Evaluation of the NHS Breathlessness Pilots
Report of the Evaluation Findings

Report for NHS England
31 March 2016
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Executive summary

Introduction

In July 2014, NHS Improving Quality (NHS IQ) launched a national pilot programme to improve speed and accuracy of diagnosis in patients experiencing the symptom of breathlessness. The breathlessness pilot was designed to also relate to the new models of care work referred to in the Five Year Forward View for the NHS. Three pilot sites successfully applied for £15,000 of grant funding in order to test a variety of service developments:

- Health First – a Community Interest Company covering Ashton, Leigh and Wigan.
- University Hospitals Leicester – a Foundation Teaching Trust covering Leicester, Leicestershire and Rutland.
- Wessex Academic Health Science Network - providing breathlessness services in Wessex.

This report has been prepared by the Office for Public Management (OPM) who were commissioned by NHS Improving Quality (NHS IQ) to undertake a summative evaluation of the breathlessness pilots.

Overview of the pilot site activities

The three pilot sites developed and implemented new models of symptom-led care for patients experiencing breathlessness:

- In Leicester, Leicestershire and Rutland, the first phase of the programme involved implementation of a multi-disciplinary, specialist-led diagnostic clinic for breathlessness in secondary care. Phase two is currently being rolled out, and involves implementing a pathway in primary care and improving linkages with lifestyle and behaviour change services available locally.
- In Wessex, the pilot worked with three general practices, bringing in a specialist respiratory team to proactively identify patients and deliver a ‘one-stop shop’ for diagnosis and treatment in local surgeries.
- In Ashton, Leigh and Wigan, the pilot involved Respiratory Nurses working alongside general practice staff to review patient records, to identify patients experiencing breathlessness who may benefit from attending a one-stop-shop diagnostic service, delivered within primary care settings by a team of respiratory and cardiology specialists.

All three pilots have delivered in line with the original project plans and applications submitted, and have evidenced how they have made progress towards their stated aims and objectives.

The pilots have required integrated working across primary and secondary care to varying degrees, and have relied upon strong clinical leads to design and drive forward the new models of care. This presents important learning for others, and has implications for the future commissioning of similar models: the reliance on committed, strong and credible clinical leaders must not be under-estimated, and may limit the transferability of the models more generally.

The outcomes evidence emerging from the pilots is encouraging: there have been improvements in diagnosis, reports of effective treatment plans being implemented and adhered to, and improved patient outcomes are emerging as a result. The holistic assessment of patient needs has proved particularly powerful, exploring potential causes of the breathlessness symptom rather than assuming a particular
diagnostic or treatment route is required. This in turn has helped to improve patient experience and compliance, and led to capacity building across primary and secondary care, offering potential longer term benefits and paving the way for sustained approaches to integrated care within respiratory and cardiology.

The pilot programme adopted a symptom-based approach to diagnosis, and this has generated important learning regarding the efficacy of this approach. The pilots improved the speed and accuracy of diagnosis for breathless patients, ensuring appropriate treatment (medical and / or lifestyle-related) was provided as quickly as possible, minimising the risk of exacerbation and escalation.

The integration of behaviour change and lifestyle advice within the pilots is likely to prove particularly important moving forward, with increasing focus at national and local levels on personal responsibility and minimising the increasing burden on the NHS as a result of poor lifestyle choices. However, this area of the pilot has proved challenging to implement: whilst advice and educational materials have been given to patients, integration with lifestyle services has not yet been realised to its full potential.

This last point is illustrative of the pilots overall: the three sites remain on a journey, as do the clinicians and patients involved. Realising the full extent of the outcomes of the pilots will take years, and the full scale of the impacts cannot be evidenced within this evaluation. However, the early indications are encouraging: the models do appear to have led to positive outcomes for patients and clinicians involved, and also seem to offer the potential for realising system-level and economic impacts, albeit over a longer time period and with scaling up of the models.

The evidence emerging at site level has clearly been sufficiently convincing for local providers, and in some cases, commissioners. All three services have developed sustainability plans, with commissioning decisions already having been taken to sustain the diagnostic approach to breathlessness in one site. The evidence indicates that multiple commissioning needs may be met as a result of the pilots.

The care models piloted also align with the NHS New Care Models (Vanguards) core principles, in particular principle one: care and support is person centred: personalised, coordinated and empowering. The focus on addressing needs holistically and actively engaging patients in care planning and self-management demonstrated within the pilots aligns with this future direction of travel for NHS services in England, and consequently offers examples that others may wish to learn from when planning their own breathlessness pathways.

**Recommendations for policy makers**

**Recommendation 1: Explore the scope for a national dataset regarding breathlessness.** We suggest that further research might usefully inform the scope of this dataset, recognising that breathlessness services vary significantly in their design and implementation across different CCGs. Whilst local needs and provision will vary, developing a national, standardised set of indicators regarding breathlessness would enable evidence to be captured and assessed by NHS England in order to inform future policy making and funding decisions. We suggest that this dataset might useful include metrics regarding:

- Waiting times for respiratory and cardiology diagnostic tests.
- Outcomes of the tests (lifestyle advice as well as medical treatment).

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1 NHS England, New Care Models: Empowering Patients and Communities (December 2015)

Details of where diagnostic services are provided.

**Recommendation 2: Conduct a light-touch follow up evaluation.** This evaluation was time-limited and ran until the end of pilot delivery. However, the longer term benefits and system-wide impacts will not be realised for many months, and in some cases, years to come. With this in mind, we recommend that NHS England commissions a light-touch follow up evaluation, to explore the longer term impacts of the pilots at a local level. Commissioning this work now will enable pilot sites to set up relevant data collection and monitoring arrangements. This might usefully include an economic assessment, to robustly assess the costs and financial benefits emerging as a result of different breathlessness pathways, ideally including comparator data (retrospective or compared to localities without clear breathlessness pathways in place).

**Recommendation 3: Disseminate learning across the respiratory and cardiology community.** The pilot leads are keen to share their learning more widely across their peers, and we suggest that this enthusiasm be utilised to share learning regarding the approaches adopted and impacts emerging. The leads may usefully be able to act as peer leaders.

**Recommendation 4: Seek to increase public awareness regarding breathlessness symptoms.** Patients presenting with breathlessness as part of the pilots received varying diagnoses, although over a fifth from the ALW site received lifestyle and behaviour change advice as part of their treatment. Lifestyle advice and behaviour change was recognised as vital across all three of the pilot sites. This indicates that patients themselves may be able to take pre-emptive action to avoid or reduce the risk of breathlessness, and to reduce symptoms once they do occur. However, given that some breathlessness is clearly the result of important conditions requiring medical treatment, it is important for patients to receive accurate, easy to understand advice about when and where to present with symptoms of breathlessness, as well as actions they themselves can take to reduce the risk of it occurring in the first place.

**Recommendation 5: Highlight the potential savings emerging as a result of earlier diagnosis.** The wider evidence base indicates that addressing COPD, heart failure and asthma appropriately and as early as possible can lead to reduced mortality, reduced severity of condition, reduced need for costly interventions and medications, and can lead to fewer days of work being lost. We suggest that it may be useful to highlight the potential longer term savings emerging as a result of improved pathways for treating breathlessness when presented in primary care, and seek to reduce or remove any disincentives in the system (in terms of tariff payments).

**Recommendations for local NHS organisations, including provider and commissioner organisations**

**Recommendation 6: Build education and awareness within primary care.** The pilots highlighted varying levels of awareness of, knowledge about, confidence in and enthusiasm for addressing the symptoms of breathlessness within primary care. This indicates the need for improved consistency across primary care. If conditions were identified and appropriate treatment / advice given within primary care wherever possible, there are likely to be efficiency savings for local healthcare economies. If nothing else, GPs and practice nurses need to be kept informed about locally available services and referral routes, which in itself takes time and effort, and should be factored into any service specifications and delivery plans for breathlessness services.

**Recommendation 7: Encourage consistency in coding within primary care.** The pilots highlight the importance of accurate, consistent coding of respiratory and cardiology diagnoses within primary care. This is important when using the GRASP tool, but is also vital across the different pathways and approaches. For example, coding COPD as mild, moderate or severe, as opposed to simply ‘COPD’, is important, and a
lack of graded coding can sometimes indicate that the appropriate diagnostic tests have not been carried out. With this in mind, we recommend that local commissioners and providers encourage accurate coding within their service specifications and delivery plans, and educate primary care clinicians accordingly. This also aligns with NICE guidance regarding respiratory conditions\(^2\).

**Recommendation 8: Build in evaluation and monitoring requirements from the outset of future programmes.** It is vital to develop appropriate and robust monitoring and performance management processes for any new intervention, whilst ensuring pragmatism in data collection approaches. Whilst we recognise that local programmes will vary in design and delivery model, and consequently local data collection will vary accordingly, we suggest that commissioner and provider might want to consider an economic assessment of the intervention, mapping the pathways of care being provided, and capturing patient experience data, as standardised measures.

**Recommendation 9: Consider opportunities for wider impacts.** This pilot has highlighted the potential for the breathlessness pathway to impact on other conditions outside of cardiology and respiratory services, potentially offering significant long-term returns on investment and addressing multiple commissioning priorities. We recommend that the full potential of this pathway be considered in future commissioning, with monitoring of patient outcomes devised and implemented accordingly, in order to demonstrate the full potential impact of the model. This may help with financing the pathway and indicate the data collection and evaluation requirements. Linked to this, it may be useful to explore the potential for other symptom-based pathways, given the evidence emerging from the breathlessness pilots.

**Recommendation 10: Providers should engage commissioning leads at the outset.** The pilot programme has demonstrated the short-term impacts that can emerge from this model of care, and its potential to achieve significant broader longer-term impacts. However, in order to influence commissioning decisions, commissioners must be fully aware of the models and their potential benefits. The pilot highlighted the importance of providers and commissioners developing and maintaining relationships, to ensure providers can be appropriately involved discussions regarding emerging learning, potential improvements and the sustainability of the service.

**Recommendation 11: Consider how the programme aligns with broader local programmes and priorities.** The pilots have all been sustained to varying degrees in all three pilot sites as a result of alignment with other local programmes. This is likely to be a critical success factor in future programmes, and we recommend that providers clearly demonstrate how activity to address breathlessness may help commissioners to achieve multiple objectives and aims.

**Recommendation 12: Ensure logistical considerations are fully explored in advance.** The pilots struggled in differing ways with addressing logistical issues, including staffing levels, accessing suitable venues, and ensuring smooth funding flows. These challenges are largely to be expected as inherent in pilot programmes with short term funding. However, we suggest that all aspects of logistics should be carefully considered in any service contract, to try to avoid these issues happening under commissioned services. Commissioners may usefully wish to request information regarding staffing, venues, funding flows etc. within service specifications.

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\(^2\) NICE, Chronic obstructive pulmonary disease in over 16s: diagnosis and management, June 2010
[https://www.nice.org.uk/guidance/cg101/chapter/1-guidance](https://www.nice.org.uk/guidance/cg101/chapter/1-guidance)
Introduction

This report has been prepared by the Office for Public Management (OPM) who were commissioned by NHS Improving Quality (NHS IQ) to undertake a summative evaluation of the breathlessness pilots running in three sites across England. This report presents the findings from the evaluation, exploring site-specific and programme wide findings, and their implications for future commissioning and activity aimed at tackling the symptoms of breathlessness.

Overview of the programme and pilots

NHS IQ\(^3\) was established to drive improvement across the NHS in England. Hosted by (and now subsumed within) NHS England, NHS IQ’s work was designed to meet the needs and challenges of the NHS and was closely aligned to the five domains of the NHS Outcomes Framework. By providing improvement and change expertise on the five big killers to prevent premature mortality, the Living Longer Lives team aligned their work with Domain One of the NHS Outcomes Framework.

In July 2014, NHS Improving Quality (NHS IQ) launched a national pilot programme to improve speed and accuracy of diagnosis in patients experiencing the symptom of breathlessness.

In order to overcome some of the immediate challenges to developing these changes to services, NHS IQ secured funding to support the testing of new models of care and changes to the breathlessness pathway. The breathlessness pilot was designed to also relate to the new models of care work referred to in the Five Year Forward View for the NHS.

Three pilot sites successfully applied for £15,000 of grant funding in order to test a variety of service developments. The pilot sites were all sited in different healthcare settings:

- Health First – a Community Interest Company providing breathlessness services covering Ashton, Leigh and Wigan (ALW).
- University Hospitals Leicester – a Foundation Teaching Trust covering Leicester, Leicestershire and Rutland (LLR).
- Wessex Academic Health Science Network - a respiratory improvement programme providing breathlessness services in the Wessex area.

**Programme Aim**

The programme was designed to improve the speed and accuracy of diagnosis of the cause(s) of breathlessness in patients experiencing breathlessness symptoms, by testing new models of symptom led care for patients experiencing breathlessness.

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\(^3\) As of 1\(^{st}\) November 2015, NHS Improving Quality ceased to exist in its own right, and improvement functions transferred into NHS England. The evaluation and programme have continued as originally planned, reporting to the Sustainable Improvement Team within NHS England.
Objectives of the breathlessness pilot

The objectives of the pilot programme were:

1. To test new models of care in various care settings.
2. To improve the outcomes of patients referred with breathlessness.
3. To encourage innovation in pilot sites to develop patient centred services.
4. To describe what a cohort of breathless patients is diagnosed with.
5. To test the feasibility of a one stop shop model of clinic for patients with breathlessness.
6. To develop business cases to help likeminded commissioners to commission a local breathlessness service in the future, including costings.
7. To develop case studies with real life patient and staff stories to assist with the spread of new breathlessness models into other areas.
8. To improve patient satisfaction with the breathlessness management plan.
9. To improve utilisation of respiratory kit in primary care e.g. Spirometers.
10. To inform the development of guidance on a national breathlessness pathway.

Overview of the evaluation

OPM was commissioned by NHS IQ in November 2015 to undertake a summative and formative evaluation of the breathlessness pilots. The evaluation ran until the NHS IQ funding for the pilots ended in 31 March 2016, and was designed to explore the following key questions:

- Did the pilots achieve their aims and objectives?
- What were the key success/ failure factors?
- Have the service succeeded in developing a model of care that can be spread to other areas?
- Is there a convincing commissioning business case for commissioners demonstrating value for money and improved outcomes?
- Which stakeholders have been engaged in the development of the new pathways?
- Are the new models sustainable?
- How important was clinical leadership and engagement in the success of the pilot?
- What was the impact of the programme on the experience of staff and stakeholders involved?
- What was the impact of the programme on service users’ (patients’ and/or carers’) experience and outcomes?
- What lessons can NHS England and the wider NHS learn from these pilots?
- What unexpected outcomes occurred as a result of the programme, either adverse or positive? Were there any unintended consequences? What were they? What impact did they have?
- Which measures for improvement can the programme take forward into the next stage of the work to adopt at a regional and a national level?
Evaluation methodology

The evaluation methodology is detailed below. For details of interviewees and documents reviewed, please see Appendix 4.

Project inception

OPM evaluation leads met with programme leads from NHS IQ in November 2015, to explore the evaluation aims, objectives and background insights in further detail. Following this meeting, OPM evaluation leads developed a succinct project initiation document for the evaluation, acting as a work-plan for the study and detailing some of the key considerations underpinning our approach.

National stakeholder interviews

OPM undertook initial scoping interviews with key stakeholders involved in the programme steering group, to understand the national policy landscape and strategic underpinnings of the programme, as well as their reflections on progress to date and key learning emerging.

Document review

OPM researchers undertook a review of programme and pilot site documentation provided by NHS IQ programme leads. This included the initial application forms completed by the three pilot sites and their interim findings PowerPoint presentations (November 2015). This review helped to inform our discussions with local project stakeholders and helped us to identify emerging learning and impact evidence.

Scoping meetings with pilot site project leads

Following project inception, OPM developed a succinct briefing sheet which we then emailed out to all pilot site project leads, to inform them about the study and seek their participation in an initial interview or meeting. OPM met with project leads from the ALW and Wessex pilot sites, and carried out a telephone interview with the lead from the LLR site.

Following these initial calls and meetings, site leads provided OPM with the names and contact details for other stakeholders involved in the pilots at local level.

Fieldwork with key local stakeholders

OPM undertook focus groups, interviews and discussions with key stakeholders involved in the pilots. This included patients, GPs, Consultants, Respiratory Nurses, Project Coordinators and others involved in the local pilot sites either directly or indirectly.

The fieldwork explored key reflections on the progress, activities and focus of the pilots, the key learning emerging, and the potential to spread the models more widely, as well as the potential commissioning case underpinning any sustainability model.

Analysis and reporting

OPM undertook interim analysis and reporting in early February 2016, to share emerging insights with programme leads at national and pilot site level. Findings were presented to programme steering group members for exploration and discussion, and priorities were agreed for the final stages of data collection.
OPM developed eye-catching written case studies summarising the work and impact of the three pilot sites, which have been appended to this report and can also be read as stand-alone documents (see Appendix 1-3). The case studies have been validated by and provided to each of the site leads, to help them to showcase the impacts emerging as a result of their work and the key lessons learnt.

The final report was prepared for NHS IQ and wider audiences to review in late March 2016, and should be read in conjunction with the accompanying PowerPoint slide-pack of the key evaluation findings.

Caveats to the findings

When reviewing the findings presented in this report, it is important to keep in mind the following key considerations.

- The evaluation was delivered over a relatively short timescale (four months in total from inception to completion); this has meant that it has not been possible for us to undertake follow up data collection or to include all potentially relevant stakeholders within the evaluation fieldwork.

