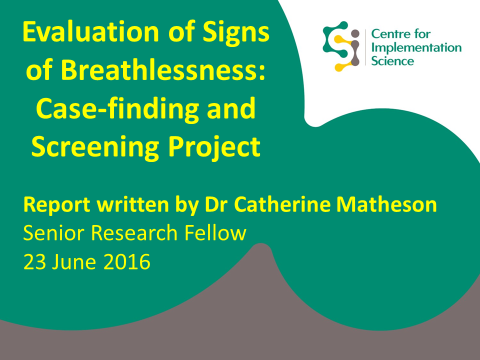
University of Southampton website[](http://wessexahsn.org.uk/)

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**Project funded by**

**Table of contents**

|  |  |  |
| --- | --- | --- |
| **Number** | **Chapter/Section** | **Page** |
|  | Project team | 3 |
|  | EXECUTIVE SUMMARY | 4 |
| 1 | **Background** | 6 |
| 1.1 | National context and policy background | 6 |
| 1.2 | Wessex AHSN Respiratory Quality Improvement Programme | 7 |
| 1.3 | Breathlessness today | 8 |
| 1.4 | Case-finding for respiratory and cardiac disease | 9 |
| 1.5 | Wessex AHSN NHS Improving Quality (NHSIQ) Breathlessness Project | 10 |
| 2 | **Aims and objectives** | 11 |
| **3** | **Methods** | 12 |
| 3.1 | Framework and design | 12 |
| 3.2 | Logistics of the project set up | 15 |
| 3.3 | Case-finding approach | 15 |
| 3.5 | Heart and Lungs Check Clinics [HLCC] | 16 |
| 3.6 | One-month post HLCC follow-up | 17 |
|  | Reviewing diagnosed patients 4, 6 and 12 months after HLCCs | 18 |
| **4** | **Results** | 18 |
| 4.1 | Case finding searches | 18 |
| 4.2 | Characteristics of the patients attending the 60 minutes diagnostic HLCCs | 20 |
| 4.3 | Patients with new respiratory or cardiac or other diagnosis | 22 |
| 4.4 | One-month post HLCC follow-up | 23 |
| 4.5 | Review of patients 4 and 6 months after HLCCs | 25 |
| 4.6 | Experience of patients attending HLCCs | 26 |
| 4.7 | Initial Health Economics | 32 |
| **5** | **Discussion** | 34 |
| 5.1 | Increased access to early accurate diagnosis of breathlessness | 34 |
| 5.2 | Partnerships primary and secondary care, increased skills of HCPs and improved patient experience, education and quality of life | 36 |
| **6** | **Conclusion** | 38 |
| 6.1 | Strengths | 38 |
| 6.2 | Limitations | 39 |
| **7** | **Recommendations** | 40 |
|  | **REFERENCES** | 41 |
|  | **APPENDICES** | 46 |

**Dr Catherine Matheson** undertook the evaluation, the literature review, the data interpretation, analysis and discussion, including strengths and limitations, recommendations, created all the tables, and drafted the initial 22,000 words manuscript of the evaluation report and the subsequent versions of that draft as well as the executive summary. Materials used were: framework specifications written by the funding body and the Wessex ASHN Project Initial Document, draft of methods /framework/logistics of project set up etc. very similar to that of COPD and asthma case finding and complex clinics from CLAHRC, WAHSN, WHCCG 2015, Excel spreadsheets, 2 PPT presentations, several meetings with Jayne Longstaff as well as attendance at one follow-up clinic.

**Project team**

**Jayne Longstaff**, *Respiratory Quality Improvement Nurse, Wessex Academy of Health Science Network [Wessex AHSN]* -- co-ordinated all aspects of the project i.e. buying equipment, liaising with GP practices, organising the electronic searches of patient records, developing patient information materials with support from the CLAHRC PPI champion, content of letters to patients, organising the Heart and Lung Check Clinics [HLCCs], involved in HLCCs and in MDTs after the HLCCs, conducting the one month follow-up clinics; undertaking review of patient records, as well as responding to queries and clarifying points during four meetings between February and June 2016

**Rachel Dominey,** *Senior Project Manager, Respiratory Quality Improvement Programme and Associate Director, Wealth and Enterprise, Wessex AHSN*–overview of the project, involved in designing the project and obtaining funding and in reporting back regularly to NHS IQ

**Professor Anoop Chauhan,** *Director of Research, Portsmouth NHS Hospital Trust and University of Portsmouth* – involved in the design of the project, the idea of doing a case finding initiative rather than a triage initiative and was also involved in providing training for GP practice staff and running the HLCCs

**Dr Claire Roberts,** *Clinical QI Research Fellow*– member of specialist clinical team

**Dr Frank Ratcliff,** *Project Manager, Wessex AHSN* **-** involved in helping run electronic searches of patient records

**Dr Andy Whittamore**, *Primary care clinical lead, Wessex AHSN RQIP* - interviewed by OPM as member of specialist clinical team

**Vanessa Brown**, Sponsor from NHS Quality Improvement (funding body) liaised with Rachel Dominey

**EXECUTIVE SUMMARY**

**Key results**

* Wessex AHSN Respiratory Team was among three national sites to be awarded £15,000 by NHS IQ to undertake a pilot Breathlessness project
* Out of a total of 42 patients attending Heart and Lungs Check Clinics 97.2% (n=41) were diagnosed with one or more respiratory conditions with 22 receiving more than one respiratory diagnosis (52.3%).
* The most common diagnosis was asthma (n=25) followed by sino-nasal disease (n=12), dysfunctional breathing (n=5), COPD (n=4), hypertension (n=4), GORD (gastro-oesophageal reflux disease) (n=3), ACOS (Asthma-COPD Overlap Syndrome) (n=2), asbestosis (n=2), vocal VCD (vocal cord dysfunction) (n=2), pneumonia (n=2), occupational asthma (n=1), glossitis (n=1), nasal polyps (n=1). A total of 11 out of 42 patients were referred to secondary care for further tests and diagnosis (26.1%).
* A total of 29 patients attended the one-month follow-up clinic (80% of diagnosed patients who had not moved away) either with the RQIP nurse (n=19) or with the GP practice nurse (n=10). After 4 months [for one GP practice] and 6 months [for 2 GP practices] 22 patients had good compliance with treatment.
* Compared to 12 months previously, exacerbations requiring ICS or AOB had reduced by 89.1% [46 to 5]. GP emergency visits by 83.6% [92 to 15]. OOH visits, A&E visits and emergency hospital admissions by 100% leading to savings of £8,640.
* Patient satisfaction was high with 95.6% recommending the service to family and friends and 100% satisfaction with the team that welcomed them and information received. Before the intervention appointment only 12.5% were very confident in managing their breathing problems and 20.8% were unconfident. After the intervention, no patient was unconfident and 65.2% were very confident. A typical comment was *This breathlessness project was very well organised and thorough and could help a lot of people.*

