be used in combination with beta2 agonists and muscarinic antagonists.

Take care when prescribing to older people because of pharmacokinetics, co-morbidities, and interactions with other medications.

Reduced dose in case of myocardial infarction or fluquinconazole and budesonide (or other drugs known to interact); use of an inhaled steroid may result in exacerbation.

Mucolytic therapy

Consider in people with a chronic productive cough and continue if symptoms improve.

Do not routinely used to prevent exacerbations.
The Leeds Teaching Hospitals NHS Trust

Developing an integrated COPD disease register to support quality assured diagnosis and proactive chronic disease management

**Project summary**
The Leeds Teaching Hospitals NHS Trust developed a standardised Chronic Obstructive Pulmonary Disease (COPD) register designed to proactively support diagnosis and chronic disease management across both Primary and Secondary Care.

**Project aim**
To produce an integrated standardised register to ensure all the necessary patient information is collected and recorded in one system. Thus improving the communication and information flow between Primary and Secondary Care which is highly beneficial for both patient outcomes and efficiency, and to act as a platform where diagnostic information (e.g. current smoking status) triggers patient referral for treatment (e.g. smoking cessation).

**Highlights and achievements**
- Development of an integrated register
- A decision making pathway has been developed to sit alongside the register and support a care planning consultation
- Fully implemented register in Leeds Teaching hospitals with work ongoing to convert the register into an electronic format for primary care.

Benefits of using this disease register include:
- Standardised register for both primary and secondary care
- Standardised collection of data
- Mechanism for improved communication between primary and secondary care
- Improved the information flow between primary and secondary care
- Supports the assessment of severity of disease
- Enables assessment of the impact of the disease on the patient
- Facilitates assessment of disease progression over time to identify the indications for all interventions with the impact on the patient and their chronic disease
- Consistent with the current clinical evidence and the recommendations of the national and international guidelines
- Data format will be compatible with the different information technology systems used in NHS
- The process of collecting, recording and analysing the data will be acceptable and feasible for both patients and health care organisations
- Support continuous audit of all requirements of Quality and Outcomes Framework (QOF), Quality Standards for COPD and National Institute for Health and Clinical Excellence (NICE) standard CG101.

**Learning**
- The consultation with patients was invaluable to understand their experiences, expectations and needs of a COPD service
- Support from the primary care computer systems is of paramount importance for the full implementation of the integrated register. The process of engagement and decision making is slow and requires perseverance
- A barrier to the implementation of a disease register is the lack of widely accepted and robust standards for management of patients with COPD. QOF has limited clinical value, however, this disease register can facilitate the establishment of such standards.

**Contact**
To receive a copy of the register, supplementary documentation or to request to use the register in your area contact:

Dr Doychin Dimov
Consultant Physician in Respiratory Medicine
Email: doychin.dimov@leedsth.nhs.uk

Further information including the register is also available on the following website: www.improvement.nhs.uk/lung
Case studies

The Disease Register for COPD is developed in the department of Respiratory Medicine at Leeds Teaching Hospitals NHS Trust

Correspondence: Dr Doytchin Dimov, Consultant Physician in Respiratory Medicine, St James’s University Hospital, Beckett Street, Leeds LS9 7TF. Tel: +44 113 2064523 Fax: +44 113 2064158 E-mail: doytchin.dimov@leedsth.nhs.uk

Summary of the consultation:

Patient’s goals: (enter in patient’s own words)

Smoking cessation service: □

PERSONALISED CARE PLAN

Inhaler therapy: SABA □ SAMA □ LABA □ LAMA □ ICS+LABA □

Inhalers: 1………………………………………2………………………………………3………………………………………4………………

Oral therapy: PDF4 inhibitor □ Theophylline □ Mucolytic □ Opioids □

Medication:……………………………………………………………………………………………………………………………………

Nebuliser therapy: Nebuliser trial □ Beta-agonist …………………Antimuscarinic □ …………………

Change of mouthpiece □ Servicing □

Oxygen therapy: LTOT assessment □ Prescribe LTOT at…….l/min □ Mask □ Nasal cannulae □

Ambulatory oxygen assessment □ Prescribe ambulatory oxygen at…….l/min for…..hours a day

Short burst oxygen □ Palliative oxygen □ Home oxygen follow up □

Pulmonary rehabilitation: Rehabilitation course □ Individual plan □ Exercise for 30 min 5 days a week □

Vaccinations: □ Influenza vaccination □ Pneumonia vaccination □

Self management: Self management plan □ Supply of Prednisolone 30 mg od for 7 days □

Supply of antibiotic □…………………………

Co-morbidities and systemic effects: Link to CHD register □ Link to diabetes register □