- Linked to the point above, the evaluation was commissioned part-way through the programme and commenced when delivery was well underway. This meant that OPM could not influence the data being collected at pilot site (or programme) level, and we were not able to capture baseline data or track changes over time via primary data collection.

- The two points above have led to a heavy reliance on secondary data and anecdotal reports in generating many of the findings presented in this report. OPM has not been able to independently verify reports provided by stakeholders involved in the sites at a local level, or to capture independent data regarding the impact on diagnosis, waiting times or treatments being prescribed. OPM was only able to interview patients from the ALW pilot site; all other patient experience data has been collected and provided to us by site leads.

- Many of the impacts for patients accessing the services will take months, if not years, to be realised. Likewise, many of the system level impacts will also not yet have been realised. For example, improved management of a condition may have far-reaching impacts for both that individual and the healthcare system, but it has not been possible to assess the full extent of the impacts achieved within the evaluation timescales.
Key findings at pilot site level

This section of the report describes the local activity that took place within each pilot site, and explores the findings and emerging learning from each of the pilot site areas. This section is followed by discussion of the key findings at programme level, exploring commonalities and distinctive factors, impacts and learning across the sites.

Leicester, Leicestershire and Rutland

Overview of the pilot

The overarching aim of the pilot in LLR was ‘to streamline and co-ordinate care to achieve early diagnosis and early treatment for patients suffering from non-acute breathlessness’.

The approach involved designing and piloting a specialist-led diagnostic clinic that could handle both cardiac and respiratory causes of breathlessness, providing a ‘one-stop diagnostic shop’ delivered in a secondary care setting for patients referred from primary care.

Background

The pilot set out to address a set of contextual factors and challenges relating to diagnosing, treating and managing breathlessness. Patients present with symptoms, not ‘diagnoses’, but there is a lack of symptom-based services and interventions. Following presentation, there are typically lengthy delays in diagnosis in both primary and secondary care, with an 18 week wait for clinic appointments and a further 18 week wait for some therapies in the LLR area. In addition, primary care referral to either respiratory or cardiology services can often be incorrect, leading to ‘yo-yoing’ between specialities in an attempt to provide the correct diagnosis and treatment. Linked to this, breathlessness is often multi-factorial; however, co-morbidity is frequently undetected in disease-specific services.

This is compounded by a lack of knowledge across primary and secondary care regarding existing services for people experiencing breathlessness, combined with inconsistency in available services across the locality. The pilot site evidence indicated that insufficient investigations were typically undertaken in primary care prior to referral to secondary care, and that there was silo-working between primary and secondary care (respiratory and cardiology specialties).
Activities

The pilot was situated within a wider LLR Better Care Together\(^4\) programme (long-term conditions work-stream) which is focused on achieving integrated care. The pilot was initiated following a Listening into Action\(^5\) event with a range of stakeholders.

The pilot in LLR has been implemented in two phases:

- **Phase one:** Implementation of a multi-disciplinary specialist-led diagnostic clinic for breathlessness in secondary care at Glenfield Hospital on alternate Friday afternoons.
- **Phase two:** Implementation of the breathlessness pathway in primary care via an integrated care fellowship, funded through Health Education East Midlands (HEEM). Phase two remains in development.

Alongside these initiatives work has taken place to improve the links with lifestyle and behaviour change support available in community settings.

**Figure 1 Breathlessness pathway implementation**

**Phase 1**


**Phase 2**

Implementation of a breathlessness pathway in primary care.

Links with lifestyle and behaviour change support.

**Patient journey in phase one**

In phase one, referrals did not take place directly from primary care to the breathlessness clinic. Instead, referrals to outpatient respiratory and cardiology departments were screened by clinicians, in order to identify patients with breathlessness to be invited in to the breathlessness clinic.

The benefits arising from this approach to referral were identified by local stakeholders as:

- Patients were appropriately referred to the clinic.
- It provided an opportunity to test out the one-stop approach.
- It allowed for a faster set-up of the clinic, avoiding reliance on generating awareness of the clinic amongst GPs.

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\(^4\) Better Care Together: http://www.bettercareleicester.nhs.uk/

\(^5\) Listening into Action® approach to employee engagement: http://www.listeningintoaction.co.uk/index.php
Circumnavigating any reluctance from GPs to start referring in to a clinic in a pilot phase, avoiding concerns that the pilot may not continue or prove to be effective.

Circumnavigating any confusing or conflicting messages relating to the tariff for referrals. In the pilot phase the clinic came under the same tariff as the usual referral route, but once the service is commissioned it is expected to attract a higher tariff, due to the requirement to involve two specialists and have additional tests completed.

At the breathlessness clinic patients would see one or both of the Specialist Consultants; have all diagnostic and investigative tests carried out; and see a Respiratory Physiotherapist on the same day. The aim of the one-stop diagnostic approach was that patients would leave with a diagnosis and treatment or management plan for their symptoms.

Figure 2 Breathlessness pathway in secondary care

Phase two:
Phase two is now being implemented to introduce the symptom-based pathway in primary care settings. This phase aims to provide tools and education to GPs to help diagnose breathlessness, through developing a document that includes:

- An outline of the breathlessness pathway.
- Explanation of how to use the pathway.
- Details of the tests and investigations to request.
- Tips and links to further advice.

If after following this primary care pathway the diagnosis is still not clear, then the GP would refer into the secondary care breathlessness clinic. An electronic referral form is being developed for this purpose.
Achievement of the aims and objectives

The objectives of the pilot as laid out in the application for funding are provided below alongside a status summary for each which has been drawn from the interview data.

Table 1: Progress against the aims and objectives of the LLR pilot

<table>
<thead>
<tr>
<th>Aim</th>
<th>Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>To develop a ‘breathlessness’ clinic with same day investigations, testing the feasibility of a ‘one stop’ approach.</td>
<td>The secondary care based breathlessness clinic has been set up and piloted to include Respiratory and Cardiology Consultants, respiratory physiotherapy, and same-day investigations and tests.</td>
</tr>
<tr>
<td>To develop a breathlessness pathway for referrals from primary care</td>
<td>This remains ongoing as part of phase 2 of the pilot; early preparatory work has commenced.</td>
</tr>
<tr>
<td>For the breathlessness pathway to include integration between primary care, the breathlessness clinic and secondary care.</td>
<td>This remains underway as part of phase 2 of the pilot; early preparatory work has commenced and the Listening into Action exercise paved the way for this.</td>
</tr>
<tr>
<td>To explore the potential for any of the interventions to be delivered on a generic basis such as exercise rehabilitation.</td>
<td>There is a desire to move the clinic from Glenfield Hospital to NCSEM-EM (National Centre for Sport and Exercise Medicine - East Midlands) to link with generic exercise programmes. However there have been challenges with this due to concerns from staff about having patients at the centre, since it is not a medical setting. A generic exercise rehabilitation programme has been set up at the NCSEM-EM, and the clinic leads plan to refer the majority of new patients there (as long as this is geographically reasonable).</td>
</tr>
<tr>
<td>To test the value added by integrating public health interventions (e.g. lifestyle, activity) in to the breathlessness clinic format</td>
<td>Interviewees referred to this as work that still needs to be incorporated into the pathway e.g. smoking cessation, pulmonary rehabilitation, exercise.</td>
</tr>
</tbody>
</table>

Clinical outcomes for patients

A report from UHL NHS Trust\(^6\) outlines data relating to the throughput and outcomes of the breathlessness clinic. The information below is from that report and the original dataset has not been reviewed or analysed by OPM Group.

\(^6\) UHL NHS Trust ‘Breathlessness’ project report 2015/16
In total, 54 new cardiorespiratory patients were seen over the course of six months across nine clinics. Of these, 35 had been referred to respiratory medicine and 19 had been referred to cardiology. Six patients were seen by both specialists at the same clinic session and all 54 patients were discussed in the multi-disciplinary team (MDT) meeting with both Consultants.

Table 2 below compares the timescales from referral to diagnosis for the breathlessness clinic to the other existing single-specialty clinics. Key outcomes listed in the report include:

- **26 patients (48%) were discharged back to the GP after the first visit only.**
- **21 patients (39%) were discharged back to GP after a single follow up** in the breathlessness clinic.
- **1 patient was seen twice in the breathlessness clinic** (suspected pulmonary hypertension).
- **6 patients were referred to either respiratory (n=3) or cardiology (n=3) outpatients for on-going follow up; diagnoses were interstitial lung disease (n=2), severe obstructive sleep apnea syndrome (OSAS) (n=1), primary pulmonary hypertension vs heart failure with preserved ejection fraction (HFpEF) (n=1), severe valvular heart disease (n=2).**
- **2 patients who were invited did not attend the clinic (DNA, approximately 5%).**
- **For 16 patients (29.6%), further outpatient referrals to the other speciality were avoided by having the MDT approach.**
- **10 patients (18.5%) had other conditions diagnosed due to systematically undertaking simple investigations for breathlessness rather than clinician preference.**
- **18.5% could have been diagnosed in primary care** (judged to need simple investigations only, with no complex co-morbidity).
- **A third of patients needed specialist tests requiring a secondary care setting.**
- **A review by a Community Cardiologist and Respiratory Physician would have been possible in nearly two-thirds rather than a secondary care setting being essential** (as long as the ‘panel of investigations’ are available\(^7\)).
- **The clinic achieved a significantly earlier diagnosis** compared to historical data.
- **Earlier physiotherapy** was achieved by having a Physiotherapist present.

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\(^7\) The ‘usual pathway’ would involve the clinician choosing the most appropriate investigations themselves. Under the pilot pathway, typically on arrival to clinic patients would have CXR and Spirometry for respiratory, and ECG BNP +/- Echo for cardiology. Haemoglobin would also typically be performance. HADS, Nijmegan Q and activity questionnaire are rarely used.
### Table 2 Comparison of time to diagnosis between the combined diagnostic breathlessness clinic and the existing clinics

<table>
<thead>
<tr>
<th></th>
<th>Previous Cardiology and Respiratory Clinics</th>
<th>Breathlessness clinic</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time to be seen (weeks)</td>
<td>12.8 [8.3]</td>
<td>5.0 [2.9]</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Time to diagnosis (weeks)</td>
<td>16 [7]</td>
<td>5.1 [8.0]</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Time to physio (weeks)</td>
<td>19 [13]</td>
<td>&lt;2 weeks</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>New to follow up ratio</td>
<td>2:10</td>
<td>8:2</td>
<td>NA</td>
</tr>
</tbody>
</table>

**Number of visits**

<table>
<thead>
<tr>
<th></th>
<th>Previous Cardiology and Respiratory Clinics</th>
<th>Breathlessness clinic</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>29%*</td>
<td>48%</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>39%*</td>
<td>39%</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>26%*</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>6%</td>
<td>No data available</td>
<td></td>
</tr>
</tbody>
</table>

Numbers in square brackets = standard deviation.

"It is not known whether these patients have been discharged back to the GP definitively. This describes the number of visits patients have received.

Reflecting the data outlined above, local stakeholders recognised that patients received a **diagnosis more quickly** than through previous routes, and that the need for follow-up visits has reduced. There was also a sense that the value of taking a holistic approach to the symptom of breathlessness lies in being able to **address root causes rather than just treating the symptoms**.

"One thing that has gone particularly well is how quickly the patients are processed. It has reduced the number of re-visits for further investigations, and streamlined the whole process. It has minimised any potential delays in diagnosing and treating the patients."

Principal Clinical Physiologist (Respiratory)

The example overleaf illustrates how the pathway can have a positive impact on outcomes for patients, the length of the diagnostic pathway, and the time involved in appointments.

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8 Table from UHL NHS Trust ‘Breathlessness’ project report 2015/16
Case study example

“We came across a patient who was sent across from primary care with suspicion of heart failure. The patient was sent to the general cardiology clinic, but we picked the case up for the breathlessness clinic because they were breathless. In the interim, a CT scan was requested, and when we saw the images we saw that it wasn’t heart failure, it was interstitial lung disease. So we saw the patient and they were treated with steroids from that first day.

“Imagine if the patient had gone through the usual referral system, they would have been to the wrong specialist, referred back to the GP, then referred back to respiratory, and the pathway would have taken months. In fact, the patient was treated within just one month of referral.”

Respiratory Medicine - Clinical Fellow in Integrated Care

Patient experiences

UHL NHS Trust surveyed 10 patients who attended the breathlessness clinic, and reported that all 10 respondents rated the care as excellent and indicated that they were treated with respect and dignity. All patients cited that the main reason for their visit had been dealt with to their satisfaction, and that they would all recommend the service to family and friends.

The remainder of the information in this section relates to clinician perspectives of patient experience. We were unable to speak to patients involved in the LLR pilot directly.

The main benefit of a symptom-based diagnostic clinic for patients was perceived to be that patients would see specialists and undergo the necessary tests all on the same day, resulting in a quicker diagnosis and/or answers to their questions. Interviewees described a number of knock-on benefits to patients as a result of the one-stop approach:

- Patients have more confidence in their diagnosis and treatment because they can see they are being treated by a team working together.
- Patients are better able to understand and accept their diagnosis because they receive consistent messages from different professionals on the same day.
- If patients misinterpret the information they are given, this is picked up on the same day during conversations with different clinicians.
- Patients receive a more specific symptom-focused approach.
- Patients receive care from clinicians with a keen interest in tackling breathlessness as a symptom.
- Patients feel better cared for because they have not been on a long waiting list or passed between specialists via cross-specialty referrals.

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9 Summary taken from UHL NHS Trust ‘Breathlessness’ project report 2015/16. Actual data and the responses to other questions in the questionnaire have not seen by OPM Group.
- Patients receive a more holistic picture of their symptoms, causes and options for treatment and management, including both clinical and lifestyle factors.

- Patients are more compliant with treatment and management options because they feel more positive about the experience and confident in the diagnosis.

- Behaviour change is achieved, with patients being more likely to take on board messages regarding lifestyle factors as a result of having their needs assessed holistically and causes of their breathlessness explained fully.

Patient perception was seen to be an important factor in the successful treatment and management of breathlessness following a diagnosis, and that perception can be shaped by their experience of the diagnosis process.

“The problem with giving a diagnosis is perception. If somebody is seen at an early stage and is given an answer they understand and accept it’s a lot easier to give that answer, than it is to have somebody thinking it’s their heart for months and months but when they finally see the Heart Specialist they’re told they’re actually just not very fit – that’s a much more challenging consultation. It’s much better for the patient to get the early answer rather than have their perception led astray for a long period.”

Consultant Cardiologist

The significance of reducing the number of visits to hospital is also important in relation to the fact that patients with breathlessness are often elderly, frail, or have mobility issues, and consequently reducing the number of times they have to go to hospital appointments is particularly beneficial. There was a perception that patients preferred attending the clinic for a long day of appointments rather than attending multiple shorter appointments over a period of time.

These benefits in terms of patient experience can also lead to improved clinical outcomes (through reducing the time to diagnosis and improving compliance with treatment and management) and direct cost savings (through time saved by not seeing the patients on multiple occasions). For example, in the case of respiratory physiotherapy:

“With the patients who are referred via the normal process of waiting on our waiting list, by the time they get to us that’s another 3 months later and they’ve often forgotten what the Consultants said, or misinterpreted what has been said. Compliance is usually not great and knowledge is not great so we end up spending longer with those patients than when we see them in the breathlessness clinic. Also, we’re only seeing patients from the breathlessness clinic two or three times but for those who come via the waiting list we often see them for over a year.”

Senior Respiratory Physiotherapist

**Unintended outcomes**

The unintended outcomes include:

- Increased opportunities for learning across primary and secondary care, and a receptiveness to this.

- Recognition of the role of patient perception of their own condition and patient experience of the diagnosis pathway in determining compliance with treatment.
A holistic approach can tackle the root causes of other conditions, as well as treating the presenting symptom.

**Improvements needed**

Based on the identified success factors and challenges, there are three key areas for development for this pilot, all of which are currently underway:

**Funding**

The two priorities relating to funding are to clear funding blockages that currently exist in the system, and to present a case for commissioning the clinic on an on-going basis.

**Implementing the pathway in primary care**

Implementing the breathlessness pathway in primary care is in progress and aims to address some of the issues identified around patients being referred without sufficient prior investigations by involving GPs in creating an effective pathway and supporting them to develop their knowledge and skills in diagnosing and treating breathlessness.

**Improving links with lifestyle and behaviour change support**

There is a desire to improve links with lifestyle and behaviour change support services such as smoking cessation, pulmonary rehabilitation, exercise programmes, obesity management, and relaxation classes, some of which could be incorporated within the clinic and some of which patients could be referred on to for follow-up support.

“The clinic is embedded in a wider exercise in both diagnosis and prevention. You don’t want to think of this on its own because it will have less impact; it is part of a wider change in how this problem is managed.”

- Consultant Respiratory Physician and Secondary Care Clinical Lead of the Long Term Conditions work stream of the LLR Better Care Together programme

**The commissioning case, sustainability and potential for the model to be spread**

The patient pathway to diagnosis is shorter and fewer follow-up appointments are required for patients that are seen at the breathlessness clinic, compared to historical data from the standard single-specialty routes. Those involved in running the clinic also feel very positive about the clinical outcomes, benefits for patients, cost efficiencies, and opportunity for improved MDT working.

However due to the relatively small dataset of 54 patients there is also a need to be cautious about extrapolating these benefits.

Funding is critical for sustaining the model. The team are presenting a commissioning case locally and hope to hear a decision by the end of March 2016.

The other key factors for sustainability of the MDT approach and symptom-based pathway relate to implementing the pathway within primary care and improving links to lifestyle and behaviour change support in the community.