**Strengths**

* Improved patient outcomes and efficiencies were created through inter-organisational working and collaboration of resources and skills across primary and secondary care.
* Longitudinal element: following up patients 4 to 6 months after the HLCCs
* Compared to case finding for asthma and COPD in Wessex AHSN, NIHR CLARHC Wessex/WHCCG (2015) that also used the same GRASP suite of electronic tools the diagnostic yield was 97.2% compared to 59%. This suggest a more efficient manual filtering system following the electronic case finding searches of patient records and that a case finding approach based on symptoms rather than a specific condition may be more cost effective and that a diagnostic multi-disciplinary clinic is more effective than a clinic run by RQI nurses who could only provide a suggested diagnosis. This model is more in line with multi-disciplinary collaboration and inter-professional learning than other secondary care based models (WHO, 2010; Barwell et al, 2013)
* Two of the GP practices are part of 11 Vanguards programmes for new model of care in Wessex and South East Hampshire has 10 GP surgeries interested in rolling out this new model of care over the next 2 years

**Limitations**

* No feedback collected from GP practice staff and healthcare and medical staff involved (Bevan and Fairman, 2014)
* No evidence of the extent to which skills of HCPs and GPs have been increased and of the transferability of the newly acquired skills
* Limited patient feedback for third GP practice, quantitative data for only eight patients and qualitative data for only three patients out of 23 who attended the HLCC (Avis, 1997)

**Key recommendations**

* Development of accessible integrated respiratory services should include representation from primary and secondary care, including both physicians and nurses, and ideally organisations that promote innovation across both.
* Ensure that the skill mix of the specialist clinical team reflects the broad nature of respiratory and cardiac conditions to account for all presenting patients and their potential diagnosis.
* Build in evaluation, monitoring sustainability and potential spread from the start, not just expect that cost savings in the first year may be reinvested to fund a second year
* Collect data on the experience views of healthcare and medical staff especially HCPs and GPs in GP practices about the ease of use and functionality of the newly created pathway/model of care as well as suggestions for improvement
* Continue to build education, training and mentorship in GP practices
* Encourage and train GP practices to use GRASP suite of tools and manual filtering to identify patients with breathlessness symptoms but no diagnosis
* Collect data about education electronically or otherwise, training and mentorship given and especially received to provide evidence of the extent to which skills have been increased and of the transferability of the newly acquired skills
* Using validated questionnaires and/ or open-ended questions, collect evidence beyond basic satisfaction i.e. about the views and experience of patients, including the opportunity to provide suggestions for improvement
* Using interviews (telephone or otherwise) and/or focus group collect data on the experience and views of patients
* Using validated questionnaires collect data on the quality of life and education of patients after HLCCs – the one month follow-up clinic is a good opportunity to do this
* Further mentorship and education clinics should be planned between the practice staff and the clinical project team to consolidate learning and make this new model of care or new pathway sustainable in the long term.
* Work with GP practices and CCGs to encourage more standardised and more consistent coding of breathlessness
* Involve patients and carers and all levels of staff, including patient groups, in co-designing and evaluating the service and piloting surveys (Lockett et al 2012; Hayes et al, 2014; Bevan and Fairman, 2014)
* More marketing and awareness raising would have been beneficial
* The outstanding benefits to patients and GP practices and to CCGs need to be better disseminated, including in peer refereed academic publications

**1. Background**

**1.1. National context and policy background**

Using data from the Global Burden of Diseases, Injuries, and Risk Factors Study, Murray et al (2013) calculated the contribution of preventable risk factors, and ranked the UK compared with a group of high-income countries with similar levels of health expenditure in 1990 and 2010. Despite six decades of universal free health care and widespread public health initiatives and substantial increases in health expenditure, the UK’s health outcomes or longevity ranking against the average of 14 other original members of the European Union, Australia, Canada, Norway, and the USA (EU15+) over the past 20 years has failed to improve (Murray et al 2013).

The performance of the UK in terms of premature mortality is persistently and significantly below the mean of EU15+ and requires additional concerted action. In terms of premature mortality, worsening ranks are most notable for men and women aged 20–54 years in part because of dramatic increases in drug and alcohol use disorders (Murray et al 2013). The UK has significantly greater rates of age-standardised YLLs[[1]](#footnote-1) for ischaemic heart disease, chronic obstructive pulmonary disease, lower respiratory infections, breast cancer, other cardiovascular and circulatory disorders, oesophageal cancer, preterm birth complications, congenital anomalies, and aortic aneurysm. The leading risk factor in the UK was tobacco (11.8% of DALYs[[2]](#footnote-2) followed by increased blood pressure 9.0% and high body-mass index (8.6%). In addition, diet and physical inactivity accounted for 14.3%of UK DALYs in 2010 (Murray et al 2013).

West Hampshire clinical commissioning group [WHCCG], Wessex AHSN and the National Institute for health Research [NIHR] collaboration for leadership in Applied Health and Care [CLARHC] Wessex identified improved earlier diagnosis and innovative management of COPD and asthma as a priority. The ***Living Longer Lives* programme at NHS Improving Quality** aims to work with a wide range of partners across health and social care to **reduce the number of people who die too soon from illness or disease that could have been prevented or treated** ensuring that England’s rates of premature mortality for these diseases move from being among the worst in Europe to being the best (NHSIQ n.d.).

Raising public awareness of symptoms and early diagnosis of disease is one of three themes in the Living Longer Lives programme. For the most part, programmes under this theme have focused on raising awareness and improving diagnosis of symptoms pertaining to a particular clinical condition or disease, e.g. the *Be Clear on Cance*r campaign. This is in part because of much of the work is driven by partners/stakeholders who have legitimate, vested interest in realising improvement in a particular area, e.g. the major healthcare charities. However, it is also a result of the fact that referral pathways, services, and payment systems in the NHS are largely organised around clinical specialities and do not readily accommodate patient referrals within and between specialities, or facilitate clinical collaboration or organisational integration (Brown 2014, p1).

**1.2. Wessex AHSN Respiratory Quality Improvement Programme**

Wessex Academic Health Science Network [Wessex AHSN] is a membership organisation comprising all CCGs and provider NHS Trusts across Wessex.

***Figure 1: Wessex AHSN***



The Wessex AHSN respiratory quality improvement programme aims to improve respiratory health and reduce inequalities and variation across Wessex and to improve the patients’ quality of life and patient experience and to increase: early accurate diagnosis of respiratory disease; effective self-management and patient education; access to specialist services across Wessex, including pulmonary rehabilitation; patient experience of care and quality of life; skills and practices of healthcare professionals; and the development of effective service pathways for respiratory care and evaluation of cost effectiveness of outcomes (Wessex HIEC Partnership and WAHSN 2013)

The Wessex AHSN respiratory quality improvement programme is working with 10 CCGs, 9 providers and 5 Universities, including the Centre for Implementation Science based at the University of Southampton. More specifically, it operates collaboratively delivering joint solutions through a wide range of partners spanning universities, NHS Trusts, community care organisations, commissioners, patient groups, industry and national clinical respiratory bodies. (Wessex HIEC Partnership and WAHSN 2013).