Depression/anxiety treatment plan □ Bone densitometry □ Treatment for osteoporosis □

Nutritional supplementation and exercise plan □

Multidisciplinary management: Community respiratory team □ Community matron □

Telehealth supported pathway □ Social services □ Occupational therapist □

Secondary care follow up □

Palliative care: Refer to palliative care team □ Other palliative care interventions……………………………………

Other recommendations: ………………………………………………………………………………………………………………………

……………………………………………………………………………………………………………………………………………………………..Next clinical review in…….months

The Disease Register for COPD is developed in the department of Respiratory Medicine at Leeds Teaching Hospitals NHS Trust

More documents are available on the NHS Improvement at: www.improvement.nhs.uk/lung
Leicester County and Rutland PCT

How good is our management of chronic obstructive pulmonary disease?

**Project summary**
Leicester County and Rutland Primary Care Trust worked with Optimum Primary Care (OPC) using software to extract primary care data. In order to target education and intervention appropriately an evaluation was conducted to determine how well asthma and chronic obstructive pulmonary disease (COPD) were being diagnosed and managed. Following the results of this evaluation it was evident that a significant variation in quality and consistency existed, which was not routinely visible through the current standard measures and reports.

**Project aim**
- Develop an accurate baseline of current performance in primary care
- Provide practices with individualised patient reports on their system to support improved management
- Stratification of patients by disease severity
- Identification of high risk patients
- Assist in the planning of service development
- Identify scope for targeted intervention to optimise therapy and reduce admissions.

**Highlights and achievements**
OPC software was used to extract routinely recorded data from participating practices. The data is automatically compared with the National Institute for Health and Clinical Excellence (NICE) COPD rule sets to identify any discrepancies between current and suggested optimal care for each patient. This is automatically fed back into the practice system forming personalised recommendations for that patient; this information will also inform the patient’s next review as well as creating aggregated reports. Those patients with a recorded diagnosis of COPD of approximately 10% did not have COPD on spirometric criteria:
- Over 50% of patients had no FEV1 (Forced Expiratory Volume) or FVC (Forced Vital Capacity) values within two years of diagnosis. The cost of therapy for misdiagnosed COPD patients could amount to £86k pa – this represents a potential saving, depending on what their accurate diagnosis would be
- 30% of patients required optimisation of therapy, which could reduce the likelihood of admission
- Approximately 7% of patients were identified as high risk patients using the DOSE index.

**Learning**
Existing data sets and Quality Outcomes Framework measures give only a limited understanding of quality. The marked variation in recording of FEV1, COPD severity, exacerbation recording, smoking history, medicines use, referral for pulmonary rehabilitation and other aspects of care potentially indicates significant difference in quality of care and related impact on secondary care and prescribing. Making this visible helps to target appropriate intervention to improve management.

As patients with moderate or severe disease account for significant numbers of admissions, there is scope for improved management of these patients to have considerable impact on acute activity.

**Contact**
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Woodbrook Medical Centre
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**The DOSE index**
The DOSE index (MRC Dyspnoea Scale, airflow obstruction, smoking status and exacerbation frequency) is a simple, validated tool for assessing the severity of COPD and guiding management, for use in routine clinical settings.
The Victoria Practice, Aldershot, Hampshire

Reducing waste and increasing adherence in use of medicines for chronic obstructive pulmonary disease

Project summary
Victoria practice employed a clinical pharmacist to conduct reviews for asthma and COPD patients that has reduced prescribing costs and improved patient’s COPD assessment test (CAT) scores.

Project aim
• Review asthma and COPD patients’ use of medicines
• Identify opportunities to improve quality and reduce waste in prescribing
• Evaluate the cost effectiveness of a clinical pharmacist as part of the primary care team.

Highlights and achievements
The pharmacist sees COPD and asthma patients routinely for review. These consultations are specifically structured around previous National Prescribing Centre (NPC) concordance training, using open questions which help to understand the patients’ current attitude to their medicines and to set realistic goals for improvement for the future.

During these consultations inhaler technique is evaluated and an InCheck Dial trainer device is also used in order to determine that patients are achieving the optimal inspiratory flow for their device. Patients using metered dose inhalers (MDIs) are also given a 2Tone Trainer device and advised to check their inspiratory flow once a month at home.

The pharmacist is an independent prescriber, who holds COPD and clinical pharmacy diplomas. This ensures that the pharmacist is able to review and revise current medication, but working in the practice she also has the opportunity to discuss any significant concerns with the practice’s lead GP.