“To be sustainable we need a move away from the very segmented specialty approach. There is a need to work across and find different ways for teams to work together, not just in
secondary care but also involving community specialists in things like referring. We need to look at innovative ways of working in general practice and seeing everything as more of a flexible model.”

Service Improvement Manager for Long Term Conditions, CCG

The wider commissioning environment can also have a significant impact on the design and success of a pilot. In the case of Leicester, Leicestershire and Rutland, the different CCGs work together and services are commissioned across the CCGs based on an overall plan. The aim is to avoid duplication and ensure nothing gets missed because the clinical leadership team has oversight across all the CCGs. In the context of this coordinated commissioning environment, the breathlessness clinic has been effective, but in another scenario lacking this oversight and coordination there could be problems with identifying the patients who are eligible for the clinic:

“You also need the right kind of commissioning environment for it to work. It works here because we commission across Leicester and Leicestershire across different CCGs, but if you have it just in one area you can get into a postcode lottery situation with confusion about who is eligible, and it can be quite unfair. The screening process becomes more complicated than the service itself in that case.”

Service Improvement Manager for Long Term Conditions
Wessex

Background

The Wessex Academic Health Science Network (AHSN) decided to apply to take part in the programme after attending a breathlessness symposium hosted by NHS IQ. Working with their advisory group (composed of a range of local healthcare stakeholders), Wessex ASHN took the strategic lead in developing a proposal, which was originally planned as a strategic pilot to develop a community triaging model to create pathways for patients experiencing breathlessness. The original plan was for the model to have been rolled out to CCGs outside of the pilot timeline, for implementation and testing.

However, the Wessex ASHN project team and clinical leads decided to take a more proactive approach to both introduce the strategy and roll-out the delivery model within the pilot timeframe. This approach was designed to allow them to test effective pathways for patients with breathlessness and attract in-kind resources from secondary and primary care.

Activities

A Respiratory Nurse, Clinical Lead and several Consultants led the delivery of the pilot out of three GP surgeries across Wessex: Badgerswood, Wickham and The Grange. Badgerswood and Wickham were part of the first phase of delivery; both have similar population sizes (approx. 12,500) and composition of patient population. A few months later (phase two) the Grange Surgery was added as a pilot site, offering a different mix of demographics and local factors (i.e. population of 6000, located in a valley with heavy pollen and the predicted highest asthma rates in the country).

The pilot delivery model was designed to provide a ‘one-stop shop’ for patients exhibiting breathlessness symptoms but for whom no diagnosis has been given. Each clinic ran for one day in Badgerswood and Wickham and for two days in The Grange. A follow-up patient ‘mentorship’ clinic was held at each site one month later. GP surgeries were chosen as partners because of their interest in taking part, but also because the pilot clinics were reliant on in-kind resources coming from secondary teams at the Queen Alexandra Hospital in Portsmouth, surgeries needed to be within a 30-minute drive from the hospital.

The pilot model in Wessex was set-up to provide opportunities for education and capacity building both amongst patients and practice staff. On the clinic days the patients met with the Lead Respiratory Nurse to discuss their diagnosis, to build understanding around how to best manage it going forward. Patients were then invited to a mentorship clinic one month on to review compliance with their treatment, evaluate the impact of the treatment so far, and ensure the patients felt confident managing the condition.
The pilot integrated a bespoke education approach allowing Nurses to follow patients through the pathway and ask questions of the specialists as they went through the diagnosis process. The specialist team also led a MDT lunchtime training session on the topic of breathlessness. After the clinic, Clinicians came together again for a MDT meeting to discuss each patient’s diagnosis and the decision making, to promote better understanding and future good practice.

“As part of the model we wanted to not only improve patient care and diagnosis but also develop education and education for the practice we were in – so we were leaving a legacy with them.”

Respiratory Nurse Lead

The delivery model consists of three key stages: identifying patients to take part; diagnosing patients on the day; and following up with patients to ensure treatment is understood and adopted.

Stage 1 – Identifying patients to take part

Before the clinic, breathless patients without existing appropriate diagnoses were identified using GRASP\(^{10}\) (a proactive case finding tool developed by NHS IQ that scans practice records for certain codes and symptoms, that works with any GP system to scan practice records), and the equivalent asthma audit tool. Wessex ASHN decided to use the GRASP tool because:

- It is free for clinicians to use.
- It is perceived to be an easy to use tool.
- The GRASP tool could be left in the surgeries after the pilot and contribute to the pilot’s legacy.

Once GRASP had identified patients in each of the GP surgery locations, a manual filtering process was required by the Respiratory Nurse who prioritised ‘high-risk’ patients to take part based on how recent their

exacerbations were, the number of exacerbations they experience, and the overlap of their symptoms between COPD, asthma and heart failure.

Patients were then sent a letter by the pilot team (using each GP surgery’s letterhead) inviting them to take part in the pilot clinic and explaining the purpose. Before the clinic, the Respiratory Nurse and GP team telephoned the patients to ensure they understood the programme and to confirm their attendance.

A total of 19 patients attended out of 34 invited in phase one (Badgerswood and Wickham surgeries) and 23 patients of 35 invited in phase two (The Grange). Of those patients who could not attend, the reasons included prior commitment, post-surgery recovery, and booked holidays. The clinic had only two patients who did not attend after confirming, which is a clear success for the pilot since the DNA numbers are known to be high for respiratory appointments in both in primary and secondary care.

Staff thought the typically high rate of DNAs in respiratory care may be because of how intangible breathlessness can seem, at times acute, and being an internal issue to the body (out of sight, out of mind). Others thought the reduced DNA rate within the pilot may be based on the location of the appointment and how easy it was to access:

“I was surprised that all the patients turned up. At the clinics at the hospital we usually get a lot of patients who don’t come. I don’t know if it’s because we’re not in the practice and it’s too far to come.”

Specialist Clinical Team Member

Stage 2 – Diagnosing the patient

Patients were reviewed in a carousel-style clinic. This included:

- A 20-minute initial assessment by the Respiratory Nurse Specialist.
- A 20-minute assessment by a specialist Respiratory Physician (Consultant Respiratory Physician or GP/Academic with a special interest in respiratory), working alongside the clinical practice staff.
- A 20-minute follow up education session with the Respiratory Nurse Specialist.

On the day, Consultants led physiology assessments and various other testing if needed that would normally have required a secondary care referral (i.e. ECG, Spirometry, BNP for heart failure, blood pressure, skin prick testing):

“When the patients arrived, they had their lung functioning testing done with one of the physiologists (and could have allergy testing if needed), then they came in and saw me. And I had access to their GP records so I could see where we’d flagged them up as coming into the clinic – I could look back and see how many times they’d come in with breathlessness, what medications they had, if they had any infections, and see the whole history – that was really useful because we don’t have access to that in the hospitals.”

Specialist Clinical Team Member

All patients received a definitive diagnosis at the end of the one hour appointment with the exception of two patients who were sent onto secondary care because of the severe nature of their diseases (e.g. lung fibrosis).

“I saw the patients – they were all really receptive. A lot of them had been having symptoms and infections for a while. So it was bringing it all together with the tests that we could bring and
giving them the diagnosis. Most of them we gave a diagnosis to on the day. A couple had to come to hospital to have more detailed tests – we had a few more unusual diagnoses, lung fibrosis or [exposure to] asbestos that had to be brought to hospital. Profession Chauhan – the lead consultant – was there if I had any queries to support me from medical point of view."

Specialist Clinical Team Member

Once patients received a diagnosis, they would see the Lead Respiratory Nurse and receive through a self-management education session (i.e. for those diagnosed with asthma how to properly use inhalers, etc.). This session included education around what their diagnosis was and what it meant for them.

Stage 3 – Patient follow-up

Patients returned one month later for a follow-up ‘mentorship’ clinic run by the Lead Respiratory Nurse, designed to consolidate their learning and check on how they were improving – and escalate their treatment if they had not responded. Practice Nurses also attended this clinic so the patient was aware that their practice knew what was happening.

Difference of the pilot approach

The Wessex ASHN has run several pilots to address specific diseases, including an asthma project in 2014 and COPD clinic in 2015. The breathlessness pilot is the first time work is being done on this scale in Wessex focused on a symptom rather than being disease specific:

“I’m not aware of any other pilot where a specialist team have proactively sought patients from those three disease areas and then deployed a specialist team into those areas.”

ASHN Programme Lead

Past pilots have followed a similar model of bringing secondary care into community based GP settings, but this was always for patients with a known diagnosis that had markers of being high risk. The breathlessness pilot built on this model to try to collaborate more with GPs and provide care closer to patients’ homes.

Wessex ASHN used the GRASP tool previously for identifying cases in past pilots, but breathlessness was a new experience because of its unspecific nature.

The secondary team were able to do a lot of tests in the primary care setting that would normally not be possible because of expertise and equipment available.

“We could bring specialist testing to the patient rather than the patient having to trek up to the hospital. The practices are quite remote and rural, quite a long way from the nearest hospital (half hour drive).”

Specialist Clinical Team Member

The team also introduced innovative tools directly to patients to aid with the self-management of their conditions. For example, patients with asthma were given an insertable mouthpiece that makes a harmonica noise to indicate if the medicine is reaching the lungs correctly.
“In the GP surgery – there’s been lots of learning. You’re just more aware of approaches to take to breathlessness symptoms. We’ve been taught better procedures, like inhaler techniques. That’s something quite big really because if patients aren’t taking they’re inhaler properly they aren’t getting their medication. I say to them it’s like being given a pill and then throwing it down the sink – if you’re not taking it properly then you’re not getting it to the right area.”

GP Practice

Achievement of the aims and objectives

The pilot in Wessex combined a mentorship model with new care innovations and relationship building amongst primary and secondary care. This approach has been highly successful in meeting NHS England’s aim to improve the speed and accuracy of diagnosis of the cause(s) of breathlessness, and in improving patient satisfaction with the breathlessness management plan.

The Wessex team focused on proactively finding and diagnosing ‘at-risk’ patients with symptoms of breathlessness. The high volume of patients with undiagnosed respiratory symptoms highlights the unmet need of patients with undiagnosed breathlessness in community settings – a need that this pilot model began to address. The pilot acted as a trailblazer in setting out a successful model that improves patient pathways for symptoms that are not disease specific; previous pilots have focused on known respiratory and cardiac diseases.

The pilot offering a one-stop clinical review locally has enabled patients to receive a definitive diagnosis on the day alongside support in understanding their condition and how to effectively manage it. Many of the patients had comorbidities, and the most common diagnosis given was asthma.

Clinical outcomes

Seven of the 42 patients diagnosed were referred to hospital because of the severity of their condition – for example arising due to exposure to asbestos, or occupational asthma. In some cases patients with very serious diseases were identified that may not have been picked up otherwise.

In the 6 months following the pilot clinic, there was a reduction in the number of exacerbations amongst patients who attended by 93% and a decrease in visits to the emergency department or hospitalisations by 100%.

The pilot has established a condensed and focused model for improving patient outcomes by offering high-quality diagnosis and implementation of self-management plans. Patients attended a follow-up ‘mentorship’ clinic one month after their diagnosis to discuss their experiences in the interim and ensure they were complying with treatment and managing their condition. Of those patients who attended, 70% were compliant with treatment and 96% felt more confident managing their breathlessness symptoms.
Case study example

“There was one gentleman who had recently been bereaved. He had lost his wife and was housebound with a number of mental and physical issues. He was terribly breathless and didn’t go out. After getting the diagnosis, within the month his whole life had completely changed. He’s now walking to the shops; he can walk without feeling breathlessness. He’s listening to the radio and now singing every day. It’s a transformation from someone who was housebound and very tearful when we first met him, to now where he looked happy and was smiling and grateful. The impact is clear he is now mentally and physically well. I had these types of stories throughout the day.”

Respiratory Nurse Lead

Patient experiences

Patients felt reassured having their symptoms taken seriously and seeing that their primary and secondary care teams were working together with all the information available.

“I've seen a couple of letters that have come through – from some of the patients, who had symptoms, and we started the medication and their symptoms have resolved completely. The time we spent and the tests we did were reassuring for the patients when we were able to tell them the diagnosis. And they felt that we had done all the tests and reached the diagnosis with all the information we had. So the patients found it a positive experience. They also appreciated seeing the specialist team with their own GP and practice nurses – they then knew the GP surgery was involved and understood what was going on.”

Specialist Clinical Team Member

The one-stop clinic is a helpful way to diagnose and treat breathlessness. Patients were able to receive a quick and accurate diagnosis, and receiving a definitive diagnosis positively impacted on patients' mental and physical health. Patients also spoke about the positive effect the clinic had on their quality of life, feeling relief and reassurance in understanding their symptoms and confidence in self-managing.

In a one-stop shop setting, the Wessex pilot was also able to offer patient education to understand why the doctor had diagnosed them with the condition and support with self-management.

Feedback from patients was overwhelmingly positive from all the pilot clinics both in terms of patient experience of the clinic and interventions made. Patients spoke about the positive impact the diagnosis and self-managing support had on their quality of life, symptoms and well-being.

Survey results revealed that 100% of patients were satisfied with their experience, 70% had good compliance with treatment, and 96% felt confident managing their breathing symptoms post clinic.
“We did a lot of assessment of patient experience in clinics, and 100% appreciated the experience. They liked the idea that specialists were coming and helping their GPs look after them, they appreciated that after one clinic a lot of them were going away with a diagnosis and a cause of their symptoms, and that they were having it taken seriously. We captured the feedback with a mix of quantitative and qualitative – some semi-structured interviews and questionnaires.”

Specialist Clinical Team Member

Embedding secondary care expertise and testing in primary care brought the best of both worlds to the patient. Working alongside GPs, the specialist respiratory team was able to access full patient records and gain an in-depth understanding of the patient’s history. This allowed the team to give the patient a more holistic assessment of the cause of breathlessness symptoms, and assign a bespoke management plan based on the patient’s condition and history.

“How having the qualified people on site to look at you as a whole – and they have access to clinical records from the clinicians here so you get a holistic approach to the patients’ wellbeing. From that point of view, it has all sorts of benefits – some of them regarding the logistics, and some of them from the patient care point of view.”

GP Practice

Patients who took part in the pilot were left with the reassurance of a definite diagnosis, or a plan of action of what they needed with support put in place. The specialist respiratory team spent up to one hour with each patient undertaking the necessary testing and analysis to ensure an accurate, efficient and quality diagnosis was assigned.

“The numbers were small but all 19 patients had a formal diagnosis and then could get on with life to manage their diagnosis.”

ASHN Programme Lead

For many of the patients who took part in the pilot clinic, their symptoms had greatly improved or resolved completely after starting treatment.

Suggested improvements

Limited pilot resources and funding meant only ‘high-risk’ patients could be seen. Stakeholders felt that the limited scope given by NHSIQ stifled the clinic’s potential.

“We’d hoped to do more work than we were able but with the amount of funding we were very restricted. The way we set up the project was to use some online computer tools to try to identify people with codes or symptoms who didn’t necessarily have a diagnosis. Because of the small amount of funding we were only able to take a very small number of people to look at. We’re currently looking at a follow-on project where we’re looking at a bigger picture but it would have been good to have done that originally.”

Specialist Clinical Team Member

The Wessex pilot could have improved at meeting the objective of developing case studies with real life patient and staff stories to assist with the spread of new breathlessness models into other areas.
The case for commissioning, potential for the model to be spread, and sustainability

The model adopted by Wessex offers the potential for both short and long-term savings for NHS England:

- In the short-term, calculations done by the Wessex ASHN reveal that the pilot clinics cost £142 per patient to run (excluding in-kind contributions), compared with approximately £241 tariff for cardiac and respiratory outpatient referral appointments.

- There may also be longer-term savings in terms of improving patient self-management thereby avoiding exacerbations and improving patient quality of life (mental and physical health). This also links with potential savings and improved quality of life as a result of reduced emergency admissions to secondary care.

The Wessex ASHN and its local health partners are considering how best to adopt and spread the work. They are currently launching MISSION ABC, which makes a case for expanding this pilot model to offer a ‘one-stop shop’ in Asthma, Breathlessness and COPD. They also see a potential for this model to address other diseases such as diabetes, which can also be linked to breathlessness symptoms. There has been widespread interest from CCGs in adopting the model, so the Wessex ASHN is working to strengthen the commissioning case and encourage CCGs to take up and test the approach.

Although the case finding tool identified very different numbers in phase one and two based on contextual factors, the model produced consistent patient outcomes in both phases – positively impacting quality of life by improving the speed, accuracy and quality of diagnosis and treatment. As the pilot progressed, the specialist team became more confident and familiar with the clinic process, enabling the team to more effectively gauge the appointment timings and open up more time to engage with the local practice staff.

The model has already attracted widespread interest from GP practices across Wessex, and the Wessex ASHN believes the pilot offers an easy off the shelf approach that could be spread. To adopt the model would involve: running the GRASP case finding tool; looking at the different parameters and having someone with the clinical acumen to exclude those patients who had been diagnosed with other diseases that explain symptoms (i.e. thyroid, cancer, etc.); and finally delivering the one day clinic requiring a specialist clinical delivery including a Respiratory Consultant, an expert Respiratory Nurse, Biomedical Scientist, Specialist Registrars and physiologists with an interest in respiratory medicine. Ideally cardiac consultants are also aware of the project and on call to assist.

If spread, the stakeholders exploring the model would be able to build on the learning from the pilot by adopting the most efficient timings for effective diagnosis and ensuring the maximum number of patients could be seen. For consistency and quality of diagnosis, it would also be important to understand the limitations of the GRASP case finding tool as depending on the codes assigned by GPs, which can vary depending on area and expertise. Going forward, the team would need to consider how to encourage consistency of approach amongst primary care physicians, including coding symptoms in similar ways and following management protocols around breathlessness.