**1.3. Breathlessness today**

Breathlessness can be caused by a number of potentially serious and life-threatening conditions (WAHSN, 2015). Although this list is not exhaustive, unexpected breathlessness is most likely to be caused by one or more of the following health conditions:

* Obesity or being unfit
* Anaemia, which is a low level of oxygen in the blood due to a lack of red blood cells or lack of haemoglobin
* Asthma that is not controlled properly
* Chronic obstructive pulmonary disease (COPD), which is permanent damage to the lungs usually caused by years of smoking
* Heart failure *i.e.* the heart is having trouble pumping enough blood around the body, usually because the heart muscle has become too weak or stiff to work properly
* Problems with the heart rate or rhythm, such as atrial fibrillation (an irregular and fast heartbeat)

Shortness of breath, or breathing difficulty, or breathlessness is one of the most common reason for visiting a hospital accident and emergency department (WAHSN, 2015). University Hospitals Leicester NHS Trust found that 67 out of 154 acute admissions (43.5%) were for breathlessness (Evans, 2015). Long term/chronic breathlessness affects about 10% of the general population but 30% of elderly people experience breathlessness (Baxter, 2014). Epidemiological data show that about 50% of obese patients are breathless and up to 70% of elderly obese complain of some degree of breathlessness (AoMRC 2013; RCP 2013). Up to 93% of people with heart failure, mainly elderly, suffer from breathlessness (NHS Networks 2014). Despite such high prevalence rates, breathlessness is only referred to once in the Action on Obesity and is not actually discussed (AoMRC 2013; RCP 2013). Breathlessness is mentioned as a reason for encounter in about 1% of the recorded consultations in general practice (NHS Networks, 2014).

Breathlessness and anxiety with panic disorder ten times more common in the population with COPD than in the general population. However, anxiety is under-diagnosed and under-treated in primary care (NHS Networks 2014). The sensation of breathlessness may be perceived as a consequence of the normal ageing process and patients may not even bring this as their GPs who are often uncertain of the extent to which breathlessness warrants an intervention and what that intervention should be (NHS Network 2014).

There have recently been various projects linked to breathlessness, including examinations of the historical, philosophical, cultural and anthropological aspects of breathing and breathlessness (Durham University 2015). However, breathlessness is most often associated with COPD, a chronic progressive condition that accounts for one death every 20 minutes in England and Wales (Rand Corporation 2015). IMPRESS is a project about breathlessness that draws together evidence and experience on COPD, heart failure, anxiety, obesity and anaemia and offers practical resources for clinicians, patients and public health on the prevalence and incidence of long term breathlessness in adults, including an algorithm for assessment (NHS Networks 2014).

Notwithstanding the lack of consistency and clarity in defining breathlessness and differentiating between chronic and acute breathlessness and in recording symptoms of breathlessness (Simon et al, 2013, the evidence-base cost-effectiveness linking early diagnosis and treatment of COPD does not exist for chronic and disabling breathlessness (NHS Networks 2014). A generic approach to diagnosis and treatment of breathlessness is likely to help patients and would be of interest for commissioners (Troosters and Remoortel 2009; Evans et al 2010).

**1.4. Case-finding for respiratory and cardiac disease**

Early diagnosis and hence prevention progression are likely to result in beneficial healthcare savings (BLF 2007; DH 2011). This is why national health policy initiatives in the UK advocate case-finding for various diseased, including COPD because of its cost saving potential (NICE, 2010; DH, 2011). Early diagnosis of COPD and optimisation of treatment thereafter has potential cost savings for the NHS of more than £1billion over 10 years (DH, 2011). However, national directives have not flagged up the most efficient strategies for case-finding for COPD or for other respiratory or cardiac diseases.

Early respiratory diagnosis opportunities are often missed by GPs despite patients consulting for years with lower respiratory symptoms, but being only diagnosed several years down the line (Jones et al, 2014). A recent systematic review of the literature concluded that a combination of symptom-based questionnaires sent to patients with risk factors for COPD or distributed opportunistically when patients attend the GP practice and the use of hand-held micro-spirometry seems to be most effective in case finding (Haroon et al, 2014)

Another approach to case-finding for COPD is an electronic review of GP practice databases to identify patients with symptoms suggestive of particular diseases *e.g*. COPD but who have not yet been diagnosed with a particular condition or illness (Jones et al 2014). National Health Service Improving Quality (NHSIQ) has promoted various electronic case finding or audit tools called ‘GRASP’ developed by PRIMIS at the University of Nottingham. GRASP-COPD, Asthma audit tool (AAT) and GRASP-HF are part of the available PRIMIS GRASP electronic tools. They were specifically designed to enable GP practices to audit their COPD, asthma and heart failure patients and include the possibility of identifying patients with undiagnosed COPD, asthma and heart failure. These GRASP tools do not rely on patient response to self-reported questionnaires and are compatible with any GP clinical electronic systems (e.g. EMIS Web, Vision, System One). They use a series of predefined READ code algorithms[[3]](#footnote-3).

A number of Clinical Commissioning Groups (CCGs) in Wessex (Portsmouth, Fareham and Gosport) have incentivised GRASP-COPD as a case finding tool (WAHSN/CLAHRC/WHCCG, 2015). The Asthma Audit Tool (AAT) is an efficient and effective tool for identifying patients with poorly controlled asthma or at risk of deterioration needing minimal nurse-led filtering. GRASP-COPD is an efficient way of searching both in terms of time and yield (proportion of patients seen to a proportion of patients with a diagnosis suggested) but requires significant modifications in order to make it fit-for-purpose without the inclusion of a nurse-led filter. (WAHSN/CLAHRC/WHCCG, 2015).

There is therefore a need to further test pathways enabling early detection of potentially undiagnosed breathlessness. One of these pathways is identifying patients with breathlessness read codes but no diagnosis in GP practices.

**1.5. Wessex AHSN NHS Improving Quality (NHSIQ) Breathlessness Project**

The Wessex AHSN NHSIQ Breathlessness project is embedded in both the Wessex AHSN Respiratory Quality Improvement Programme and the Breathlessness Programme of Living Longer Lives NHSIQ to pilot new models of care, which facilitate earlier diagnosis and treatment for people who experience breathlessness as a symptom**.**

The Wessex AHSN NHSIQ Breathlessness project was one of three selected national test sites selected by NHSIQ (Dominey, 2016). Given the need for further improvement in preventing premature mortality and the current interest in person-centred or integrated care, attention is now turning to raising public awareness of symptoms common to a number of conditions which could be prevented or treated more successfully through earlier diagnosis, and to facilitating referral pathways and services which provide joined up care so that patients are not passed ‘from pillar to post’ through the system in order to undergo the necessary diagnostic tests and to receive the correct treatment (Brown 2014, p2)

Next to pain, breathlessness[[4]](#footnote-4) is the most common symptom for which patients seek help and relief from their doctor. Approximately two thirds of cases of breathlessness in adults are due to a pulmonary or cardiac disorder. In about a third of cases, diagnosis will be multifactorial. 70% of all terminal cancer patients suffer breathlessness in their last six weeks (Borton et al 2014 quoted in Brown 2014, p2)

From 24 February to 23 March 2014 Public Health England piloted a Breathlessness Campaign Pilot in Oldham and Rochdale, using local press, radio and posters with the message “if you’re getting breathless doing things you used to be able to do easily then go and see your GP”. The campaign evaluation identified a range of clinical conditions or causes of breathlessness of people presenting to their general practitioner and the potential development of rapid access diagnostic services for people with breathlessness and the value of future regional and national awareness raising campaigns (Brown 2014). Following this success, the campaign was up scaled to a regional pilot running for four weeks in the East of England. Whereas the local pilot had used only press and radio advertising and posters, the regional campaign was spearheaded by television advertising in the Anglia broadcasting region: 13% of those who claimed to see the adverts, made an appointment to see their GP (Dominey, 2016).