Patients complete a CAT at their first appointment with the pharmacist which is then repeated at follow up where an intervention has been made in order to measure and document the effects and outcomes. Patients who do not need a face to face follow up appointment are contacted by phone two to three weeks after their appointment. Where a significant intervention such as change of medication was made during the course of the project, 8 out of 10 patients showed reductions in CAT score of between 5 and 17 points.

CAT scores
The COPD assessment test (CAT) is a simple validated test of 8 questions that objectively measures the impact of COPD on the person’s life. A high score indicates the condition is having greater impact on the person’s life; a low score indicates less impact. Patients are encouraged to complete it independently, as the test allows them to express themselves in a way that permits a common understanding of the issues affecting them. Ongoing use and comparison of consecutive scores can reveal whether impact is changing over time, providing a useful framework for discussion to help optimize treatment.

More information is available at www.catestonline.co.uk/hcpbenefits.htm
The practice has demonstrated a sustained reduction in prescribing costs of £1300 per month on respiratory chapter medicines when other practices in its group were showing an increase.

**Learning**

Allowing 30 minute appointments provides sufficient time with the patient so all aspects of the consultation can be covered. Making this time available for the patient is important to establish a rapport with the patient.

To reduce ‘do not attends’ (DNAs) the receptionists phones the patient the day before their appointment with a reminder; this also allows time to contact other patients if there is a cancellation.

Looking at the total prescribing picture for the patient can help identify waste.

Ensuring that repeat prescriptions for different medications are synchronized in terms of quantity prescribed can reduce over or under ordering. This also increases the reliability of patients having the medication and taking it correctly.

Process mapping at the practice has revealed scope to work more closely with the local pharmacies to reduce potential waste in repeat prescribing systems.

Enhancing the skill mix in the practice team has brought more general knowledge and sharing into the practice such as an increased awareness of medication costs, benefits waste of different medication and additional cover within the team.

**Contact**

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NHS Blackpool

Formalising self management planning in Blackpool

Project summary
With high prevalence of chronic obstructive pulmonary disease (COPD) within the region along with high rates of smoking, high mortality and high spending, improving care planning and patients’ ability to self manage were seen as priorities by the Primary Care Trust (PCT). At that time there was no formalised self management plan in use locally so a format was developed in conjunction with patients. This initiative is now in use across all 22 Primary Care teams and in the acute unit, with over 1000 plans distributed by October 2011.

Project aim
• Develop consistent written self management care plans for all patients, as a key component of an integrated COPD pathway
• Develop patient education materials and/or programmes together with educational support for clinicians adopting new ways of working
• Identify and promote the evidence base for self management plans to gain clinical commitment for their use
• Agree an integrated approach to implementation, including promotion of the plans and embedding their use in clinical and social care practice and other care settings
• Develop structured education programmes appropriate to local needs and skilling healthcare professional to deliver the plan
• Evaluate the impact on patient confidence and outcomes.

Highlights and achievements
A comprehensive plan was developed in conjunction with patients and adopted across primary and secondary care. The plan was tested with clinicians and patients to check terminology, content and the process of delivery before rolling out, which both improved quality and increased buy-in from clinicians.

Training and education sessions were provided to participating practices to ensure that the plan was delivered appropriately and consistently, to maximise effectiveness.

Educational events and training sessions supported the roll out of the plan which embedded the ethos and methodology necessary to deliver it successfully. Training included the whole team so that everyone was aware of and engaged in the process.

Plans were distributed to all GP practices, community matrons, case workers, pulmonary rehabilitation, acute trust, early supported discharge team and the relief nursing team. When a plan is issued in secondary care, the named contact in the patient’s practice is informed to facilitate seamless follow up. The plan also formed part of the Commissioning for Quality and Innovation (CQUIN) payment framework with the acute trust to help embed its use as best practice. This helped reduce confusion for patients by standardising the information they were given and also helped assure continuity.

Training sessions were also run for social care workers to equip them with additional skills to support patients in their own homes by using My Breathing Book as an information tool. Community pharmacists also have access to the plan as a reference tool.
The impact is being evaluated by a patient questionnaire, approved by Clinical Governance and funded by Partnerships and Patient Engagement through local commissioners.

**Learning**

Strong links and good personal working relationships help build bridges and develop a consistent approach to delivery. Clinical education is important to ensure the plan is used properly and consistently and to promote both behavioural and cultural change. Pulmonary rehabilitation referral rates improved with implementation of the plan, with awareness of the educational component and additional time staff can offer patients.

A simplified version of a written self management plan is useful for those patients or carers who are less confident or literate.