The model offers a route to early diagnosis and improving patient self-management of their breathlessness condition. These improvements have the potential to offer long-term savings reducing the number of exacerbations and advanced diagnosis.

“The pilot definitely reflects a more proactive approach to the traditional ‘let me sort something out when there’s a problem’. Being proactive in medicine is going to be much more important in the future, than reacting.”

Specialist Clinical Team Member
The pilot approach also prioritised opportunities for learning amongst both staff and patients. This builds capacity and knowledge in local GP surgeries so patients are likely to be more effectively diagnosed when they initially present with breathlessness symptoms, saving on referrals and offering a less stressful patient journey.

“I think by going out and doing the education side of things you hopefully have a knock on effect for the rest of the practice as well as for all the patients even if you haven’t seen them. Some people were given a diagnosis and they’re not actually going to get better, but by knowing what’s wrong with them that can often make things a lot easier and they can get the right support.”

Specialist Clinical Team Member

Through building in opportunities for primary care education, the model leaves a legacy of training and capacity building in GP practices, but it also allows GPs and practice nurses to know who the respiratory leads are in secondary care when they make referrals. In secondary care, having close working relationships with GP practices means if there are problems that arise with patients, the clinical leads have the rapport to be able to reach out and problem solve together.
Overview of the pilot

The pilot service in ALW involved reviewing primary care records to identify patients with symptoms of breathlessness who may benefit from diagnosis and review in a breathlessness clinic, involving secondary care cardiology and respiratory specialists undertaking tests in a primary care setting close to patients’ homes.

Figure 5: Overview of the Ashton, Leigh and Wigan area

Background

The pilot was originally designed in 2010 by Atherleigh Patient Focus (a practice based commissioning group) and implemented by Health First, a community interest company (CIC) operating in the North West of England. It was then commissioned by Wigan Borough CCG. Practice nurses and GPs identified a need for patients presenting with breathlessness to receive an accurate diagnosis as quickly as possible, and to have their needs looked at holistically, to identify the root cause of the symptoms and ensure the most appropriate treatment plan could be put in place. Patients had previously often been ‘passed around the system’, with different secondary care consultants and specialists carrying out diagnostic tests for discrete conditions, without assessing the potential causes of the patients’ breathlessness in full. Travelling can be difficult for this group of patients, as can attending multiple appointments on different days.

Activities

The pilot involved:

- **Integrated working** across primary and secondary care, with specialist Respiratory and Cardiology Consultants providing care in primary care settings for patients identified via proactive review of primary care records. Respiratory Nurses worked alongside Practice Nurses to undertake the reviews of patient records.

- **Consultant-led clinics held in primary care** on a weekly basis, rotating around different practices across the borough depending on patient referrals.

- An **overarching focus on early and accurate diagnosis**, including an enhanced review and diagnostic service which screened for heart failure, asthma, COPD and other causes of breathlessness; provided medication and treatment reviews; delivered lifestyle advice and self-management plans; and supported practice nurses to sustain the approach via a mentoring service.

- The service provided a **single ‘point of care’**, with patients accessing the clinic receiving BNP testing and results on the day, immediately followed by spirometry, echo-cardiograph, lifestyle and self-management advice.

- Follow up for patients with persistent symptoms, including follow up appointments in primary care and targeted seasonal advice for those identified as most at risk.

Desk-top guidance has been produced for GPs to assist with managing patients with COPD, whilst mentoring and guidance has been provided to practice nurses.

Figure 6: Overview of the breathlessness pathway in primary care, in Ashton, Leigh and Wigan

The NHS IQ pilot funding enabled the team to hire a B-type natriuretic peptide (BNP) testing machine for use in the weekly breathlessness clinics, to pay for a locum Physiologist to undertake echocardiographs in the clinic, and to roll-out the pilot across half of the local GP surgeries (33), increasing from a third of practices being covered under the previous existing scheme.
“The main USP is that it’s been about finding patients, not waiting for patients to be referred. We’ve proactively searched for patients, going into practices to gain their trust, working alongside practice teams to search their computer systems for patients with undiagnosed problems.”

Advanced Nurse Practitioner

The programme was initially developed by a Nurse Partner (Advance Nurse Practitioner) from a practice in the borough, working alongside GPs and respiratory leads.

**Patient experience**

The pilot in ALW impacted positively on patient experience, with the vast majority of patients who responded to a short self-completion survey issued by Health First rating their experience as ‘excellent’ or ‘very good’.

The findings from the survey are shown in Figure 5, below, and the headlines can be summarised as:

- 94% felt the clinician who provided their care was competent.
- 94% rated their overall experience as excellent or very good.
- 90% felt involved in planning their care.
- 91% felt their concerns (if they had any) were addressed.
- 92% felt they were treated with dignity and respect.

![Figure 7: Patient experience survey findings, Ashton, Leigh and Wigan breathlessness pilot](image)

(Base: 136 Patients who accessed the breathlessness clinic)

In addition to the secondary data provided by the Health First team regarding the clinics, OPM carried out short telephone interviews with two patients who had accessed the clinics. The patients were overwhelmingly positive about their experiences in the clinic, feeling that their needs had been met and that
they had been listened to. The patients were also grateful for the follow up appointments there were provided with within primary care settings, and for the time taken by the clinicians to explain their conditions.

**Case study example**

Patient A had a very positive experience using the breathlessness service. She found the staff very informative and was particularly positive about the way all her questions were answered in a clear and straightforward way; this helped her understand what was happening and reduced her anxiety.

- “I found out quite a few things I didn’t know regarding my complaint”
- “When I asked questions I was given a direct answer I could understand fully, which was very reassuring.”

The participant was also reassured by having check-ups scheduled every six months, and added that the service was quick. After diagnosis in the clinic, the prescribed medication made her feel much better and allowed her to resume her fairly active lifestyle. She could not think of anything that needed improving with the service.

- “I’m fine in myself now, I feel much better. I’m normally quite an active person and it was dragging me down quite a lot.”
- “It reassured me and my husband that I now know what I’m dealing with, and that lots of people have it. It took away the worry factor; you think all sorts, especially when it’s a chest problem.”

Clinicians involved in delivering the pilot reported that it had a positive impact on patient experience, increasing patients’ levels of knowledge and confidence in managing their condition, and ensuring that patients feel their needs have been considered holistically. In addition, delivering the service in the patient’s usual primary care setting is also thought to improve their experience, by minimising travel times and helping the patient to feel more familiar with their surroundings during diagnosis.

- “I see the patients in their usual GP surgery. They feel more confident, less panicky about their condition afterwards. They really love the service. They feel at ease.”

  Consultant in Respiratory Medicine

In line with the findings from the LLR site, patients have good compliance with their treatment plan and the advice provided.
Clinical outcomes

The ALW pilot reported both anecdotal impacts on individual patients as well as changes in the numbers of patients diagnosed with heart failure, asthma and COPD in participating practices. The data provided to us as part of the evaluation focused heavily on diagnoses and prevalence amongst patients going through the pathway. For example, prevalence data collected by the pilot leads\(^\text{12}\) indicates that:

- One practice that joined the pilot in 2014 increased the number of patients on the asthma register from 56 to 275 over a ten-month period (391.07% increase).
- All practices except one recorded an increase in patients with heart failure over the same ten-month period since joining the pilot.
- Those who had been on the pilot for the full five-year period had a mean average increase in the number of patients with heart failure of just over 40%.
- All but one of the practices on the five year pilot had an increase in patients on the COPD register, with a mean average increase of 37.3%.

When the BNP-testing results are considered, individual patient-level data regarding 38 patients who experienced the BNP-testing pathway reveals that:

- Spirometry results revealed that eleven of the 38 had a mild or moderate obstruction (29%), whilst five had a severe or very severe obstruction (13%).
- The vast majority had high Body Mass Index (BMI), with the mean average across the cohort being 31.7 (classed as ‘obese’).
- Only two of the patients had a BMI in the ‘healthy’ range (18.5 to 25), with the remainder all being classed as overweight, obese or morbidly obese.
- Seven of the 38 patients were current smokers (18%); 22 were ex-smokers (58%), and 9 had never smoked (24%).
- Eight of the 38 patients who received BNP-testing were provided with obesity as the sole or joint cause of their breathlessness (22%), eight were diagnosed with new or worsening COPD (22%), whilst seven had newly diagnosed, worsening or poorly managed asthma (18%).
- One patient was diagnosed with suspected lung cancer, one was referred for further cardiology tests whilst another was referred to the Respiratory Consultant.

There has been increased diagnosis of heart failure as a result of the pilot. One practice increased the number of patients diagnosed as experiencing heart failure from 119 to 222 over a 10-month period after joining the pilot (an 86% increase). Other conditions that have been diagnosed in the clinics include valve disease, atrial fibrillation, bronchiectasis, pulmonary fibrosis; emphysema, lung cancer, and patients eligible for lung transplants. This has enabled appropriate treatment and advice to be provided swiftly.

Anecdotally, clinicians report that patients receiving a diagnosis and treatment plan that involves behaviour change (for example, losing weight or stopping smoking) are more inclined to accept the diagnosis and

\(^\text{12}\) Data regarding heart failure, COPD and asthma prevalence was collected from 2010 to February 2015 for the first cohort of practices taking part in the local pilot. Data was collected from April 2014 to February 2015 for practices involved in the roll-out of the pathway across half of the borough. These timescales for data collection do not align with the NHS IQ pilot timescales.
advice offered, due to increased understanding of the underlying causes of their symptoms and feeling their needs have been considered holistically.

Linked to this, pilot leads report that there has been a **30% increase in people classing themselves as ‘ex-smokers’** 5-months after accessing the service.

Pilot leads also report medicines management savings of £40,000 over a 6-month period across the borough, as a result of changes to existing medications to more appropriate prescribing, and does not include newly diagnosed patients commencing medication for breathlessness for the first time\(^\text{13}\).

**Suggested improvements**

The main challenge related to unacceptable variations in the near patient BNP testing compared to Venus sample lab-generated results which were run in parallel. This led to the BNP-testing element of the pilot being halted mid-way through the pilot. The breathlessness clinics continued, but the testing element did not prove effective. With this in mind, we suggest that any future BNP testing processes be thoroughly trialled and evaluated before being rolled out more generally, to ensure accuracy.

Other challenges included the lead-in time needed to establish relationships with GPs and practice nurses, although this was mitigated by the lengthy duration of the pilot. The team also ensured individual post-holders acted as relationship managers with each practice, to build up trust and provide continuity.

**The case for commissioning, potential for spread, and sustainability**

As a result of the success of the Breathlessness service, Wigan Borough CCG has recently commissioned a Primary Care Respiratory Service to be rolled out across the whole of Wigan Borough. This Service will be delivered by British Oxygen, not Health First, following a competitive tendering process. The BNP pathway will continue across the borough.

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\(^{13}\) Data regarding medicines management savings was produced and analysed by pilot site leads in ALW, so we cannot verify the impacts or savings reported.
Key findings - programme level learning

In this section of the report we explore the key learning across the pilot sites, exploring commonalities across the sites and programme level impacts, as well as reflections on the programme design, focus, set up and monitoring.

Stakeholders involved

Across all three of the pilot sites, core stakeholders have included Respiratory Nurses, Respiratory and Cardiology Consultants, Programme Leads and Coordinators, as well as GPs and Practice Nurses. In the Wessex and LLR sites the work was overseen by a local steering or advisory group, to facilitate alignment with broader local programmes of work.

Other clinicians involved in the pilots to varying degrees have included Physiotherapists, Physiologists, Rehabilitation Specialists, an Echocardiograph Technician, and Nurse Managers.

Leicester reported effective engagement with Commissioners from the LLR CCG, whereas the other pilot sites reported less engagement with commissioners.

It has proved vital to engage specialist cardiology and respiratory leads, whilst also engaging primary care practitioners, and striking a balance between specialist versus generalist involvement has proved important in both diagnosis and awareness raising.

Engagement with lifestyle and behaviour change specialists and programmes has varied; the LLR pilot stakeholders in particular identified this as an area for improvement moving forward, and all three of the pilot sites are likely to have benefitted from closer engagement with lifestyle and behaviour support services currently available locally.

Impacts and outcomes achieved

In this section of the report we explore the key impacts achieved overall as a result of the pilots.

The impacts for patients can be categorised as impacts on patient experience and impacts on clinical outcomes. Both categories of impacts were evident across all three pilot sites, and are explored below.

Impact on health outcomes

Patients involved in the pilots received appropriate, tailored treatment and support to address their needs, whether this required lifestyle change or medical intervention. The positive patient experience (explored below) is perceived as correlating with increased compliance with treatment and self-management plans. Clinicians involved in the pilots report that patients who feel listened to, who perceive their needs have been considered holistically, and can understand the rationale for any advice or treatment they have been given, are more likely to follow that advice and / or take the medication as prescribed. Patients are reported to be more receptive to lifestyle or behaviour change advice (for example, stopping smoking, losing weight, taking exercise) than they may be if provided with this advice during a routine GP appointment, as they are provided with an explanation of how this relates to their symptoms of breathlessness, and appreciate that diagnostic tests have been undertaken to ascertain the cause.
This is evidenced in the follow up appointments data, which indicates that patients have improved health outcomes following their attendance at the clinic, and in ALW there are reports of a 30% increase in people classing themselves as ex-smokers following attendance at the clinic.

It is also likely that the pilots have had broader impacts on patients' health. The treatment of the causes of breathlessness may well impact on other conditions. For example, patients losing weight may well avoid a future diabetes diagnosis, and those stopping smoking will reduce their risk of contracting certain types of cancer. In addition, patients whose needs have been addressed are less likely to experience ongoing anxiety and stress associated with the uncertainty of an undiagnosed condition (as evidenced by the patient feedback from ALW). Patients may consequently experience improved mental health and quality of life more generally, feeling that their needs have been addressed and that they are better able to self-manage their condition.

**Impact on patient experience**

The evidence indicates that the impacts of the pilots of patient experience are unanimously positive, and can be summarised as enabling patients to feel:

- More **confident in their diagnosis and treatment** – as a result of seeing a coordinated team working together to address their needs.
- Better **able to understand and accept their diagnosis**. This is as a result of receiving consistent messages from different professionals, who have provided their care on the same day. Linked to this, any misinterpretation of information by patients can be picked up on the same day in discussion with other clinicians.
- That they are **seen quickly**, avoiding long waiting lists and being passed between specialists or having to attend multiple appointments.
- That they **receive a more holistic picture** of their symptoms, causes, and options for treatment and management, and feel involved in planning their own care.
- Both **clinical and lifestyle factors are covered** and given equal weight within the consultations, avoiding jumping to conclusions regarding potential causes of their breathlessness.

In addition, patients have to **attend fewer hospital appointments for diagnostic tests**, which in itself can help patients to **avoid transport costs and time spent** travelling and waiting for appointments. This is likely to be particularly important for patients with breathlessness, who typically are more likely to be older and have mobility issues than the general population.

Patients also reported **improved quality of life after receiving care in the clinics**, with reduced symptoms and feelings of control over their condition(s) leading to improved mental health and general wellbeing.

"They’re brilliant. My life has improved. I was struggling to walk and get about and mow the lawn, I’m a lot better now than I was. I think it’s down to them."

Patient interviewee
**Impacts on staff involved in the pilots**

The impacts on staff involved in the pilots can be summarised as:

- **Improved confidence in identifying, diagnosing and treating breathlessness appropriately.** This impact was particularly felt within primary care settings in Wessex and ALW as a result of the capacity building and education work delivered as part of the pilots, but was also reported by specialists who appreciated the holistic view of patient needs provided within the care models.

- **Staff involved report increased confidence that they are addressing patient needs holistically, and have increased knowledge and understanding of the services available across primary and secondary care.**

- **There is improved morale and job satisfaction.** Staff reported feeling part of a strong team. Clinicians reported feeling a sense of reward from delivering the service to patients in a more timely and positive way compared to historical ways of working. This was reported across all three pilot sites, and was seen as offering important benefits in terms of staff retention and productivity. Staff who are motivated and passionate about the service they provide are also arguably better able to act as peer champions, to enthuse others.

- The services have provided **reassurance for GPs and practice nurses** that there is someone with specialist respiratory or cardiology knowledge that they can **call on for help or advice if needed.**

- **Improvements in relationships and understanding** have taken place between disciplines such as between the cardiology and respiratory departments, or between Consultants and Respiratory Physiotherapists; between Clinicians and Administrative Staff (such as those managing outpatient clinics in LLR); and between primary and secondary care.

Staff involved in the pilots commented that it had been useful for their own personal development, and overall reflected that it had been a positive experience, welcoming the longer term potential to improve pathways for patients experiencing breathlessness.

**Process learning and reflections**

**What worked well**

The pilot sites all made good progress with developing and implementing new pathways for patients experiencing breathlessness. Relevant clinicians and patients were engaged, challenges were largely overcome or mitigated so that progress could continue, and the pilots were all implemented largely in line with the original applications and leads’ expectations.

The pilots have all delivered against their original aims and objectives, and generated useful learning for others. Patients have been identified, referred into the pathway, diagnosed and treated, with positive experiences and outcomes reported as a result. Clinicians in primary care have also been upskilled, and integration of services has occurred, both across specialism and between primary and secondary care.

A successful breathlessness pathway that achieves better outcomes for patients will undoubtedly need to involve building a close working relationship between primary and secondary care teams. The pilots model different approaches for establishing this relationship, resulting in stronger communication channels
between teams, an appreciation of each other’s work and remit, as well as facilitating a more holistic view of the patient.