NHS IQ’s LLL indicated that they would “pilot ‘rapid access’[[5]](#footnote-5) models for breathlessness clinics in three areas in 2014/15 and evaluate outcomes before rolling out new models from 2015-18” (Brown 2014, p2). Wessex AHSN respiratory team sent an expression of interest to bid to be one of three pilot sites (Dominey, 2016). Wessex AHSN Respiratory Team was among three national sites to be awarded £15,000 to undertake a pilot Breathlessness project. Wessex AHSN focussed on testing the suite of GRASP HF, GRASP-COPD and Asthma case-finding/audit tools to find patients with undiagnosed breathlessness in primary care with specialist support to manage them in primary care (Wessex AHSN 2015).

Unlike, the Wessex ASHN respiratory team, the other two national pilot tests [also awarded £15,000 each] had an existing service that already made savings which was supported by their respective CCGs. One was a community service funded by the CCG through reinvesting savings made. The other was a secondary care initiative whereby respiratory and cardiology were already working together but becoming national pilot test formalised the process. Prior to the bid for £15,000, the other two national pilot tests had incentivised the GP practices to participate in the existing services which consisted of a consultant and a specialist nurse upskilling the GP practice team and delivering care one afternoon per week. The GPs would refer patients to specialist nurses and to secondary care (and to pulmonary rehabilitation if required) if the patients showed respiratory and cardiac problems and had not yet been diagnosed (Dominey, 2016).

**2. Aims and objectives**

The main aim was to use the case-finding GRASP-COPD/GRASP-HF/Asthma audit tool (AAT) to identify patients with symptoms of breathlessness but no cardiac or respiratory diagnosis in order to test a new model of care to facilitate access to accurate diagnosis in an efficient and effective way. The objectives were:

1. To form partnerships with primary and secondary care across Wessex to inform improved access to appropriate services across Wessex
2. To increase the skills and practices of healthcare professionals and in particular to assist with the education of practice nurses and/or healthcare staff delivering respiratory care and to promote the use of Multidisciplinary Team/Meetings
3. To improve patient experience and education leading to effective self-management improve patients’ quality of life by providing accurate, relevant and timely information by creating links and relationships with various health care providers
4. **Methods**

**3.1. Framework and design**

The lead for the project was Rachel Dominey, Senior Projects Manager for Respiratory Quality Improvement (Wessex AHSN) who liaised with NHS IQ at regular intervals throughout the duration of the project. Jayne Longstaff, Specialist Respiratory Quality Improvement Nurse [SRQI Nurse] (Wessex AHSN] co-ordinated all aspects of the project

* Initial set up meeting with the GP surgeries (practice agreement, IT support, clinic logistics and identifying practice educational needs)
* Facilitating practices running the GRASP suite of tools
* Identifying patients’ cohorts through GRASP and manual identification
* Inviting, managing and co-ordinating patient attendance to all clinics
* Creating all ‘Breathlessness’ project clinical material (patient referral letter, clinical review forms, patient feedback forms, GP referral forms)
* Managing all clinical resources for the clinics (e.g. equipment, staff, documentation)
* Setting up and managing education training for practices and mentorship clinics

Wessex AHSN through the Centre for Implementation Science (CIS)[[6]](#footnote-6) (University of Southampton) led the evaluation. The evaluation focussed on the extent to which the objectives were met and the extent of which the new case finding breathlessness pathway was effective at both organisation (hospital, community) and patient level.

* 1. Organisation level

1. Comparing baseline data from the previous 12 months against matched data during the project implementation phase
2. Survey of/interview of healthcare and medical staff about the ease of use and functionality of the newly created pathway/model of care
3. Observations in the field from project team
   1. Patient level data
      1. Survey of/ interview with patients on their experience of the breathlessness pathway
      2. Survey of /interview with of patients on the brealthlessness pathway as a way of managing their disease more effectively

The project was divided into 2 phases:

* 1. Set up [May to July 2015]
  2. Implementation [July 2015 to January 2016 which included evaluation from January 2016 to March 2016 ]

As Wessex Academic Health Science Network [WAHSN] is a membership organisation comprising all CCGs and provider NHS Trusts across Wessex, local governance arrangements were through the Joint WAHSN/CLAHRC Advisory Board (a Wessex- wide Board). Following an email inviting expressions of interest sent to 4 CCGs local to QAH for practices who may be interested in participating in the pilot, clinicians were engaged through the Joint WAHSN/CLAHRC Advisory Board

The resources required to complete the project were:

* Project management/breathlessness pathway redesign
* Funding
* Backfill/staffing
* Equipment
* Training
* Communications (e.g. stakeholder engagement) and marketing

Non-engagement of stakeholders was expected to be the key risk and challenge while funding and resourcing for the project was anticipated to be a potential risk in the developmental stage of the project. It was expected that the innovation would be sustained in future by way of savings generated through the pathway redesign to be reinvested to provide funding for further development/roll out of the pathway/new model of care.

**Set up phase**

The set up phase ran from March 2015 to July 2015. The Wessex AHSN Respiratory Quality Improvement Team scoped the project having been given delegated authority from the joint CLAHRC/AHSN Respiratory Advisory Board following the successful Expression of Interest.

* Project plan (e.g.scope) developed
* Key information to the project was relayed back to the Wessex AHSN Advisory Board in March 2015 in preparation for roll out across the test site and monthly updates with NHS IQ Clinical documentation materials were developed [by JL]
* Practices identified and engaged

Project resources and staffing planned

**Implementation phase**

The implementation phase ran from July 2015-February 2016

* Identifying patients and recruiting patients
* Diagnostic clinics took place with invited patients
* Tailored education of primary care HCP’s
* Follow up clinics took place
* Evaluation of the project

Planning and signing up GP practices took place in April/May 2015, identifying and recruiting patients in June/July 2015, and delivery of clinics 1 and 2 in July/August 2015 and follow-up clinics in September 2015. From December 2015 to January 2016 patients were identified and recruited for Clinic 3. Delivery of Clinic 3 took place at the end of January 2016 and the follow-up clinic at the end of February 2016. The evaluation process began in December 2015.

The Wessex AHSN Breathlessness Steering Group, including representatives from the Wessex AHSN, NHS IQ and Portsmouth Hospitals NHS Trust (PHT), agreed that two different clinics would be held at the patients’ own GP practice. GP practices were sought from CCGs whose locality was accessible to the Queen Alexandra Hospital (PHT). Governance arrangements agreed by the Project Board stated that the GP would remain clinically responsible for the patient and the Specialist HLCCs team would be guests in the GP Practice.

An email from Wessex AHSN was sent to the 4 CCGs with GP Practices in an acceptable distance for patients to attend the Queen Alexandra Hospital [QAH]. Further communication was instigated with interested GP Practices through face to face meetings with the Project Manager and Respiratory Quality Improvement Nurse [RQI Nurse]. Monthly steering group meetings ensured that the project was delivered within the timescale and a fortnightly teleconference took place between the Wessex AHSN and NHS IQ Programme Managers.

Two practices (GP practice 1 from West Hampshire CCG and GP practice 2 in from South Eastern Hampshire CCG) responded to the invitation. A further practice (from South Eastern Hampshire CCG) was held in reserve for the second iteration (GP practice 3).