It can be difficult to evaluate or attribute impact in the short term. Information governance issues made it difficult to track impact by NHS number as originally planned. Alternative process measures may help in the interim, or individual sites may be able to monitor their own patients, but it is important to get acknowledgement that impact on high level admission data will take longer to work through. Total resource use per patient per year may be a better indicator of integrated care that includes self management planning. Self management planning may be best seen as an integral component of a care bundle approach to delivering holistic, best practice care.

It takes time!

---

**What is normal for you?**

It is important to know how you are when you are well.

**Be aware of your daily condition:** Use this CAT score to monitor your daily condition.

**Note:**
1. Colour and amount of sputum you produce
2. How breathless you are at rest and on walking
3. How much you can normally do

**What is your normal sputum like?**

1. It is also important to monitor your sputum. Changes in colour and amount of sputum can suggest an infection.

<table>
<thead>
<tr>
<th>Colour</th>
<th>Amount of Sputum daily</th>
<th>Advice</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Some (up to a teaspoon)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>A little (up to a tablespoon)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Moderate (up to 3 tablespoons)</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>A lot (a cupful or more)</td>
<td></td>
</tr>
</tbody>
</table>

2. Visual aids can help determine how breathless you are feeling

<table>
<thead>
<tr>
<th>Not breathless</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Very breathless</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>😊</td>
<td>😊</td>
<td>😊</td>
<td>😊</td>
<td>😊</td>
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<td>😊</td>
<td>😊</td>
<td>😊</td>
<td>😊</td>
</tr>
</tbody>
</table>

**Normal for you** (enter score from above)

**Breathless scale for grading the degree of your breathlessness**

1. Not troubled by breathlessness except on strenuous exercise
2. Short of breath when hurrying or walking up a slight hill
3. Walks slower than contemporaries on the level because of breathlessness, or has to stop for breath when walking at own pace
4. Stops for breath after about 100 m or after a few minutes on the level
5. Too breathless to leave the house, or breathless when dressing or undressing

**Normal for you** (enter score from above)

---

**Contact**

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Veor Surgery, Camborne, Cornwall
A systematic approach to implementing self management action plans

Project summary
To ensure all chronic obstructive pulmonary disease (COPD) patients could recognise and respond appropriately to any worsening of their condition the practice wanted to discuss a self management action plan with each of them before winter set in. In spite of a significant rise in exacerbations, the proportion of reported exacerbations resulting in admission was only 5% that winter compared to 8% the previous year, and patients made greater use of planned appointments and telephone support to manage changes in their condition.

Project aim
• Ensure every COPD patient is reviewed and has discussed self management action for exacerbations in the run up to the winter period
• Issue antibiotics and steroids in line with local guidelines to all appropriate patients
• Evaluate the safety and impact of issuing rescue medication to patients in relation to untoward incidents, admissions and use of primary care.

Highlights and achievements
The team reviewed existing resources and re-allocated time to set up 20 specific COPD self management clinics, each offering six 30 minute appointments. 122 patients were reviewed for the project, and 100 patients agreed self management action plans during a three month period.

Receptionists contacted patients the day before their appointment with a reminder to reduce the chance of them not attending.

Consultations included discussing with the patient general health and wellbeing (using a COPD computer template), what to look out for when becoming unwell, prescribed medicines and their use, inhaler technique, spirometry check and recording a COPD Assessment Test (CAT) score, sent to the patient for completion in advance.

Patients were encouraged to start antibiotics in line with local guidelines and to contact the practice for advice and follow up.

Exacerbations during the severe winter period were 117 (60 in previous year) but admissions and GP appointments remained stable. Patients made more use of telephone consultations and planned nurse appointments rather than urgent contacts, indicating early intervention gave better control and outcomes.

Proportion of exacerbations seen by GP or nurse

Think ‘ABC’ to self-manage your COPD

Able to do usual activities?

Bit more breathless than usual?

Coughing up coloured sputum or phlegm?

Don’t delay, start your tablets today.

October 2009 - March 2010

October 2010 - March 2011

Proportion of exacerbations seen by GP or nurse

October 2009 - March 2010

October 2010 - March 2011

Proportion

Percentage

0.9

0.8

0.7

0.6

0.5

0.4

0.3

0.2

0.1

0

Seen by doctor

Seen by nurse

Case studies
Learning
Inviting patients to discuss self management in August and September meant there was less likelihood of illness or bad weather affecting patients’ ability to attend.

The professional conducting the review should be able to prescribe antibiotics and steroids, and be confident to examine and assess the patient, including distinguishing between exacerbation and heart failure. This helps avoid additional referrals back to the GP.