In terms of the processes that worked particularly well, the following have all emerged as particularly successful elements:

- The joined up working between secondary care and primary care clinicians involved in the pilots, with improved communication and joined up working, leading to improved understanding of each other’s roles, pressures and ways of working.
- The identification of patients has worked well, despite the varying approaches adopted in the different pilot sites.
- The capacity building elements, with generalist staff being educated regarding spotting, diagnosing and treating the symptoms of breathlessness more effectively.
- The speed and pace of the pilots, with all delivering activities within the pilot timescales, and developing sustainability plans based on the commissioning case proven.
- The holistic overview of patients’ needs, ensuring accurate diagnosis and appropriate treatment and self-management planning.
- Delivering care in settings that are accessible to patients has proved particularly effective.
- Across the pilot sites, DNA rates have been lower than would be typical in respiratory and cardiology secondary care services. This is credited with being partly due to the accessibility of the services, as well as the perception amongst patients that their needs will be considered holistically. We suggest that this might also be due to the effective identification of patients – i.e. there are many fewer inappropriately referred patients.
- The one stop shop element evident across all three pilot sites has been particularly effective, despite the challenges inherent in establishing and maintaining such a service (explored below). Patients have welcomed the opportunity to attend on just one day, rather than attending several appointments spread over weeks or months, and clinicians have found the format useful for sharing learning, improving relationships and improving access to treatment more quickly.

**Challenges encountered**

The main challenges experienced by the pilot sites relate to engagement, embedding the work, GP knowledge and coding, logistics and capacity.

**Engagement**

In terms of engagement, the main challenges encountered relate to the **lead-in time required** to build knowledge and awareness of the newly established pathways, particularly within primary care. The ALW pilot revealed the need to attend Network meetings for GPs, as well as engaging in 1-1 discussions with primary care colleagues, in order to build understanding about the pathway and confidence in its credibility and potential value. This is time consuming and cannot be delivered overnight, and would need carefully factoring into any roll-out of the pilot pathways across other localities. However, it may be less difficult to reassure colleagues of the pathway’s credibility and value if it is commissioned as ‘business as usual’ in a locality, rather than being delivered as a pilot programme, whereby clinicians are concerned the model is **not fully ‘tried and tested’** and may not be sustained longer term.
The challenge of engagement is exacerbated when there is a **high rate of turnover within primary care**, with a constant cycle of engagement being required in order to maintain awareness levels.

**Embedding the work**

Pilot sites experienced challenges in **embedding the culture change required** in order for the pathways to be effectively sustained and impacts maximised. The relatively short pilot timescales limited the scope for culture change to take place and become embedded, particularly given the size and geographical dispersal of the local primary care practices. Implementing the new models of care requires openness to change, but more importantly, a willingness to collaborate and work in an integrated way with colleagues across secondary and primary care, sharing specialist knowledge and accepting that individual clinicians or areas of specialism may not have all the answers to address a patient’s needs. This is something that the pilot site leads remain committed to addressing during the next stages of their work.

Other challenges encountered related to the **short-term funding** in itself; as outlined above, this limited the scale and scope of the work, and created uncertainty for clinicians and patients. This is a common feature in any pilot programme, but it limited the extent to which the pathways could be embedded and become ‘business as usual’. The funding for the pilot did not reach the teams in all sites who were meant to receive it as quickly as had been originally intended, due to **‘blockages’ within internal systems**, causing frustration. Whilst this was identified as a common challenge with pilot programmes, it is important to ensure smooth funding flows, in order to avoid future pilot participants from being deterred from participating, and to avoid undue pressure being placed on resourcing systems.

> "It seems to always be a problem when we commission pilots – the money doesn’t necessarily trickle its way through to where it should go. We pay for extra capacity but the people providing the service don’t actually get it."

Service Improvement Manager, CCG

**Varying GP knowledge and coding**

The GRASP tool used in Wessex **relied heavily on the coding used by GPs** regarding breathlessness symptoms. However, the pilot indicated significant variation in the quality of this coding, with inconsistencies across the pilot general practices. Given that this challenge emerged as an issue when working with just three practices, it will be important for others seeking to use the GRASP tool to be mindful of this.

Likewise, the pilot in LLR revealed that many of the patients referred into the pathway could actually have been diagnosed and treated within primary care. This indicates a **need for improved knowledge and confidence regarding breathlessness** amongst primary care clinicians, and reduced variation across practices.

**Logistics and capacity**

From a logistical perspective, the **variations in the BNP testing results** experienced in the ALW pilot site caused significant challenges, resulting in the use of the machine being temporarily put on hold until a more accurate replacement could be found. Again, this challenge is not likely to be unique to this pilot programme, and the variation damaged clinician confidence in the results being generated.

Other logistical challenges related to securing **access to appropriate settings for clinics** (finding sufficient space that was easily accessible and suitable for running the diagnostic tests and housing
multiple clinicians), and ensuring venues were booked in a systematic way, avoiding ad hoc bookings and consequential peaks and troughs in delivery. This is particularly challenging when clinics rotate around different locations, requiring effective coordination and forward planning.

In the LLR site, there were limited resources for undertaking all the required tests in the clinic, for example there is only one cardio-pulmonary exercise system, and therefore the number of patients that can be seen is limited to 2-3 patients per clinic. This particular challenge is likely not be unique to the pilot programme and indicates the importance of careful planning and coordination.

In addition, it has been hard to predict in some cases how many patients will attend the clinics. Although DNAs have been considerably lower in the pilots than under alternative respiratory and cardiology pathways, in ALW in particular there were challenges regarding patient need for clinics occurring ‘in fits and starts’, making it difficult to plan capacity and schedule clinics appropriately.

Staffing has also been a challenge, with locum use adding to the pilot costs. Again, this is an issue that is not likely to be unique to the pilots, and is experienced across the NHS more generally. In the LLR pilot site, it proved too difficult to secure the Cardiologist’s time released for the clinic, and as a result the clinic ran without a Cardiologist. There were also challenges in releasing funding for a Nurse and Healthcare Assistant to support the clinic.

Another capacity challenge related to the time required to manually search through records and / or prioritise patients for referral onto the pathway. This relied on the core team’s capacity, and indicates the importance of the models being appropriately resourced with dedicated, sufficiently knowledgeable staff. In Wessex, although the GRASP tool identified hundreds of patients who could benefit from the service, the pilot’s limited funding and resources meant the team had to pragmatically prioritise ‘high-risk’ patients whose symptoms overlapped between COPD, asthma, and cardiac symptoms.

A minor challenge related to patients being unable to attend the clinic on their allocated day due to other commitments. Although this was not a major challenge within the pilots, it will be important for others seeking to replicate the models to consider how / whether alternative dates and times might be offered for such patients, to ensure they receive the optimum care available.

Planning for sustainability

There have been challenges in terms of sustaining the pilots. Whilst the ALW pathway (diagnostic) is being sustained (commissioned to be delivered by British Oxygen on a five-year basis), this is not being delivered in exactly the same format or by the same team as in the pilot programme, leading to staff seeking alternative employment and concerns regarding the potential lack of consistency for practices and secondary care partners. Staff morale was negatively impacted during the final months of the pilot, as a result of the sense of uncertainty.

In LLR there is a desire to move the clinic to the National Centre for Sports and Exercise Medicine – East Midlands (NCSEM-EM). However, there have been some challenges in doing so, relating to having the right facilities in place, funding, and concern from NCSEM-EM staff about having patients on that site.

Overall however, it should be noted that none of the challenges experienced posed barriers to progress during the pilot timescales; it the vast majority of cases pilot leads were able to overcome or mitigate the impact of the challenges.
Critical success factors and other lessons learnt

The learning from the pilots highlights several critical success factors, culminating in the other key lessons learnt from the pilots. These can be thematically grouped to encompass:

- Core requirements relating to service delivery.
- Wider relationships and partnership building.
- Alignment with strategic priorities and the broader local context.
- Other lessons learnt.

Core requirements relating to service delivery

The pilots all relied on a core team to help oversee and coordinate the clinics. It is unlikely that the pilots would have happened in the same way or been coordinated as effectively without this core team driving forward activity and ensuring logistics were in place to facilitate delivery. The core team typically involved admin or coordination / support staff, as well as a clinical lead with a respiratory background or particular interest in tackling breathlessness. This clinical leadership was a critical success factor in its own right; providing credibility with primary and secondary care colleagues, and ensuring the pathways were tailored to address the needs of patients and the system as a whole. This peer champion role proved important.

The clinical leads in all three sites undertook a huge amount of preparatory work in case finding patients and making the logistical arrangements to enable the secondary specialist team to run the ‘one-stop shop’ style clinics.

For example, in Wessex, the ASHN took a lead in developing the proposal, while the lead Respiratory Consultant and the lead Respiratory Nurse were instrumental in implementing the concept on the ground. Their work secured buy-in from key local stakeholders, including the partner GP practices and Queen Alexandra Hospital in Portsmouth. Both clinical leads championed the pilot from the beginning amongst local partners, and are key in establishing an ongoing commissioning case.

The clinical leadership also ensured the pilots were grounded in ‘lived experience’, based on a shared recognition amongst clinical stakeholders of the pitfalls inherent in pre-existing pathways for breathlessness. This clinical leadership ensured solutions were developed that were both practicable to implement and effectively focused on tackling the key issues affecting patient care.

Without this strong clinical leadership, it is unlikely that the pilots would have progressed as successfully or secured the same level of clinical buy-in and engagement.

The enthusiasm, interest, and energy of individuals were critical success factors for this pilot. These qualities were seen as being vital for driving the initiative forward and overcoming challenges at all levels, from the initial set-up, through to day to day implementation, through to putting forward a case to commissioners. In ALW, the team worked with the same specialist Consultants throughout the pilot, to ensure continuity and to support relationship building. In all three sites, a core team of dedicated individuals led the work from the outset, taking personal responsibility and ‘ownership’ for the success of the pilot.

This critical success factor poses a challenge in terms of replicating or spreading the model; the same level of dedication and passion may not be found in every locality. In addition, the capacity to drive and lead change locally again may not be evident amongst all those with the necessary enthusiasm or commitment.
Providing care in accessible venues, and minimising the number and spread of appointments for patients proved critical in securing attendance at the clinics and generating high levels of patient satisfaction with the services. Providing a follow up when needed also proved important in reassuring patients.

**Wider relationships and partnership building**

Collaboration with a wide variety of stakeholders at an early stage was key. Interviewees from the LLR pilot site referred to the success of the initial start-up phase of the pilot where the Lead Consultant held a Listening in Action\(^{14}\) event including individuals from primary care, secondary care, community care, as well as Physiotherapists and Rehabilitation Specialists, to involve everyone and pool ideas. This early involvement of stakeholder across different disciplines was also perceived to help with raising awareness of and championing the work more widely, in order to ensure commissioners gained awareness of the pilot prior to putting a commissioning case forward.

“There is an initiative called Listening in Action, a process to listen to feedback from frontline clinicians… There’s not much link between primary and secondary care usually so this is a good way to bring us together and find ways of shortening the pathway for patients and get them to a diagnosis faster.”

CCG Lead GP and Primary Care Clinical Lead of the Long Term Conditions work stream of the LLR Better Care Together programme

In relation to the primary care implementation phase, early engagement with GPs and collaboration to design the primary care breathlessness pathway has been similarly useful. **Emphasising the opportunities for learning** has been a useful aspect of this work, particularly since GPs are seen to have varied levels of confidence and knowledge about diagnosing and managing breathlessness. Taking a supportive approach and engaging with GPs to design a primary care pathway that can address these issues is seen as an important success factor. The ALW pilot also highlighted the importance of taking the time to engage with GPs collectively and on a one-to-one basis, to secure buy-in, build relationships and trust, and overcome any concerns.

The majority of the stakeholders demonstrated a high level of commitment to learning and supporting the learning of others. Interviewees frequently referred to the opportunities for learning across disciplines as a key benefit for clinicians and other staff involved.

“It’s good for learning on both sides – we learn from each other about how we work and how we think. It’s an exchange of professional skills. We can learn so much from each other through interdisciplinary collaboration.”

Respiratory Medicine - Clinical Fellow in Integrated Care

Small changes in communication can make a big difference. Through working together on the pilots, primary and secondary teams learned more about each other’s systems, decision making processes, and how to best support the other when making diagnosis and referrals in the future.

\(^{14}\) Listening into Action\(^{\circledR}\) approach to employee engagement: http://www.listeningintoaction.co.uk/index.php
Case study example

An early learning that emerged from the Wessex pilot and was easily addressed was to adjust the way secondary teams wrote abbreviations in their consultation notes. For example, where secondary consultants used the term ‘HDM’, GPs would have no idea what this meant, so the made an easy adjustment to use the word house dust mite.

“This pointed out that terms we might use on a daily basis, may not be so straightforward in a different setting. We need to think about how we communicate with each other effectively.”

Specialist Clinical Team Member

Equally, it’s important to make other health stakeholders, such as pharmacists aware of the project.

“We had one issue with a pharmacist when a particular patient diagnosed with asthma was doubled their dose of inhaler medication. The pharmacist was right to question the dose because it differed from the national guidelines. In this instance, the patient alerted their doctor who alerted us and we were able to confirm the prescription. It points out that there are lots of people it’s important to involve to create a smooth patient journey. We need to make sure that wherever the patient goes, they understand the project we’re running.”

Lead Respiratory Nurse.

Team working is critical to success, and the clinicians and support staff involved in providing the breathlessness service report open dialogue and flexibility, with a strong sense of trust, loyalty and collaboration. Team members and practice staff have contact details for one another, to call for advice or guidance.

This team work and open dialogue did not happen overnight: nurses in the team each work with different practices, and took the time to build up trust and confidence amongst the practice nurses, GPs and admin staff within those practices. This helped to ensure there was open dialogue regarding patient care, and practice staff understood the benefits of the service.

As outlined above, strong communication skills and engagement have been important enablers. The improved relationships have led to a more consistent message being delivered to patients; clinicians report identifying ways to overcome challenges or blockages; and determining factors to improve and develop the clinic and service into the future.
“We had a meeting for everyone involved to introduce themselves and this was good to see a structure of a team. It’s been important that both Consultants know what each other does.”

Senior Respiratory Physiotherapist

It is important for providers to engage commissioners from the outset, and sustain this throughout: The Health First team have presented some impressive results from the breathlessness service. However, engagement with the CCG has not been as consistent or open as might have been useful in hindsight.

Alignment with strategic priorities and the broader local context

The pilots were delivered at a time of increasing focus on delivering care closer to home, shifting care out of secondary care settings wherever possible. The pilots operated in line with this broader aim, providing breathlessness clinics in primary care settings or outside of traditional secondary care settings. This aligns well with the ambitions set out in the NHS Five-Year Forward Plan.

The focus on integrated care also aligns well with the Health and Social Care Act, and is likely to prove vital in sustaining the models moving forward.

Embedding the pilot within the wider context locally has proved vital in all three of the pilot sites.

This helped to secure commissioner interest as well as engaging primary care clinicians. These findings are explored in greater detail under the subsequent sections of this report.

Other lessons learnt

The key learning points (and suggested improvements, where relevant) are detailed below. These are presented from a provider perspective, but may also offer learning for commissioners and policy makers.

Systematising processes: The GRASP case finding tool is a free and well-suited tool to identify patients with breathlessness symptoms. However, its limitation is that it is reliant on the data, which may vary depending on the types of codes GPs tend to enter. There is an opportunity going forward to become more systematic in coding the symptoms.

“We were well aware that there might be some people that we miss because of the way they’d been coded – but even if we could impact upon 5 people’s lives that had been coded that was a good enough reason to go ahead.”

AHSN Programme Lead

Joining up care is important for creating smooth patient journeys. For patients with breathlessness there can be lots of different medical professionals inputting into their care, assessment, and diagnosis. The patients can sometimes be the only person joining things up. The pilot model allowed patients to receive quick and accurate secondary care joined up with their GPs service. This minimised miscommunication and instilled confidence amongst patients that their journey was understood.

When trialling a new model of care, it may be useful to have a back-up plan in place. In ALW, the BNP testing machine had a higher than acceptable rate of variation in results when compared to laboratory testing. This meant the BNP testing element of the pilot was temporarily halted following the testing and diagnosis of the initial 40 patients. The team continued to provide diagnostic tests and follow up treatment
in the clinics, but accepted that same-day test results were not possible without access to an accurate testing machine.

Finally, **considering patient needs holistically** proved vital in securing buy in. The service is reported to be successful in all three pilot site areas, despite the differing delivery models, as a result of **addressing the symptom** of breathlessness and considering all potential causes for this. Clinicians bought into the concept of this, particularly when it was backed up by local prevalence data and the potential efficiency savings offered by the model.

**Spread, sustainability and developing a case for future commissioning**

In this section of the report we explore the case for sustaining the new models of care, exploring the case for commissioning and implications of spread.

The case for addressing breathlessness as a symptom has already been made within the wider evidence base, as presented by Aspinall in 2014:

“There are a number of models in existence or being developed for diagnosing disease by focusing on breathlessness as a symptom, including rapid access breathlessness clinics and diagnostic pathways for breathlessness. Rationales for developing breathlessness clinics include the fact that care pathways for aspects of breathlessness tend to be disease-specific and do not take satisfactory account of multi-morbidity, though cost-effectiveness data is lacking. Harmonisation of approaches across diseases is needed to reduce current unwarranted variation in diagnostic rates, systematic review evidence having shown that cross-boundary working can increase the speed of diagnosis. Such clinics have the potential to focus diagnostic services on symptoms at the point where people present to primary care, to address multi-morbidity, and the complex interaction and need for parity of esteem between mental and physical health.