***Table 1: Profile of the 3 GP practices***

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **GP practices** | **CCG** | **Population**  **[rounded up]** | **Area** | **GPs** | **Practice nurses** | **Nurse practitioner** | **Healthcare assistants** |
| 1 | West Hampshire | 12,000 | semi-rural | 9 | 4 | 0 | 2 |
| 2 | South Eastern Hampshire | 12,000 | semi-rural | 4 | 2 | 1 | 1 |
| 3 | South Eastern Hampshire | 6,000 | semi-rural | 5 | 3 | 0 | 2 |

The three GP practices all have similar demographics and are located in semi-rural areas. GP practices 1 and 2 have a comparable patient list while GP practice 3 is half the size of the other two.

* 1. **Logistics of the project set up**

The Project Team (0.8wte Band 7 nurse) met with the practice teams including a GP, nurse and manager/administrator (where possible) to agree the steps to go through to set up the project. IT support from the practices for running electronic searches on their databases and to install and run GRASP-COPD/GRASP-HF/Asthma audit tool (AAT) was agreed.[[7]](#footnote-7) No direct financial incentives were offered to the GP practices. They were offered bespoke training sessions by a specialist secondary care team led by Professor Anoop Chauhan.

* 1. **Case-finding approach**

Using the case finding module of the search tools for GRASP-COPD/GRASP-HF/Asthma audit tool (AAT) a search was run electronically by RQI nurse. Patients had to be adults with no COPD or asthma or heart failure diagnosis, a breathlessness READ code and two or more exacerbations in the previous 12 months. More specific criteria were then used to refine the searches. (See table 2).

***Table 2: Inclusion criteria for electronic case-finding GRASP-COPD/GRASP-HF/Asthma audit tool (AAT) searches***

|  |  |  |
| --- | --- | --- |
| **Condition** | **Inclusion**  **Exclusion** | **Criteria** |
| Asthma | Inc  Inc | * Prescribed inhalers and/or oral steroids in last 12 months * Symptoms relating to SOB, wheeze, cough in last 15 years |
| COPD | Inc  Inc | * Respiratory exacerbations in last 3 years * SOB on exertion, chronic cough, wheeze, dry cough, nocturnal wheeze and nocturnal SOB for the last 15 years |
| Heart Failure | Inc  Inc  Exc | * MRC>1 and/ or SOB on exertion * Borg score and New York Heart association (none identified) * LVSD, HF, AF, Heart valve, cardiomegaly or cardiomyopathy |

The electronic searches were followed by manual reviews taking into account both exclusion and inclusion criteria (See table 3).

***Table 3: Inclusion and exclusion criteria for manual searches***

|  |  |
| --- | --- |
| **Exclusion criteria** | **Inclusion criteria** |
| Under secondary care  Respiratory or cardiac diagnosis  Pregnancy  Housebound  Active cancer  At the GP’s discretion | Out of hours visits in past 12 months  Hospitalisations in past 12 months  ED visits in past 12 months  Hypoxia  Regular SOB symptoms  Prescribed respiratory or cardiac medicines |

The RQI established a list of patients which was further reviewed by the GPs.

* 1. **Heart and Lung Check Clinics [HLCCs]**

At each site, a 60-minute diagnostic secondary care specialist-led HLCCs was held for the symptomatic patients who had been invited and had attended. The 60-minute diagnostic HLCC appointment included:

* A 20- 30-minute initial assessment by the respiratory physiologist:
  + Tests as requested by the clinician
    - PFTs [Pulmonary function tests] ( including reversibility)
    - FeNo  [Exhaled Nitric Oxide Levels]
    - Blood pressure and pulse
    - Pulse oximetry
    - ECG [Electro-cardiogram test]
    - BMI [Body Mass Index]
    - Skin prick allergy tests
    - Cardiac BNP [B-type natriuretic peptide in blood]
  + Questionnaires
    - Epworth [Sleepiness Scale[[8]](#footnote-8)]
    - GERD [Gastroesophageal reflux disease[[9]](#footnote-9)]
    - SNOT [Sino-Nasal Outcome Test 20symptoms and social/emotional consequences of nasal disorder]
    - MRC [MRC Dyspneoa Scale[[10]](#footnote-10)]
    - RCP [3 questions for asthma care[[11]](#footnote-11)]
    - CAT [COPD Assessment Test[[12]](#footnote-12)]
    - Nijmegen [16 questions *re* hyperventilation syndrome[[13]](#footnote-13)]
    - ACQ [Asthma Control Questionnaire[[14]](#footnote-14)]
* A 20-minute assessment by a specialist respiratory physician (consultant respiratory physician or respiratory Registrar), working alongside the clinical practice staff
  + History
  + Examination
  + Assessment of test results
* A 10-20-minute follow up education session with the respiratory quality improvement nurse
  + Inhaler technique
  + Smoking cessation
  + Self-management plan
  + Education
  + Follow-up advice

Not all diagnostic instruments were used systematically on all patients. The Consultant and registrar determined which test and questionnaires were necessary, supported by the physiologist and respiratory quality improvement nurse

* 1. **One-month post HLCCs follow-up**

Following the diagnostic 60 minutes HLCCs all patient records were given to their registered GP for review (referral, treatment change and in order to confirm the diagnosis). All patients reviewed faced three possible outcomes:

1. Referred to their GP practice for simple follow-up (for the more benign cases)
2. Invited to attend a follow-up mentorship clinic four weeks later held by the RQI Nurse within the GP practice
3. Sent for further tests or specialist referral in secondary care

The post HLCC 30-minute follow-up mentorship clinic was undertaken by the RQI Nurse to see how patients ertr getting on. For practical reasons the treatment of newly diagnosed patients is often not started immediately after the HLCC, but a couple of days afterwards once the GP had reviewed and agreed the patients records.

Some patients may be asked to keep a peak flow diary to bring with them during the education and mentorship follow-up session. This is to ascertain or refute a diagnosis of asthma or to check the extent to which the treatment is working, some tests might be performed again as required during the follow-up clinic e.g. FeNo Test [Exhaled Nitric Oxide Levels] and Pulmonary Function Tests [PFTs] *e.g.* to determine FEV1 % predicted, FVC % predicted and FEV1-FVC <70.

Checking correct inhaler technique using placebo inhalers with or without a spacer and self-management review are also part of the education and mentoring follow-up process, after which patients will continue to see one of the GP practice nurse who have been upskilled and mentored by the Specialist Respiratory Quality Improvement Nurse. During this follow-up clinic the RQI Nurse enters information directly into the patients’ record. (GPs and nurses tend to write up the notes by hand and they are then entered into the patients’ records.)

Tests might be full Lung Function Tests [LFTs], CXR, MRIs or CT scans to be fully reviewed by a respiratory consultant. Specialist referral include review by a physiotherapist for dysfunctional breathing.

* 1. **Review of patients at 4, 6 and 12 months after HLCCs**

The RQI Nurse went systematically go through the patients’ notes to make an evaluation of each patient in order to gage the extent to which their condition was well controlled and well-managed 4 and 6 months following each of the HLCCs. Any patients who remained uncontrolled were referred back to the GP practice for further review.

1. **Results**
   1. **Case finding searches**

The first two electronic searches found 328 patients with COPD, 98 patients with asthma and 17 patients with heart failure and 586 patients with COPD, 82 with asthma and 35 with heart failure for GP practice 2. Such high numbers were clearly unmanageable within the scope of the project. It was therefore decided to focus on patients whose name came up under at least 2 of the 3 conditions, in other words, those that overlapped between at least 2 conditions for the manual searches. A draft list of patients was manually compiled by the RQI Nurse. The patients on this list were further manually reviewed by all the GPs. A further 4 patients from all 3 sites were added to the list by GPs who felt fitted the inclusion criteria and were invited for review.