Allowing 30 minute appointments gives adequate time to address the patient’s concerns and ensures their understanding when discussing self management. Setting up specific clinics to reach all patients initially was time consuming, but did not create the backlog of other work that the nurses had expected. Once the system is established, new patients can be booked in for appropriate appointments on diagnosis.

Contact
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**Breathe Easy North Staffordshire and NHS Stoke on Trent**

**How support groups can impact on patients’ ability to self manage**

**Project summary**
NHS Stoke on Trent and Breathe Easy North Staffordshire (BENS) demonstrated how patient support groups can be integrated into the patient pathway, with a 25% increase in attendance at the local group and 70% of members reporting greater awareness of what to do when they become unwell. The area has high deprivation along with high smoking and COPD prevalence; increasing patients’ understanding of how to manage their own health is an important part of the local strategy to address this.

“…seeing the way other sufferers cope with their illness has made me feel that I can do the things I previously felt I could not.”

**Project aim**
- Analyse current membership of groups and referral sources to identify gaps
- Increase the total number of patients involved in the group and representation from a wider group of practices by raising awareness and clarifying referral routes
- Develop effective patient and carer information to support self management
- Increase patients’ healthy behaviour and confidence to self manage by providing appropriate messages, information and support
- Identify the impact that group membership has on patient outcomes.

**Highlights and achievements**
- 75% of members say they are more confident and 90% have a better understanding of their condition since joining the group
- A member of the local community respiratory team attends each meeting to answer questions and concerns, and to promote relevant self management messages. If any common themes are identified this can then be addressed at an organisational level
- Enquiries and membership have increased, with a 25% increase in attendance at meetings, as a result of making the referral process more consistent across a number of practices and ensuring that Breathe Easy and British Lung Foundation (BLF) support are highlighted at diagnosis
- Information packs on the local support group and BLF are provided to practices to give to patients on diagnosis and increase the reliability of referral to the group. Information is also included in discharge information packs
- BENS members now provide input to the local pulmonary rehabilitation programme, promoting the role of the local support group
- Representation from BLF at the local respiratory implementation group has enhanced understanding and awareness of what Breathe Easy and BLF can offer to enhance patient experience and self management
- A quarterly newsletter and a welcome pack are provided to members.
- Group members completed a questionnaire on the impact of the group on their confidence and self management (see box).

Since joining Breathe Easy…

75% said they felt **more confident** in managing their condition

88% indicated they felt **more hopeful** about the future

94% said they had **a better understanding** of their lung condition

70% felt they had **more knowledge** of what to do if they become unwell

76% felt they had **more awareness of the support** available to people living with a lung disease
Learning

- If health professionals are to consistently promote membership of a local support group, they need to be convinced that the programme and advice it offers are appropriate and valuable. This can be achieved through engagement at both a strategic and operational level.

- Personal contact with local practices can help raise awareness of the support available via the local group and increase referrals to the group. This is helpful because patients often report receiving only limited information at diagnosis, whereas referral to the BLF / Breathe Easy group can provide another early source of information and support, to enhance the opportunities for understanding their condition and what they can do to manage it.

- It is not easy to measure impact on health care resource use for small group numbers, but patient-reported measures and personal stories emphasise the value of group support in enhancing quality of life and confidence which provides a powerful message.

Contact

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Acknowledgments

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In addition, the following people have provided a source of expertise and support and their help is gratefully acknowledged:

Phil Duncan, Director,
NHS Improvement - Lung

Ore Okosi, National Improvement Lead,
NHS Improvement - Lung

Catherine Thompson, National Improvement Lead, NHS Improvement - Lung

Alex Porter, Senior Analyst,
NHS Improvement - Lung

For more information please contact: Catherine Blackaby, National Improvement Lead, NHS Improvement - Lung, Email: catherine.blackaby@improvement.nhs.uk or Zoë Lord, National Improvement Lead, NHS Improvement - Lung, Email: zoe.lord@improvement.nhs.uk
References

1 An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England, Department of Health, July 2011

4 The National COPD Resources and Outcomes Project Final Report, Clinical Effectiveness & Evaluation Unit, Royal College of Physicians, London, May 2009
NHS Improvement

NHS Improvement’s strength and expertise lies in practical service improvement. It has over a decade of experience in clinical patient pathway redesign in cancer, diagnostics, heart, lung and stroke and demonstrates some of the most leading edge improvement work in England which supports improved patient experience and outcomes.

Working closely with the Department of Health, trusts, clinical networks, other health sector partners, professional bodies and charities, over the past year it has tested, implemented, sustained and spread quantifiable improvements with over 250 sites across the country as well as providing an improvement tool to over 1,000 GP practices.

NHS Improvement

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