“Currently, nearly all breathless patients present in primary care. The GP may initiate a range of investigations: peak expiratory flow rate (PEFR), spirometry, electrocardiography (ECG), brain natriuretic peptide (BNP) (if heart failure is suspected) and (if results are abnormal) referral for echocardiography which (if abnormal) results in an automatic cardiology outpatient referral. The length of time and amount of resources to achieve an accurate diagnosis for complex patients are drawbacks, high numbers of patients being currently misdiagnosed and receiving incorrect treatment.”

Breathless patients can **often ‘fall through the cracks’** between primary and secondary care because of the unspecific nature of the symptoms. High numbers of patients are currently being misdiagnosed and receiving incorrect treatment as a result. Patients may require multiple referrals to respiratory and cardiac specialists based in hospitals whilst awaiting diagnosis, and this risks possibly exacerbating their symptoms in the meantime.

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[http://www.nhsiq.nhs.uk/media/2582027/breathlessness-scoping-research-full-report.pdf](http://www.nhsiq.nhs.uk/media/2582027/breathlessness-scoping-research-full-report.pdf)
“One thing we were seeing a lot of was that patients were being pigeonholed with a diagnosis, sometimes incorrectly as well, so the quality of diagnosis wasn’t there. When patients were, for example, given a diagnosis of COPD they weren’t also assessed for heart failure, obesity or general unfitness. So we were finding that people’s breathlessness wasn’t being managed very effectively and quite often the root cause of their breathlessness wasn’t being managed at all.”

Clinical Delivery Team Member

The breathlessness pilots all received £15,000 of pump-priming funding from NHS IQ in order to set up and test the efficacy of the new pathways at a local level. The key stakeholders involved in all three pilot sites report that significant additional in-kind contributions were essential in order to make progress with the piloting, including staff time, the use of venues and equipment, and educational activities. This study was not commissioned as an economic assessment, and consequently costing data has not been obtained from the pilot sites in order to ascertain the exact resourcing requirements, or indeed, to monetise the outcomes emerging. However, despite this there are a number of conclusions that we are able to draw from the available evidence regarding the commissioning case and potential to spread the models more widely.

The evidence base on which the pilot was initially commissioned indicated that patients who require multiple investigations, spread over multiple secondary care appointments, generate high levels of costs for the NHS, and do not necessarily receive their care as quickly as would be ideal. This risks exacerbation of symptoms and deterioration of the patient’s health, as well as negative impacts on their quality of life. This in turn may reduce their productivity and potential to actively participate in society; all of which can have potentially devastating impacts on mental health, as well as impacting on other physical illnesses and long-term conditions. This can lead to increased costs to the NHS more generally, as a result of co-morbidities and more intensive treatments being required due to delayed diagnosis and treatment.

The breathlessness pathways offer an approach that seeks to mitigate this, by providing holistic diagnostic testing and treatment plans to patients via a one-stop shop model. Whilst the models require considerable resources in terms of specialist and generalist staffing, venue and equipment access, and training and awareness raising materials, the approach is felt by leads from all three pilot sites to offer the potential to avoid future care costs for patients following the pathway.

Based on the prevalence data generated by the pilot sites, the breathlessness pilots offer potential to impact not only on asthma, COPD and heart disease, but also on wider respiratory and cardiology diseases and conditions, many of which have high mortality rates and / or require costly treatment:

- The ALW pilot alone is reported to have generated reports of medicines management savings of £40,000 within a six-month timescale; if this pilot was scaled up to cover the whole of the borough, let alone on a national basis, the cost efficiencies could be significant.
- In the short-term, calculations done by the Wessex ASHN reveal that the pilot clinics cost £142 per patient to run (excluding in-kind contributions), compared with approximately £241 tariff for cardiac and respiratory outpatient referral appointments.

Details of the wider evidence base regarding the breathlessness services and the commissioning case can be found in Appendix 5.

A proactive attempt towards **mainstreaming** in all three sites was highlighted as a success factor in the pilot sites, particularly in relation to preparing a case to put forward for ongoing commissioning. One pilot was initially located in an improvement and innovation unit, but was moved to sit under the respiratory
working group and has been incorporated into their delivery plan, which helped the work to be viewed as part of day-to-day delivery.

Getting commissioners on board from an early stage was viewed as an important part of this, because a supportive commissioner can help to enable the successful implementation of a pilot initiative. The relationship between the clinical team and the lead commissioner for respiratory health appeared to be strong in terms of working together to understand and evidence the impact of the pilot, although there remained significant anxieties among clinicians about whether the clinic would be commissioned.

**Uncertainty about the future sustainability** of the clinics and on-going commissioning has created anxiety among those involved. There is a keen awareness that funding is difficult in the NHS at the moment and a perception that in order to have a service commissioned there is a need to demonstrate the value of that service first. However this is a challenging environment to work within because after all the energy, time, and resources have been put in to a pilot there is always a risk that it will not be commissioned on an on-going basis. A learning point from this experience has been to **attempt to get buy-in from senior managers to support the programme**, because although managers at intermediate levels may be supportive, that buy-in does not necessarily reach as far as those responsible for the decision-making.

In terms of delivering the clinic effectively, the success of the clinic was influenced by clinicians’ **specific interest in the symptom of breathlessness**. While this was seen as a success factor, it also raised some concerns because it makes it difficult to find cover if one of the specialists is away on leave or is off sick. This reliance on the energy and interest of individuals also raises concerns relating to the sustainability of the clinic, because if a specialist leaves then it could be challenging to replace them with someone who has the same specialist interest.

In Wessex, the focus on ABC (asthma, breathlessness and COPD) has proved powerful in making the commissioning case, whilst in ALW the programme leads across key performance indicators for the pilot that aligned with CCG commissioning priorities, including reducing emergency admissions and generating medicines management savings. In LRR, the pilot leads benefitted from alignment with the broader integrated care programme, being delivered locally through the Better Care Together programme. This was seen as a success factor. Similarly, linking the secondary care based breathlessness clinic to primary care pathways and to post-diagnosis community care and lifestyle interventions was also viewed as an important part of the pilot in terms of securing buy in and making the case for future commissioning. For the next phase of the breathlessness pathway in LLR (where **primary care implementation** will take place), the main challenges are perceived to be the geographical spread of the population, heterogeneity in the level of knowledge and resources available in different GP surgeries, and variation in GP attitude and interest in breathlessness.

In terms of sustaining the work within the pilot sites, in all three the breathlessness pathways are being sustained in one form or another, with commissioner buy in to the model and the outcomes being achieved. This indicates that the evidence threshold required by commissioners has been met, at least in these three localities.

However, in order to strengthen the case, the evidence emerging from the pilots only tells part of the story. It will be important to track both patient outcomes and system level impacts longer term, to ascertain the full scale of the impacts emerging. Given that the breathlessness clinics are only operating in tightly defined geographical localities, it is likely that the evidence would be available to facilitate the evaluation of outcomes across areas with breathlessness pathways in place against those without pathways in place. This would require a longer, significant piece of work but is likely to strengthen the commissioning case further.
The wider evidence base indicates that commissioners will seek to consider the following factors when considering commissioning breathlessness services:\(^{16}\):

- The existing evidence base within a given locality and evidence of need, including assessment of existing local provision against the IMPRESS algorithm\(^{17}\) (an evidence-based integrated approach to diagnosis and treatment of breathlessness).
- Alignment with other priorities at a local and national level.
- Consideration of where services should be located.
- The opportunity for capacity building and other ‘added value’ elements of the model.
- The extent to which services should be delivered universally across practices or within selected ‘interested’ practices.
- The availability of diagnostic equipment and portability of this.

Aspinal (2014) reflected that breathlessness services are likely to need to vary across localities, depending on all of the above factors:

> “It is unlikely that one organisational model will fit all circumstances and that models will evolve to reflect local resources, local needs, and the priorities set by consultants, hospitals, and clinical commissioning groups”.


\(^{17}\) www.impressresp.com
Conclusions

In conclusion, the pilot programme delivered three new pathways, all slightly different, aimed at effectively tackling the symptom of breathlessness. All three have delivered in line with the original project plans and applications submitted, and have evidenced how they have made progress towards their stated aims and objectives.

The pilots have required integrated working across primary and secondary care to varying degrees, and have relied upon strong clinical leads to design and drive forward the new models of care. This presents important learning for others, and has implications for the future commissioning of similar models: the reliance on committed, strong and credible clinical leaders must not be under-estimated, and may limit the transferability of the models more generally.

The outcomes evidence emerging from the pilots is encouraging: there have been improvements in diagnosis, reports of effective treatment plans being implemented and adhered to, and improved patient outcomes are emerging as a result. The holistic assessment of patient needs has proved particularly powerful, exploring potential causes of the breathlessness symptom rather than assuming a particular diagnostic or treatment route is required. This in turn has helped to improve patient experience and compliance, and led to capacity building across primary and secondary care, offering potential longer term benefits and paving the way for sustained approaches to integrated care within respiratory and cardiology.

The integration of behaviour change and lifestyle advice within the pilots is likely to prove particularly important moving forward, with increasing focus at both a national and local level on personal responsibility and minimising the increasing burden on the NHS as a result of poor lifestyle choices. However, this area of the pilot has proved challenging to implement: whilst advice and educational materials have been given to patients, integration with lifestyle services has not been realised to its full potential.

This last point is illustrative of the pilots overall: the three sites remain on a journey, as do the clinicians and patients involved. Realising the full extent of the outcomes of the pilots will take years, and the full scale of the impacts cannot be evidenced within this evaluation. However, the early indications are encouraging: the models do appear to have led to positive outcomes for patients and clinicians involved, and also seem to offer the potential for realising system-level and economic impacts, albeit over a longer time period and with scaling up of the models.

The evidence emerging at site level has clearly been sufficiently convincing for local providers, and in some cases, commissioners. All three services have developed sustainability plans, with commissioning decisions already having been taken to sustain the diagnostic approach to breathlessness in ALW. The evidence indicates that multiple commissioning needs may be met as a result of the pilots.

The care models piloted also align with the NHS New Care Models (Vanguards) core principles, in particular principle one: care and support is person centred: personalised, coordinated and empowering. The focus on addressing needs holistically and actively engaging patients in care planning and self-management demonstrated within the pilots aligns with this future direction of travel for NHS services in

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18 NHS England, New Care Models: Empowering Patients and Communities (December 2015)
England, and consequently offers examples that others may wish to learn from when planning their own breathlessness pathways.

**Recommendations**

**Recommendations for policy makers**

**Recommendation 1: Further explore the scope for a national dataset regarding breathlessness.** We suggest that further research might usefully inform the scope of this dataset, recognising that breathlessness services vary significantly in their design and implementation across different CCGs. Whilst local needs and provision will vary, developing a national, standardised set of indicators regarding breathlessness would enable evidence to be captured and assessed by NHS England in order to inform future policy making and funding decisions. We suggest that this dataset might usefully include metrics regarding:

- Waiting times for respiratory and cardiology diagnostic tests.
- Outcomes of the tests (lifestyle advice as well as medical treatment).
- Details of where diagnostic services are provided; e.g. in primary care or secondary care settings.

**Recommendation 2: Conduct a light-touch follow up evaluation.** This evaluation was time-limited and ran until the end of pilot delivery. However, the longer term benefits and system-wide impacts will not be realised for many months, and in some cases, years to come. With this in mind, we recommend that NHS England commissions a light-touch follow up evaluation, to explore the longer term impacts of the pilots at a local level. Commissioning this work now will enable pilot sites to set up relevant data collection and monitoring arrangements. This might usefully include an economic assessment, to robustly assess the costs and financial benefits emerging as a result of the different breathlessness pathways, ideally including comparator data (retrospective or based on comparison localities without clear breathlessness pathways in place).

**Recommendation 3: Disseminate learning across the respiratory and cardiology community.** The pilot leads are keen to share their learning more widely across their peers, and we suggest that this enthusiasm be utilised to share learning regarding the approaches adopted and impacts emerging. The leads may usefully be able to act as peer leaders.

**Recommendation 4: Seek to increase public awareness regarding breathlessness symptoms.** Patients presenting with breathlessness as part of the pilots received varying diagnoses, although over a fifth from the ALW site received lifestyle and behaviour change advice as part of their treatment. Lifestyle advice and behaviour change was recognised as vital across all three of the pilot sites. This indicates that patients themselves may be able to take pre-emptive action to avoid or reduce the risk of breathlessness, and to reduce symptoms once they do occur. However, given that some breathlessness is clearly the result of important conditions requiring medical treatment, it is important for patients to receive accurate, easy to understand advice about when and where to present with symptoms of breathlessness, as well as actions they themselves can take to reduce the risk of it occurring in the first place.
Recommendation 5: Highlight the potential savings emerging as a result of earlier diagnosis. The wider evidence base indicates that addressing COPD, heart failure and asthma appropriately and as early as possible can lead to reduced mortality, reduced severity of condition, reduced need for costly interventions and medications, and can lead to fewer days of work being lost. We suggest that it may be useful to highlight the potential longer term savings emerging as a result of improved pathways for treating breathlessness when presented in primary care, and seek to reduce or remove any disincentives in the system (in terms of tariff payments).

Recommendations for local NHS organisations, including provider and commissioner organisations

Recommendation 6: Build education and awareness within primary care. The pilots highlighted varying levels of awareness of, knowledge about, confidence in and enthusiasm for addressing the symptoms of breathlessness within primary care. This indicates the need for improved consistency across primary care. If conditions were identified and appropriate treatment / advice given within primary care wherever possible, there are likely to be efficiency savings for local healthcare economies. If nothing else, GPs and practice nurses need to be kept informed about locally available services and referral routes, which in itself takes time and effort, and should be factored into any service specifications and delivery plans for breathlessness services.

Recommendation 7: Encourage consistency in coding within primary care. The pilots highlight the importance of accurate, consistent coding of respiratory and cardiology diagnoses within primary care. This is important when using the GRASP tool, but is also vital across the different pathways and approaches. For example, coding COPD as mild, moderate or severe, as opposed to simply ‘COPD’, is important, and a lack of graded coding can sometimes indicate that the appropriate diagnostic tests have not been carried out. With this in mind, we recommend that local commissioners and providers encourage accurate coding within their service specifications and delivery plans, and educate primary care clinicians accordingly. This also aligns with NICE guidance regarding respiratory conditions 19.

Recommendation 8: Build in evaluation and monitoring requirements from the outset of future programmes. It is vital to develop appropriate and robust monitoring and performance management processes for any new intervention, whilst ensuring pragmatism in data collection approaches. Whilst we recognise that local programmes will vary in design and delivery model, and consequently local data collection will vary accordingly, we suggest that commissioner and provider might want to consider an economic assessment of the intervention, mapping the pathways of care being provided, and capturing patient experience data, as standardised measures.

Recommendation 9: Consider opportunities for wider impacts. This pilot has highlighted the potential for the breathlessness pathway to impact on other conditions outside of cardiology and respiratory services, potentially offering significant long-term returns on investment and addressing multiple commissioning priorities. We recommend that the full potential of this pathway be considered in future commissioning, with monitoring of patient outcomes devised and implemented accordingly, in order to demonstrate the full

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19 NICE, Chronic obstructive pulmonary disease in over 16s: diagnosis and management, June 2010
https://www.nice.org.uk/guidance/cg101/chapter/1-guidance
potential impact of the model. This may help with financing the pathway and indicate the data collection and evaluation requirements. Linked to this, it may be useful to explore the potential for other symptom-based pathways, given the evidence emerging from the breathlessness pilots.

**Recommendation 10: Providers should engage commissioning leads at the outset.** The pilot programme has demonstrated the short-term impacts that can emerge from this model of care, and its potential to achieve significant broader longer-term impacts. However, in order to influence commissioning decisions, commissioners must be fully aware of the models and their potential benefits. The pilot highlighted the importance of providers and commissioners developing and maintaining relationships, to ensure providers can be appropriately involved discussions regarding emerging learning, potential improvements and the sustainability of the service.

**Recommendation 11: Consider how the programme aligns with broader local programmes and priorities.** The pilots have all been sustained to varying degrees in all three pilot sites as a result of alignment with other local programmes. This is likely to be a critical success factor in future programmes, and we recommend that providers clearly demonstrate how activity to address breathlessness may help commissioners to achieve multiple objectives and aims.

**Recommendation 12: Ensure logistical considerations are fully explored in advance.** The pilots struggled in differing ways with addressing logistical issues, including staffing levels, accessing suitable venues, and ensuring smooth funding flows. These challenges are largely to be expected as inherent in pilot programmes with short term funding. However, we suggest that all aspects of logistics should be carefully considered in any service contract, to try to avoid these issues happening under commissioned services. Commissioners may usefully wish to request information regarding staffing, venues, funding flows etc. within service specifications.
Acknowledgements

Our thanks go to those who have supported and facilitated the evaluation and data collection activities; without their support and active involvement this evaluation would not have been possible. Our thanks go to stakeholders at pilot site and programme level. To protect anonymity we have not identified pilot site patients. Programme steering group members are listed below and interviewees are listed in Appendix 4.