**GP practices 1 and 2** (n=12,000)

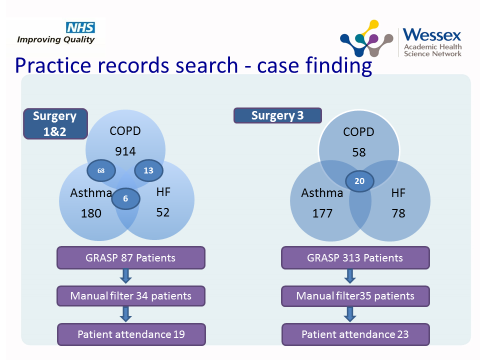
In GP practice 1 and 2 a total of 87 (49 and 38) patients whose name came up under both asthma and COPD or asthma and heart failure or heart failure and COPD case-finding tools were identified: 68 for COPD and asthma; 6 for asthma and heart failure and 13 for heart failure and COPD. Out of the initial 87 patients identified by electronic search, 53 were eliminated by manual search leaving 34 patients invited to attend the two HLCCs. Out of the 34, a total of 19 appointments were booked and 19 attended.

**GP practice 3** (n=6,000)

In GP practice 3 a total of 313 patients were identified electronically. As the number were smaller, all of them were manually reviewed by the RQI Nurse: 35 were selected but 7 were excluded after further review. Out of 313 patients 284 (90.7%) were eliminated by RQI nurse led manual search, leaving 29 patients to be invited to attend the HLCC. A total of 23 patients were booked for appointments and all attended.

If all three GP practices had a comparable prevalence, the electronic searches should have found 45 asthma cases for GP practice 3 instead of 177, 13 cases of cardiac disease instead of 52 and 228 cases of COPD instead of 58. In other words, GP practice 3 had four times more asthma cases and cardiac disease cases than expected and slightly less than four times fewer COPD cases than expected based on GP practices 1 and 2 which had broadly similar results. (See figure 2)

***Figure 2: Overview of electronic searches and manual reviews of GP practices records***

****

In the case of GP practices 1 and 2, 19 out of 34 patients invited to attend booked an appointment (55.8 %) while for GP practice 3 a total of 23 out of 35 (65.7%) did so. All 42 patients who had been booked for appointments showed up on the day.

***Table 4: Overview of the process to select those who attended HLCCs***

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **GP Practice** | **Population** | **GRASP** | **Manual filter** | **Appointments booked** | **Patient attendance** |
| 1 (n=10) | 12,000 | 87 [those intersected between at least 2 conditions] | 34 [invited to attend] | 19 | 19 |
| 2 (n=9) | 12,000 |
| 1 and 2 (n=19) | 24,000 |
| 3 (n=23) | 6,000 | 313 all | 35 [invited to attend] | 23 | 23 |

* 1. **Characteristics of the patients attending the case finding HLCCs**

**Demographics [age, gender and social history/alcohol status]**

Out of the 42 patients who attended the HLCCs, there were 18 males (42.8%) and 24 females (57.1%). The age ranged from 41 to 86 and the average age was 64. Three males were recorded as having social history/alcohol status. All three had an alcohol problem and drank a lot more than the recommended weekly units of alcohol. They were given lifestyle advice in relation to this.

***Table 5: Demographics [age and gender and social history/alcohol status] for all 3 GP practices***

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **GP practice** | **Gender** |  | **Age** |  | **Social history/**  **alcohol status** |
| **Male** | **Female** | **Range** | **Average** |
| 1 (n=10) | n=5 (50%) | n=5 (50%) | 41-86 | 72.8 | 2 (males) |
| 2 (n=9) | n=5 (55.5%) | n=4 (44.4%) | 57-80 | 65.7 | 0 |
| 3 (n=23) | n=8 (34.7%) | n=15 (65.2%) | 25-86 | 53.6 | 1 (male) |
| Overall (n=42) | n=18 (42.8%) | n=24 (57.1%) | 41-86 | 64.0 | 3 (males) |

The average age was lower in GP practice 3 with 53.5 against 72.8 in GP practice 1 and 65.7 in GP practice 3. There were also more females, 65.2%, instead of 50% and 44.4% in GP practices 1 and 2 respectively.

**Smoking cessation**

Only 4 patients out of 42 were smokers. All 4 patients were given smoking cessation advice. Of the 4 patients who were smokers, 3 accepted to be referred to smoking cessation (75%). (See table 6)

***Table 6: Smoking cessation including % of smokers offered smoking cessation advice and referred to smoking cessation***

|  |  |  |  |
| --- | --- | --- | --- |
| **GP practice** | **Smoking status** | **Advice on smoking cessation** | **Referral to smoking cessation** |
| **1 (n=10)** | 1 smoker  1 ex-smoker  5 non-smoker | n=1 | n=0 |
| **2 (n=9)** | 0 smokers  6 ex-smokers  3 non-smokers | n/a | n/a |
| **3 (n=23)** | 3 smokers\*  7 ex-smokers  9 non-smokers | n=3 | n=2 |
| **Overall**  **(n=42)** | **4 smokers**  **14 ex-smokers**  **30 non-smokers** | **n=4** | **n=3** |

\*There was no data for 4 patients

**Key baseline health indicators**

Table 5 shows broadly similar overall baseline indicators for all three GP practices.

***Table 7: Key indicators for patients in all 3 GP practices***

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **GP practice** | **MRC** | **FeNo**  **ppb** | **FEV1/FVC <70% or degree of airway obstruction** | | **BMI** | | **High**  **BP** |
|  |  | **Before** | **1 month check** | **Range** | **Average** |  |
| **1 (n=10)** | 3x1  6x2  1x4  Range 1-4 | 6<25  1>25  2>50  Range 9-55 (n=9) | n=3 | n=2 better  n=1 not recorded | 26-48 | 30.6 | 2 |
| **2 (n=9)** | 5x2 2x3  2x4  Range 2-4 | 4<25  1>25  2>50  Range 14-93 (n=7) | n=3 | n=2 better  1=same | 24-39 | 30.5 | 1 |
| **3 (n=23)** | No data | 12<25  4>25  1>50  Range <5 to 55 (n=17) | n=5\* | n=3 not recorded  n=1 better  n=1 worse | 19-36 | 27.7\*\* | 9 |
| **Overall**  **n=42** | **3x1**  **11x2**  **2x3**  **3x4**  **(n=18)** | **22<25**  **6>25**  **5>50**  **Range**  **<5 to 93 (n=33)** | **n=11** | **n=2 better**  **n=3 same**  **n=5 not recorded**  **n=1 worse** | **19-48** | **29.6** | **n=12** |

^ There was no data for 6 patients/patients unable to complete

^^ There was no data for 2 patients/patients unable to complete

^^^ There was no data for 2 patients/patients unable to complete

\* There was no data for 4 patients

\*\* There was no data for 2 patients

There were proportionally more patients with high blood pressure in GP practice 3 than in GP practices 1 and 2, *i.e.* 39% compared to 20% and 11%. However, GP practice 3 had a lower average BMI and a greater age range.

* 1. **Patients with new respiratory or cardiac diagnoses**

**Overview of all diagnoses for GP practices 1, 2 and 3**

Table 9 outlines data in relation to all the confirmed diagnoses for GP practices 1, 2 and 3. The total number of diagnoses was 64 for 42 patients, which means that many patients had more than one diagnosis.