*Programme steering group members*

Jeff Featherstone, Programme Manager, Premature Mortality Medical Directorate, NHS England

Dr. Mike Morgan, National Clinical Director, Respiratory Disease, NHS England

Dame Helena Shovelton, Patient Advocate

Dr. Huon Gray, National Clinical Director, Coronary Heart Disease, NHS England

Dr. Erika Denton, Norwich and Norfolk University Hospitals and NHS England

Vanessa Brown, Improvement Manager, Sustainable Improvement Team, NHS England

Helen Wilkinson, Improvement Manager, Living Longer Lives, NHS England

Lesley Manning, Directorate Coordinator, NHS England

Dr. Heather Heathfield, Director of Impact and Insight, OPM

Lauren Roberts, Principal Consultant, OPM.
Appendix 1: Leicester, Leicestershire and Rutland Case Study

Summary

In response to a set of challenges relating to diagnosing and treating breathlessness and in line with a wider initiative towards integrated care through the Better Care Together programme, Leicester, Leicestershire and Rutland have set up a symptom-based pilot pathway aiming to incorporate:

- Implementation of a breathlessness pathway in primary care.
- Improving links with lifestyle and behaviour change support in the community.

NHS England provided some of the funding required for this work and commissioned OPM to evaluate the pilot. This case study presents the key findings.

Key outcomes include:

- Reduction in the time from referral to diagnosis (from 16 weeks to 5 weeks).
- Further outpatient referrals avoided in 30% of cases due to multi-disciplinary team approach.
- Increase in the proportion of patients discharged from secondary care after one visit (from 29% to 48%).
- Patient satisfaction, understanding of their condition, and compliance with treatment.
- Relationship-building between clinicians, departments and primary/secondary/community care.

Background

The pilot set out to address a set of challenges relating to diagnosing, treating and managing breathlessness:

- Lack of symptom-based services.
- Delays in diagnosis.
- ‘Yo-yoing’ between specialists.
- Co-morbidity frequently undetected.
- Lack of knowledge of existing services.
- Insufficient investigations prior to referral.
- Silo working within secondary care.

It also built on opportunities through the Better Care Together programme and Listening in Action approach.

Figure 3: Source: www.bettercareleicester.nhs.uk
Description of the service

**Phase 1**


**Phase 2**

Implementation of a breathlessness pathway in primary care.

Links with lifestyle and behaviour change support.

**Phase 1 (completed):**

This phase has been supported with funding from NHS England

- Consultant reviews referrals to outpatient respiratory and cardiology departments (standard pathway referrals).
- Patients with symptoms of breathlessness identified to enter the breathlessness clinic pathway.

- Respiratory and cardiology consultants hold a joint clinic.
- Diagnostic and investigative tests completed.
- Respiratory physiotherapy.
- Joint multi-disciplinary team meeting at the end of each clinic.

- Patients leave clinic with a diagnosis and treatment or management plan.
- Follow up appointments e.g. respiratory physiotherapy.

**Phase 2 (underway):**

There is work underway to implement a breathlessness pathway in primary care through engaging with GPs, and developing a clear pathway, guidance, and digital referral mechanisms. This is funded through Health Education East Midlands via an integrated care fellowship.

There are also plans to incorporate lifestyle and behaviour change support within the clinics or via referral links e.g. exercise programmes, relaxation classes, obesity management.

“It has reduced the number of re-visits for further investigations, and streamlined the whole process. It has minimised any potential delays in diagnosing and treating the patients.”

– Dhiraj D. Vara, Principal Clinical Physiologist (Respiratory)
# Impacts and outcomes

## Clinical outcomes
- 54 new cardiorespiratory patients were seen over the course of six months across nine clinics:
  - Six patients were seen by both specialists at the same clinic session.
  - All 54 patients were discussed in the multidisciplinary team meeting.
- The average time from referral to being seen was 5 weeks (compared to 13 weeks for standard pathway).
- The average time to diagnosis was 5 weeks (compared to 16 weeks for standard pathway).
- 26 patients (48%) were discharged back to the GP after the new visit only (compared to 29% for standard pathway).
- For 16 patients (30%), further outpatient referrals to the other specialty were avoided by having the multidisciplinary team approach.
- Earlier physiotherapy was achieved through having a respiratory physiotherapist present.
- 19% could have been diagnosed in primary care.
- In nearly 2/3 of cases specialist tests requiring a secondary care setting were not necessary.

## Impacts on patients
- Confidence in their diagnosis and treatment because they are treated by a team.
- Able to understand and accept their diagnosis because they receive the same information from different professionals on the same day.
- Misinterpretations are addressed on the same day because different clinicians all understand their overall condition.
- Receive a more specific symptom-focused approach.
- Receive care from clinicians with a keen interest in breathlessness.
- Feel more positive because they have not been on a long waiting list, or have not been passed between specialists.
- A more holistic picture of their condition including both clinical and lifestyle factors.
- Compliance with treatment options because they feel more positive and confident in the diagnosis.

## Impacts on clinicians
- Improved relationships between individuals across different disciplines.
- Improved links between different departments and disciplines.
- Increased awareness and understanding of the roles, activities, and challenges associated with different areas.
- Increased opportunities for learning.
- Sense of satisfaction and reward.
- Challenges relating to funding and availability of staff, space, and equipment.

“It’s much better for the patient to get the early answer rather than have their perception led astray for a long period.”

– Dr. Will Nicolson, Consultant Cardiologist
Success factors

The following factors were identified as being important to the success of this pilot and could be relevant for others implementing similar approaches:

- Enthusiasm, energy and initiative of individuals involved.
- Clinicians with a specific interest in breathlessness.
- Collaboration with a wide range of stakeholders at an early stage.
- Taking a supportive approach that provides opportunities for learning.
- Commitment to learning and improvement.
- Effective communication, engagement, and relationship building.
- Embedding the pilot within the wider context of moving towards integrated care.
- Proactive attempts towards mainstreaming the delivery of the work.
- A coordinated commissioning environment.

Next steps

In order to sustain the work undertaken in the pilot and embed it within a wider pathway incorporating primary care, community care and the overarching integrated care agenda, the following work is now underway:

- Presenting a case for on-going commissioning of the service.
- Implementing the pathway in primary care.
- Improving links with lifestyle and behaviour change support.

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“We can learn so much from each other through interdisciplinary collaboration.”
– Dr. Irene Valero-Sanchez, Respiratory Medicine - Clinical Fellow in Integrated Care
Appendix 2: Wessex Case Study

Summary

The breathlessness pilot in Wessex ran in two phases, delivered initially in partnership with local GP surgeries in Badgerswood and Wickham and then later in The Grange. The pilot programme bridged the gap between primary and secondary care for patients experiencing breathlessness by bringing in a specialist respiratory team to proactively identify patients and deliver a ‘one-stop shop’ for diagnosis and treatment in local surgeries. Patients living with undiagnosed breathlessness as a symptom received quick and accurate testing and support to begin treatment and managing their condition immediately.

Wessex adopted a ‘mentorship’ approach to their clinics aiming not only to improve the quality of patient care and diagnosis but also to deliver bespoke education packages for the practice staff and patients. Patients were given support to develop self-management plans and introduced to innovative treatment tools to control their conditions. Local doctors and nurses followed the patient journey and received multi-disciplinary training sessions as part of improving understanding of breathlessness and approaches to identifying, diagnosing and treating the condition.

Combining a mix of mentorship, relationship building and bringing innovative tools and expertise into community settings, the pilot achieved its key goals:

- Forming partnerships with secondary care and primary care across Wessex, including the AHSN, Queen Alexandra Hospital and local GP practices.
- Assisting with the education of practice nurses delivering respiratory care.
- Increasing patient education leading to effective self-management.
- Improving patients’ quality of life by providing accurate, relevant and timely information.
- Informing the development of effective breathlessness pathways.

Key outcomes include:

- Patient satisfaction with the experience (100%), compliance with treatment (70%), and confidence managing their breathing symptoms (96%).
- Stronger links and relationships between primary and secondary care providers.
- Reduction in the number of exacerbations by 93% and decrease in visits to the emergency department or hospitalisations by 100% in the 6 months post clinic.
- OPM evaluated the impact of the breathlessness pilot clinic in Wessex based on qualitative interviews and focus groups held with nurses, doctors, and programmes leads involved in the project, as well as a review of background documents, secondary data and patient feedback provided by the Wessex Academic Health Science Network (http://wessexahsn.org.uk).
**Background**

The pilot began in April 2015 in response to a national call from NHS Improving Quality (NHS IQ) for sites to design and deliver innovative models to diagnose patients who suffer with the symptom of breathlessness. The Wessex Academic Health Science Network (Wessex ASHN) in collaboration with other local health stakeholders took the strategic lead in the programme development. The project received start-up funding from NHS IQ as well as in-kind resources from the Queen Alexandra Hospital (QAH) in Portsmouth. Local GP surgeries were selected as partners based on their interest in the area and proximity to QAH.

The specialist clinical delivery team led by Respiratory Consultant Prof Anoop J Chauhan included an expert Respiratory Nurse, Biomedical Scientist, Specialist Registrars and physiologists with an interest in respiratory medicine. Cardiac consultants were also on call at QAH to assist.

**Description of the service**

The Wessex pilot followed three stages of delivery: identifying patients to take part; a carousel style clinic to test and diagnose patients on the day; and a follow up mentorship clinic with patients to ensure treatment was understood and adopted.

**Stage 1:**

Identifying patients: the team used a proactive case finding tool called GRASP to scan practice records for symptoms associated with breathlessness, including signs of COPD, asthma and heart failure. Results prioritised ‘high-risk’ patients with overlapping symptoms, and then a manual assessment of each patient’s practice records was done to ensure there was not already a condition that explained the symptoms and that the history of exacerbations was recent.

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20 GRASP is accessible online at: [http://www.nhsiq.nhs.uk/8631.aspx](http://www.nhsiq.nhs.uk/8631.aspx)
**Stage 2:**

Taking part: once identified as ‘high-risk’, patients were invited to take part in the ‘one-stop shop’ pilot clinic based in their local surgery. Each clinic ran for one day in Badgerswood and Wickham, and for two days out of The Grange. The carousel-style clinic allowed patients to move between rooms – first having physiological assessments and undergoing various other tests where necessary, then meeting with a respiratory consultant for medical review and diagnosis, and finally receiving support to understand and manage their diagnosis.

The patient appointment took approximately one hour and all 42 patients who attended across the sites received a definitive diagnosis on the day with the exception of 7 patients who were sent onto secondary care because of severe nature of their disease.

Local surgery nurses were given the chance for a bespoke educational experience encouraged to follow patients through their journey and ask questions as they went. At lunchtime, the respiratory specialist team delivered educational workshops on the topic of breathlessness with the doctors and nurses, and also hosted multi-disciplinary team meetings to review all the patients and discuss why certain decisions were made.

**Patient Journey through the pilot clinic**

1. Full physiological assessment
   - Various other tests as necessary (respiratory, allergy and cardiac)

2. Clinical review looking at patient history and offering diagnosis

3. Self-management and follow-up involving education around diagnosis and techniques for managing

4. Follow up mentorship clinic one month after diagnosis

**Stage 3:**

**Follow up clinic:** One month on patients were invited to return to their GP surgery for a ‘mentoring’ follow-up clinic to discuss their experiences in the interim and ensure they were adopting treatment and managing their condition.

“I think by going out and doing the education side of things you hopefully have a knock on effect for the rest of the practice as well and for all the patients even if you haven’t seen them.”

– Dr Claire Roberts, specialist clinical team

“We’ve just finished the last pilot practice where I held the mentorship clinic. The patients couldn’t thank me enough for diagnosing and treating them.”

– Jayne Longstaff, Lead respiratory nurse, specialist clinical team
## Impacts for patients

- **42 high-risk patients** were seen and received a definitive diagnosis. The most common diagnosis was asthma.

- Only 1 patient of those who confirmed their attendance did not attend the clinic. This is considered a very low rate compared with previous respiratory clinics indicating effective outreach and enthusiasm to take part.

- **Feedback from patients was overwhelmingly positive** from all clinics both in terms of patient experience of the clinic and interventions made. Patients spoke about the positive impact the diagnosis and self-managing support had on their quality of life, symptoms and well-being (survey results revealed that 100% of patients were satisfied with their experience, 70% had good compliance with treatment, and 96% felt confident managing their breathing symptoms post clinic).

- **Patients appreciated that specialists were working with their GPs giving them confidence in the quality of diagnosis** as well as the reassurance that they understood how to look after them. Patients also appreciated having their symptoms taken seriously.

- **A ‘one-stop’ clinical review optimises treatment and reduces anxiety.** Receiving a definitive diagnosis positively impacted patients’ mental and physical health. In some cases, this was a combination of moving out of ‘limbo’ to understanding their condition and seeing someone in an environment they know locally, rather than travelling to hospital. There was also a reduction in the number of exacerbations by 93% and 100% decrease in visits to the emergency department and hospitalisations.

## Impacts for clinicians

- **Taking a holistic view of the patient is possible through a community based clinic:** by working out of local GP surgeries, specialist teams have access to the patient’s full medical history and gain insight from local staff into their social history in order to make the most appropriate recommendation for treatment.

- **Having time to diagnose and treat:** in primary care having half-an-hour to spend with a patient is rare. The pilot allocates up to one hour of dedicated time to ensure issues are diagnosed accurately and the patient understand how to manage their condition. This avoids multiple referrals, stress on the patient, and the chance of exacerbations.

- **Building relationships between primary and secondary care:** often secondary teams are cut off in hospitals. This model of specialist community-based delivery ensures a smoother process for the patients, but also importantly builds relationships between GPs and specialists that have the immediate and longer-term impacts of enhancing collaborative decision-making, communicating when questions or issues arise, and problem solving.

- **Upskilling and capacity building locally:** bringing secondary care expertise to GP clinics in a mentorship style format has enhanced awareness of breathlessness and improved skills for diagnoses and supporting patients to manage these conditions.

## Clinical outcomes

- **Identifying at-risk patients and accurately and confirming diagnosis:** patient feedback shows there is an unmet need in actively case-finding patients with undiagnosed breathlessness in community settings.

- **Reduction in secondary care referrals:** bringing secondary care into the community means teams are able to do a lot of tests that normally wouldn’t be possible because of expertise and equipment (including ECG, spirometry, bmp, blood pressure, skin prick testing). Only 7 patients who took part in the pilot needed to be referred to hospital for further tests.

- **Cost savings for NHS England on secondary referrals and avoidable admissions (£142 cost of clinic per patient compared to £241 tariff for outpatient appointment).**

- **Joined up care and clarifying the patient journey:** for patients with breathlessness there can be lots of different medical professionals inputting into their care, assessment, and diagnosis. The patients can sometimes be the only person joining things up. The pilot model allowed patients to receive quick and accurate secondary care within their GPs service. This minimised miscommunication and instilled confidence amongst patients that their journey was understood.
Next steps

The Wessex ASHN and its local health partners are considering a combination of the models to adopt and spread the work:

- MISSION ABC (Modern Innovative Solutions Improving Outcomes in Asthma, Breathlessness and COPD) expands this pilot model to be ‘one-stop shop’ addressing these conditions.
- There’s also potential to integrate and tackle diabetes through this work.
- Wessex ASHN is currently working with a number of CCGs across Wessex to take up the model and test the approach in community settings.
- Potential to repeat pilot clinic in another surgeries using larger cohort.
- Introducing IT tools and innovative testing/treatment tools to support enhanced management of conditions. For example, simple technologies that ensure patients know when inhaler medication is being taken correctly.
- Potential inclusion into NHS England, Vanguard & AHSN collaboration.
- Undertaking a rigorous cost analysis to show long-term savings created by the work.

Key learning

- For sustainability you need consistency of approach by primary care physicians – following reliable management protocols around Breathlessness, ensuring quality of diagnosis, and collaborating with secondary care on an ongoing basis.
- Limited pilot resources and funding meant only ‘high-risk’ patients could be seen. In the future, it’s important to fund pilots appropriately so they are able to explore the problem in-depth.
- Clinical leadership is essential for driving forward the concept and getting it off the ground – including bringing in secondary care expertise and resources and making local partners.
- Developing consistency of coding symptoms on breathlessness is crucial in being able to effectively identify patients and ensure they don’t slip through the cracks or get misdiagnosed. Case searches tended to vary based on the specialist interest of local GP practice staff and the local context.

Contact details

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Lauren Roberts, Roberts@opm.co.uk

“One thing we were seeing a lot of was that patients were going undiagnosed or were being pigeonholed with a diagnosis, sometimes incorrectly. So what we set up was a way of investigating people with breathlessness to make sure that we are detecting all the reasons for their breathlessness as accurately as possible.”

– Dr Andy Whittamore, specialist clinical team
Appendix 3: Ashton, Leigh and Wigan Case Study

Summary

In response to challenges in effectively diagnosing and treating the causes of breathlessness, a symptom-based pilot pathway has been set up in Ashton, Leigh and Wigan, incorporating:

- Practice-based patient record reviews by Respiratory Nurses, to identify patients presenting with breathlessness and at risk of deterioration.
- Implementation of a breathlessness pathway in primary care.
- Proving accurate and swift diagnosis for patients with breathlessness, including providing appropriate treatment and lifestyle advice, with follow up monitoring in primary care settings.

NHS England provided some of the funding required for this work and commissioned OPM to evaluate the pilot. This case study presents the key findings.

Key outcomes from the pilot include:

- Improved diagnosis of COPD, asthma and heart failure, with increased prevalence rates as a result, and appropriate treatment plans being put in place.
- High levels of patient satisfaction and understanding of their treatment plan.
- Increase in the proportion of patients discharged after just one visit.
- Relationship-building between clinicians and primary/secondary/community care.

Background

The pilot was originally designed in 2010 by Atherleigh Patient Focus (a practice based commissioning group) and implemented by Health First, a community interest company (CIC) operating in the North West of England. It was then commissioned by Wigan Borough Clinical Commissioning Group (CCG), before the NHS IQ funding enabled the pilot to be expanded and encompass new processes. Practice nurses and GPs identified a need for patients presenting with breathlessness to receive an accurate diagnosis as quickly as possible, and to have their needs looked at holistically, to identify the root cause of the symptoms and ensure the most appropriate treatment plan could be put in place. Patients had previously often been ‘passed around the system’, with different secondary care consultants and specialists carrying out diagnostic tests for discrete conditions, without assessing the potential causes of the patients’ breathlessness in full. Travelling can be difficult for this group of patients, as can attending multiple appointments on different days.

“The main USP is that it’s been about finding patients, not waiting for patients to be referred. We’ve proactively searched for patients, going into practices to gain their trust, working alongside practice teams to search their computer systems for patients with undiagnosed problems.”

Advanced Nurse Practitioner
Description of the service

The service involved:

- Integrated working across primary and secondary care.
- Active searching for patients in primary care with symptoms of breathlessness at risk of deterioration. Respiratory Nurses reviewed the cases in primary care, working alongside practice teams.
- Consultant-led clinics held in primary care on a 2 weekly basis, rotating around different practices across the borough depending on patient referrals.
- An overarching focus on early and accurate diagnosis, including an enhanced review and diagnostic service which screened for heart failure, asthma, COPD and other causes of breathlessness; provided medication and treatment reviews; delivered lifestyle advice and self-management plans; and supported practice nurses to sustain the approach via a mentoring service.

The service provided a single ‘point of care’, with patients accessing the clinic receiving BNP testing and results on the day, immediately followed by spirometry, echocardiograph, lifestyle and self-management advice.

Follow up was provided for patients with persistent symptoms, including follow up appointments in primary care and targeted seasonal advice for those identified as most at risk.

Desk-top guidance has been produced for GPs to assist with managing patients with COPD, whilst mentoring and guidance has been provided to practice nurses.

The NHSIQ pilot funding enabled the team to hire a BNP testing machine for use in the weekly breathlessness clinics, to pay for a locum Physiologist to undertake echocardiographs in the clinic, and to roll-out the pilot across half of the local GP surgeries (33), increasing from a third of practices being covered under the previous existing scheme.  

[Map source: www.wigan.gov.uk]
Impacts on patients and care outcomes

- The pilot enabled patients to receive an accurate diagnosis and appropriate treatment plan more quickly than would otherwise have happened.
- There has been an increase in patients on the asthma and COPD register in practices where the pilot has taken place, due to misdiagnosed patients being identified and correctly diagnosed. Appropriate treatment was then put in place.
- COPD prevalence has increased by up to 44% in practices taking part in the pilot.
- There has been a 30% increase in people classing themselves as ‘ex-smokers’ 5-months after accessing the service.
- The pilot leads reported medicines management savings of £40,000 over a 6-month period across the borough, as a result of accurate diagnoses leading to more appropriate prescribing.
- There has been increased diagnosis of heart failure as a result of the pilot. One practice increased the number of patients diagnosed as experiencing heart failure from 119 to 222 over a 10-month period after joining the pilot (an 86% increase).
- Other conditions that have been diagnosed in the clinics include valve disease, atrial fibrillation, bronchiectasis, pulmonary fibrosis; emphysema, lung cancer, and patients eligible for lung transplants. This has enabled appropriate treatment and advice to be provided swiftly.
- Anecdotally, clinicians report that patients receiving a diagnosis and treatment plan that involves behaviour change (for example, losing weight or stopping smoking) are more inclined to accept the diagnosis and advice offered, due to increased understanding of the underlying causes of their symptoms and feeling their needs have been considered holistically.
- Patient satisfaction is high; patients welcome the ‘one-stop shop’ clinics in their local GP practice rather than having to travel to hospital, and having their diagnostic tests on one day. Patients understand the diagnosis provided and have confidence in the clinicians.

“"This is the first time I felt somebody has listened to my issues around my breathing and explained my condition.”
Patient survey respondent

“"It reassured me and my husband that I now know what I’m dealing with, and that lots of people have it. It took away the worry factor; you think all sorts, especially when it’s a chest problem.”
Patient interviewee

“"When I asked questions I was given a direct answer I could understand fully, which was very reassuring.”
Patient interviewee
Impacts on clinicians

- There are anecdotal reports that practice nurses who have been mentored by the respiratory nurses have been upskilled and increased their confidence in referrals and signposting for patients with breathlessness.
- Increased job satisfaction and strong feelings of pride for staff involved in delivering the service, who are highly committed to its success and feel part of a strong team.
- Confidence that they are addressing patient needs holistically.
- Increased knowledge and understanding for individuals working in both primary and secondary care.
- Reassurance for GPs and practice nurses that there is someone they can call on for help or advice if needed.

Challenges

- Staff shortages have led to costly reliance on a locum echocardiograph technician.
- The BNP machine test results were not sufficiently accurate, forcing this element to be halted.
- It took time to build up trust amongst some practice staff and GPs, requiring regular engagement and time upfront to attend Forum events and engage in 1-1 discussions.
- The service contract has been reviewed by the CCG on an annual or six-monthly basis since its inception, limiting stability and creating uncertainty for both staff and patients.
- It has operated as a ‘postcode lottery’ service, whereby patients registered with practices in one third of the locality do not receive access to the service.

Next steps

As a result of the success of the Breathlessness service, Wigan Borough CCG has recently commissioned a Primary Care Respiratory Service to be rolled out across the whole of Wigan Borough. This Service will be delivered by British Oxygen, not Health First, following a competitive tendering process. The BNP pathway will continue across the borough.
**Key learning**

**Team working is critical to success:** The clinicians and support staff involved in providing the breathlessness service report open dialogue and flexibility, with a strong sense of collaboration, loyalty and trust. Team members and practice staff have contact details for one another, to call for advice or guidance.

**Take time to build up trust:** This team work and open dialogue did not happen overnight: nurses in the team each work with different practices, and took the time to build up trust and confidence amongst the practice nurses, GPs and admin staff within those practices. This helped to ensure there was open dialogue regarding patient care, and practice staff understood the benefits of the service.

**Ensure there is a back-up plan in place:** The BNP testing machine had a higher than acceptable rate of variation in results when compared to laboratory testing. This meant the BNP testing element of the pilot was temporarily halted following the testing and diagnosis of the initial 40 patients. The team continued to provide diagnostic tests and follow up treatment in the clinics, but accepted that same-day test results were not possible without access to an accurate testing machine.

**Engage commissioners from the outset, and sustain this throughout:** The Health First team have presented some impressive results from the breathlessness service. However, engagement with the CCG has not been as consistent or open as might have been useful in hindsight.

**Consider the patient's needs holistically:** The service is reported to be successful as a result of addressing the symptom of breathlessness and considering all potential causes for this.

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**Contact details**

**Ashton, Leigh and Wigan:**
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**OPM:**
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"Patients understand their condition, their inhalers, and why they are doing things. They know the signs of infection to look out for and what to do. We are preventing hospital admissions. Patients know they can contact the service if they have any issues."

Respiratory Nurse
Appendix 4: Data Mapping

Overview of the types of data analysed from each pilot site.

Ashton, Leigh and Wigan pilot site

<table>
<thead>
<tr>
<th>Data analysed</th>
<th>Primary or secondary</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative interviews with key programme</td>
<td>Primary data collection</td>
<td>Interviews with: Sandra Burns, Dr. Ram Sundar, Dr. Bob Kirk. Focus group with eight members of the Health First team, including Wendy Fairhurst, Sandra Burns, Respiratory Nurses and Programme Coordinators.</td>
</tr>
<tr>
<td>leads and staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qualitative interviews with patients</td>
<td>Primary data collection</td>
<td>Interviews with two patients who presented with breathlessness and attended the clinic</td>
</tr>
<tr>
<td>Prevalence data</td>
<td>Secondary data provided by Health First</td>
<td>Prevalence of heart failure, asthma and COPD (registered patients) across all participating practices in the borough, from 2010 / April 2014 to February 2015, showing total numbers and percentage change over time at practice level.</td>
</tr>
<tr>
<td>CODP Discharges</td>
<td>Secondary data provided by Health First</td>
<td>Overview of monthly CODP discharges, October 2011 to July 2013 (graph and data table)</td>
</tr>
<tr>
<td>BNP Audit data</td>
<td>Secondary data provided by Health First</td>
<td>38 patients; data shows BMI, Spirometry outcomes, new diagnosis and comments on treatment.</td>
</tr>
<tr>
<td>Audit data</td>
<td>Secondary data provided by Health First</td>
<td>February 2013 audit data, showing medication, intervention and follow up visit outcomes for 32 patients on the pathway.</td>
</tr>
<tr>
<td>Medicines management savings data</td>
<td>Secondary data provided by Health First</td>
<td>Data shows monthly medicines management savings, with annualised totals (2011-2015).</td>
</tr>
<tr>
<td>Patient experience</td>
<td>Secondary data</td>
<td>136 patients: data shows patient self-reported</td>
</tr>
<tr>
<td>Source</td>
<td>Data Type</td>
<td>Description</td>
</tr>
<tr>
<td>--------</td>
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</tr>
<tr>
<td>survey data</td>
<td>provided by Health First</td>
<td>satisfaction with elements of their care and their overall experience. Gender and ethnicity breakdowns are provided.</td>
</tr>
<tr>
<td>Ipsos Mori patient experience findings</td>
<td>Secondary data provided by Health First</td>
<td>PowerPoint slide-pack presenting experience feedback from patients with COPD, collected and prepared by Ipsos Mori, November 2011.</td>
</tr>
</tbody>
</table>
Leicester, Leicestershire and Rutland pilot site

<table>
<thead>
<tr>
<th>Data analysed</th>
<th>Primary or secondary</th>
<th>Notes</th>
</tr>
</thead>
</table>
| Qualitative interviews with key programme leads and staff | Primary data collection | Nine interviews, with: Dr. Rachael Evans, Programme Lead and Respiratory Consultant  
Dr. Will Nicolson, Cardiology Consultant  
Dhiraj D. Vara, Principal Clinical Physiologist, Respiratory  
Darren Jackson, West CCG Lead GP and Primary Care Clinical Lead of the Long Term Conditions work stream of the LLR Better Care Together programme  
Irene Valero-Sanchez, Respiratory Medicine - Clinical Fellow in Integrated Care  
Laura Norton, Service Improvement Manager for Long Term Conditions, West Leicestershire CCG  
Prof. Michael Steiner, Consultant Respiratory Physician and Secondary Care Clinical Lead of the Long Term Conditions work stream of the LLR Better Care Together Programme  
Sadie Hall, Deputy Nurse Manager for Outpatients  
Shaazia Khatri, Senior Respiratory Physiotherapist |
| Clinical outcomes and patient experience data     | Secondary data collection | Report from the pilot site including clinical outcomes and timescales data, comparing the pilot pathway with previous routes, and a summary of patient experience data: UHL NHS Trust ‘Breathlessness’ project report 2015/16  
No raw data was reviewed by OPM – the analysis was carried out by the pilot site. |
## Wessex pilot site

<table>
<thead>
<tr>
<th>Data analysed</th>
<th>Primary or secondary</th>
<th>Notes (sample sizes, timescales etc.)</th>
</tr>
</thead>
</table>
| Qualitative interviews and focus groups with key programme leads and staff | Primary data collection | Interviews with:  
- Jayne Longstaff  
- Dr. Rachel Dominey  
- Kimm Lawson  
- Dr. Ellie Lanning  
- Dr. Andy Whittamore  
- Dr. Claire Roberts  
- Sue Hazeldine  
- Claire Rogers  
- Frank Ratcliff  
- Caroline Powell  
- Catherine Matheson |
| Key background documents | Secondary data provided by WAHSN | Breathlessness project plan  
Breathlessness project inclusion criteria  
Summary of scoping research (Breathlessness final)  
Fact sheet for Respiratory Futures website  
WAHSN presentation of Breathlessness project headlines to Portsmouth QAH. |
| Patient feedback and evaluation | Secondary data provided by WAHSN | Qualitative patient feedback (freeform comments)  
Patient questionnaires  
Initial health assessment data and 6 month post-clinic assessment data  
Cost comparison summary. |
Appendix 5: The case for commissioning: published evidence

The published evidence base regarding COPD, heart failure and asthma all indicates that earlier, accurate diagnosis is critical to securing efficiency savings within the NHS. Some of the headlines from the existing evidence base for England are outlined below, to help to ground some of the impacts presented in this report within the broader cost base regarding breathlessness. The intention of this study was not to undertake an economic assessment, and we have not attempted to monetise the pathways developed as part of the pilots, or the outcomes emerging.

**Nice Guidance - heart failure**

- Approximately 67,000 people with acute heart failure were admitted into hospital in England in 2012/13. Of these people, 44% (29,500 people) would be likely to have new suspected acute heart failure and be subject to B-type natriuretic peptide [BNP] or N-terminal pro-B-type natriuretic peptide [NT-proBNP] testing under the NICE.
- The cost of a follow-up outpatient appointment for heart failure is £1645.
- The unit cost per BNP or NT-proBNP test is £28. The estimated additional cost could total £271,600 nationally (or approximately £490 per 100,000 population). This testing may reduce up-front demand for echocardiography because it can be used to select patients who need priority referral for echocardiography. The testing may also result in more appropriate heart failure management, thereby leading to fewer re-admissions.
- The cost of a cardiologist is estimated to be around £400 per 4 hour clinical session.
- An echocardiographer post costs £43,000 (Agenda for Change Band 7 at midpoint of scale) per annum including on-costs. For overtime, the hourly rate is £26 including on-costs.
- Earlier diagnosis may result in substantial savings from avoiding delay in heart failure therapy and avoiding harm from inappropriate therapy. In addition, waiting for echocardiography is one of the reasons why hospital stay can be prolonged, so delivering early echocardiography would shorten the time spent in hospital.

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21 Nice Guidance Costing Statement: Acute Heart Failure (October 2014)
https://www.nice.org.uk/guidance/cg187/resources/costing-statement-193256893
NHS England - COPD

- COPD causes 115,000 emergency admissions per year, 24,000 deaths per year and 16,000 deaths within 90 days of admission. Mortality rates are high with one in 12 patients dying during their hospital stay and one in 6 dying within 90 days of discharge.

- If the localities above the median death rate for COPD could achieve the median death rate, 3,500 lives could be saved per year. If local areas could achieve the death rate of the lower quartile areas, 7,800 lives could be saved per year.

- An estimated 2 million people have undiagnosed and untreated COPD. Over half those with moderate disease are undetected and 20% of undiagnosed have severe or very severe disease.

- 10% of emergency admissions for acute exacerbation of COPD are in people whose COPD is undiagnosed, and they are likely to have had significant disabling symptoms for some time. The acute admission (and its 14% risk of death within 90 days) could have been prevented by earlier diagnosis and proactive treatment.

- Both the NICE Quality Standard and the COPD and Asthma Outcomes Strategy recommend targeted case finding in those at higher risk of COPD. Systematic and opportunistic case finding interventions in targeted populations could have a significant impact on premature mortality in the medium and longer term. Targeting case finding on those at high risk of having undiagnosed COPD will result in earlier diagnosis and evidence-based chronic disease management. If this results in a 25% reduction in mortality in people who would otherwise have been admitted with undiagnosed COPD, it would save approximately 400 lives per year.

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AQuA - COPD

- COPD is the second most common cause of emergency admissions to acute care, is one of the most costly in-patient conditions treated by the NHS. The biggest caseload for primary care arises from respiratory conditions. COPD costs the NHS more than £800 million each year (£1.3 million per 100,000 population).
- Half of all patients with severe breathlessness due to COPD die within 5 years.
- Three respiratory inhalers are currently in the top five costliest drugs to the NHS, at a cost of over £345 million per year.
- Research undertaken by NICE during the development of COPD Guidance estimated that the average cost of a spirometry test to be £9.91, varying from £5.01 to £14.81. Based on an average sized general practice with a list of 7,000 and 200 patients on the COPD register, ensuring that they all have a Spirometry test each year would cost between £1,000 and £3,000 per year.
- Based on data regarding the North West of England, the average cost of a non-elective hospital admission for COPD in the North West in the year is £2,649 per spell. Making even small reductions in the number of acute exacerbations is likely to bring financial benefits to commissioners e.g. a 10% reduction in emergency admissions cross the North West would save £5.6 million.
- The average cost of a non-elective hospital admission for COPD in the North West in the year was £1,332 per spell. Making even small reductions in the number of acute exacerbations is likely to bring financial benefits to commissioners.
- Smoking causes approximately 80% of COPD cases and causes 86% of COPD mortality. Stopping smoking with pharmacotherapy is the most cost effective

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26 AQuA Analytics, COPD Care in the North West of England, May 2014

27 British Lung Foundation, Invisible lives: Chronic Obstructive Pulmonary Disease (COPD) finding the missing millions (2007)


30 COPD Commissioning toolkit – Managing Exacerbations specification, DH (Aug 2012)


treatment for COPD and costs £2,000 per QALY\textsuperscript{33}. There is a 50 fold difference in costs between mild and very severe COPD, indicating the importance of early intervention\textsuperscript{34}.

- Research suggests that late diagnosis has a substantial impact on symptom control, quality of life, clinical outcome and cost.
- Most people with COPD report breathlessness as being the major disabling symptom that interferes with everyday activities. A survey by the British Lung Foundation\textsuperscript{35} found that around 40\% of people with lung disease are below retirement age and a quarter of these are unable to work; costing business an estimated 24 million working days in sick leave per annum.

\textsuperscript{33} NHS North West Respiratory Clinical Pathway Team CCG Reports (2012)

\textsuperscript{34} An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in England, Department of Health (July 2011)

\textsuperscript{35} Invisible lives: Chronic obstructive pulmonary disease (COPD) – finding the missing millions. British Lung Foundation (2010)