The most frequent or top diagnosis was asthma (n=25). It made up 38.4% of all the 62 diagnoses and 59.2% of patients were diagnosed with asthma. Of those 12% (n=3) were recorded as BTS1 and 56% (n=14) as BTS2 while 32% (n=8) were recorded as BTS3. The second most common diagnosis was sino-nasal disease (rhinitis and/or post nasal drip) (n=12) which made up 18.7% of the diagnoses. Asthma and sino-nasal disease made up more than half of all the diagnoses (57.1%).

***Table 8: Overview of all confirmed diagnoses for GP practices 1, 2 and 3***

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Diagnosis** | **Number of diagnoses** | **% of total diagnoses** | **% of patients** | **Severity of condition** | **% of patients**  **with condition** |
| Asthma | 25 | 38.4 | 59.2 | 3 BTS1  14 BTS2  8 BTS3 | 12  56  32 |
| Sino-nasal disease (rhinitis/post nasal drip) | 12 | 18.7 | 28.5 |  |  |
| Dysfunctional breathing (hyperventilation) | 5 | 7.8 | 11.9 |  |  |
| COPD | 4 | 6.2 | 9.5 | Mild  Moderate | 50  50 |
| Hypertension/  cardio-vascular disease | 4 | 6.2 | 9.5 |  |  |
| Asthma – COPD Overlap Syndrome [ACOS] | 2 | 3.1 | 4.7 |  |  |
| Vocal cord dysfunction [VCD] | 2 | 3.1 | 4.7 |  |  |
| Gastro-esophageal reflux disease [GORD] | 3 | 3.1 | 4.7 |  |  |
| Asbestosis | 2 | 3.1 | 4.7 |  |  |
| Pneumonia | 2 | 3.1 | 4.7 |  |  |
| Glossitis | 1 | 1.5 | 2.3 |  |  |
| Nasal polyps | 1 | 1.5 | 2.3 |  |  |
| Occupational asthma | 1 | 1.5 | 2.3 | BTS2 | 100 |
| **Total** | **64** |  |  |  |  |

Other diagnoses were: dysfunctional breathing [n=5]; COPD [n=4], gastro-esophageal reflux disease [n=2]; asbestosis [n=2], ACOS [Asthma - COPD Overlap Syndrome] [n=2]; vocal cord dysfunction [n=2]; glossitis [n=1], nasal polyps [n=1] workplace asthma[n=1]. Only 4 patients are recorded as having a diagnosis of hypertension: 1 for GP practice 1; 2 for GP practice 2; and 1 for GP practice 3. Only the patient with the highest blood pressure (207/107) was recorded as having hypertension, but the blood pressure readings at the HLCC for GP practice 3 show elevated high blood pressure for another 8 patients >140/90 blood pressure recorded as either >140 or >90 for another 7 patients.

**GP practice 1**

In GP practice 1, a total of 9 patients out of 10 (90%) received a confirmed respiratory diagnosis. One patient was deemed to be at risk of, but not as having COPD. Two patients received more than one respiratory diagnosis (20%). On patient was diagnosed with hypertension (10%). Five patients (50%) were diagnosed with asthma, one as having COPD with rhinitis and nasal polyps, one with glossitis, one with asbestosis and hypertension, and one with ACOS [Asthma and COPD overlap syndrome] and rhinitis. All patients except one had one or more co-morbidity (90%) [See table 9 and also Appendix 3 for detailed information]

**GP practice 2**

All 9 patients in GP practice 2 were given a respiratory diagnosis (100%). Seven patients received more than one respiratory diagnosis (70%). In addition, 2 patients (20%) were also diagnosed with gastro-oesophageal reflux disease and 2 patients (20%) with hypertension. Six patients were diagnosed with asthma (66.6%), one with asbestosis, and one with rhinitis. Two asthma patients were also given a cardio-vascular diagnosis of hypertension. Four patients were diagnosed with rhinitis and one with hyperventilation. Two patients were also diagnosed with gastro-esophageal reflux disease [GORD]. Seven patients had one or more co-morbidity (77.7%). [See table 9 and also Appendix 4 for detailed information]

**GP practice 3**

All 23 patients in GP practice 3 were given a respiratory diagnosis (100%). Thirteen patients received more than one respiratory diagnosis (56.5%). One/nine patient/s (4.3%/39.1%) was/were also diagnosed with hypertension and one with gastro-oesophageal reflux disease (4.3%). A total of 14 patients (60.8%) were diagnosed with asthma, 8 patients with sino-nasal conditions [rhinitis and/or post/nasal drip], 1 patient with occupational asthma, 4 patients with dysfunctional breathing, 3 patients with COPD, 2 patients with vocal cord dysfunction, 2 patients with pneumonia, and one patient with hypertension. Only 5 patients had co-morbidities (21.7%). [See table 9 and also Appendix 5 for detailed information]

In total 41 out of 42 patients received a confirmed respiratory diagnosis (97.6%). Twenty-two patients out of 42 received more than one respiratory diagnosis (52.3%). Four patients (9.5%) were additionally diagnosed with hypertension and 3 with gastro-oesophageal reflux disease (7.1%).

**Place of diagnosis and follow-up post HLCCs for all 3 GP practices**

Table 8 shows where patients were diagnosed and where they were referred to. A total of 33 out of 42 (78.5%) were diagnosed in primary care/GP practice and 9 out of 42 in secondary care/hospital (21.4%).

***Table 9: Place of diagnosis and referral post HLCCs for all 3 GP Practices***

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **GP practice** | **Primary Care/GP** | **Secondary**  **Care/hospital** | **1 mth follow up with RQI Nurse** | **1 mth follow up with PN practice** | **Treatment**  **changed** |
| **1 (n=10)** | n=8 | n=2 | n=6\* | n=2 | n=6\* |
| **2 (n=9)** | n=7 | n=2 | n=7 | n=0 | n=7 |
| **3 (n=23)** | n=18 | n=7 | n=16\*\* | n=1 | n=14\*\* |
| **Overall (n=42)** | **n=33** | **n=11** | **n=29** | **n=3** | **m=27** |

PN = Practice Nurse

**\***One patient was also referred to ELLIPTA and Trooper studies

\*\* Three patients were also referred to pulmonary rehabilitation and one declined

* 1. **One-month follow-up clinic**

Overall, 29 out of 42 (69%) attended the HLCC follow-up mentoring and education clinic held by the RQI Nurse and 10 (23.8%) were followed up at the GP practice by the practice nurse. One out of 41 patients moved away shortly after the HLCCs and could not be followed up.

No patient in GP practice 1 was identified as having a poor inhaler technique and 6 patients had their treatment changed (60%). (See table 9 and also Appendix 3 for more details). All but one patient were found to have good compliance with their treatment. No patient in GP practice 2 was identified as having had poor inhaler technique. Seven patients had their treatment changed (77.7%). (See table 9 and also appendix 4 for more details). All but one patient were found to have good compliance with their treatment. In GP practice 3, a total of 17 patients were identified as having a poor inhaler technique (73.9%). A total of 14 patients had their treatment changed (60%). (See table 8 and also appendix 5 for more details). Overall, a total of 27 out of 42 (64.2%) patients had their treatment changed in order to better manage their symptoms and their condition. All but two patients were found to have good compliance with their treatment.

In GP practice 1, of the 3 patients with restricted lung function [FEV1/FVC] <70, two had improved (67% to 73% and 67% to 72%) and one patient did not have her lung function recorded. In GP practice 2, of the three patients with restricted FEV1/FVC] <70 lung function, two had improved and one was about the same (65 to 68, 61 to 63 and 69 to 68). In GP practice 3, of 5 patients recorded as having restricted lung function, 2 did not have their FEV1/FVC] <70 lung function checked and 1 had improved (66 to 68) and the other had become slightly worse (66 to 62) (See also table 7).

* 1. **Review (virtual) of patient clinical records: previous 12 months**

**compared to 3 and 6 months after HLCCs**

Six months after the case-finding HLCCs for GP practices 1 and 2 and four months after the HLCCs for GP practice 3, the RQI nurse reviewed the patients’ records to ascertain key outcome measures (See table 10).

***Table 10: Overview of key outcome measures in the 12 months before and 4 and 6 months after diagnostic HLCCs for GP practices 1, 2 and 3***

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Items** | **12 months before**  **n=42** | **GP**  **1+ 2**  **12 mths before**  **n=19** | **GP**  **1 + 2**  **6 mths**  **after**  **n=18** | **GP 3**  **12 mths before**  **n=23** | **GP 3**  **4 mths**  **after**  **n=23** | **4 and 6 mths after**  **n=41** |
| Exacerbations  [requiring ICS or AOB] | 46 | 15 | 3 | 31 | 2 | 5 |
| ED visits | 4 | 1 | 0 | 3 | 0 | 0 |
| OOH visits | 2 | 0 | 0 | 2 | 0 | 0 |
| Hospital admissions | 2 | 1 | 0 | 1 | 0 | 0 |
| GP non-elective visits | 92 | 35 | 10 | 57 | 5 | 15 |
| SABA | 80 | 22 | 25 | 58 | 12 | 37 |
| ICS | 13 | 7 | 26 | 6 | 13 | 39 |
| ICS nasal | 9 | 2 | 7 | 7 | 0 | 7 |
| Never smoked | 18 |  | nd | 11 | 11 | 18 |
| Smoker | 4 |  | 1 | 3 | 3 | 4 |
| Ex-smoker | 20 |  | 11 | 9 | 9 | 20 |
| Referred to smoking cessation | nd | n/d | 0 | 0 | 1 | 1 |
| Deaths | n/a | n/a | 0 | n/a | 0 | 0 |
| Moved from area | n/a | n/a | 1 | n/a | 0 | 1 |
| Diagnosis confirmed | n/a | n/a | 18 | n/a | 12\* | 41 |
| Referral to secondary care | n/a | 2 | 2 | n/a | 7 | 9 |
| Compliance with rx [poor] | n/a | n/a | 2 | n/a | 5 | 7^ |

^7 out of 32 who attended follow-up mentorship clinics had poor compliance (20%)

\*From data available, only 12 patients out of 23 who attended the HLCC in GP3 had their diagnosis confirmed. This could mean 1) that records for remaining 11 been not yet been checked 2) that their GP has not yet entered information into records 3) that the diagnosis was in error. The second option is the most likely explanation as 7 patients were referred to secondary care.

Any patients who remained uncontrolled were referred back to the GP practice for further review.Seven patients out of 29 followed-up (24%) were found to have poor compliance with their treatment i.e. 75% had good compliance (See tables 10 and 11).

***Table 11: Overview of reduction/increase in key outcome measures***

|  |  |  |  |
| --- | --- | --- | --- |
| **Items** | **12 months before** | **After 4 and 6 mths**  **n=41** | **% reduction/increase** |
| Exacerbations  [requiring ICS or AOB] | 46 | 5 | 89.1% |
| A&E visits | 4 | 0 | 100% |
| OOH visits | 2 | 0 | 100% |
| Hospital admissions | 2 | 0 | 100% |
| GP non-elective visits | 92 | 15 | 83.6% |
| SABA | 80 | 37 | 62.5% |
| ICS [oral steroids] | 13 | 39 | +66.6% |
| ICS nasal | 9 | 7 | 22.2% |
| Never smoked | 18 | 18 | 0 |
| Smoker | 4 | 4 | 0 |
| Ex-smoker | 20 | 20 | 0 |
| Referred to smoking cessation | nd | 1 | n/a |
| Deaths | n/a | 0 | 0 |
| Moved from area | n/a | 1 | n/a |
| Diagnosis confirmed | n/a | 29^ | n/a |
| Compliance with rx [poor] | n/a | 7\* | n/a |

^As per the GP records which have in all likelihood not been updated

\*25 out of 32 attending follow-up mentorship clinics (76%) had good compliance

Key outcome measures show substantial reductions in GP non-elective visits (83.6%), exacerbations requiring ICS or AOB (89.1%) and reductions in OOH visits, A&E visits and emergency hospital admissions (100%) as well as in SABA [short acting beta agonists for quick relief of asthma symptoms] (62.5%). However, there was an increase in ICS [oral steroid] (66.6%) due to the number of patients diagnosed with asthma.

* 1. **Experiences of patients (n=24)**

A total of 16 out of 19 patients (84.2%) who attended Clinics 1 and 2 and 8 out of 23 patients who attended Clinic 3 (34.7%) completed a written satisfaction questionnaire that included quantitative and qualitative data collection.Patients completed the satisfaction questionnairesin the GP practice immediately after they attended the HLCC.

**Quantitative data (n=24)**

The response rate in completing the quantitative part of the questionnaire was lower for GP practice 3 than that for GP practices 1 and 2. Only 8 patients out of 23 who attended Clinic 3 completed the satisfaction questionnaire (34.7%).Overall,out of 42 patients who attended the HLCCs, 24 completed the quantitative data collection part of the satisfaction questionnaire (57.1%).Not all questions were responded to by all those who completed the written satisfaction questionnaire.

Factors that influenced the decision to attend the diagnostic HLCC (n=24)

The top three reasons for attending the HLCC (n=47 or 64.2% of responses) were ‘improve breathing control’ (n=17 or 23.2%), ‘see specialist’ (n=15 or 21.9%) and ‘confirm diagnosis of breathing problem’ (n=14 or 19.1%) (See table 12).

***Table 12: Factors that influenced the decision to attend the diagnostic HLCC***

|  |  |  |
| --- | --- | --- |
| **Which factors were important to you in choosing to attend the clinic?** (n=16+8=24) | **Number of responses** | **Percentage of responses** |
| Improve breathing control | 10+7=17 | 23.2 |
| See specialist | 10+6=16 | 21.9 |
| Confirm diagnosis of breathing problems | 10+4=14 | 19.1 |
| Access specialty tests | 5+2=7 | 9.5 |
| Discuss new treatments | 4+3=7 | 9.5 |
| Curious | 4+2=6 | 8.2 |
| Better inhaler technique | 4+2=6 | 8.2 |
| Total number of responses | **73** | 100 |

Interest in being involved in a clinical trial (n=19)

A total of 13 patients were interested in being involved in a clinical trial (68.4%), 5 were currently taking part (26.3%) and 1 had previously taken part (5.2%) (See table 13).

***Table 13: Interest in being involved in a clinical trial***

|  |  |  |
| --- | --- | --- |
| **Would you have an interest in being involved in a clinical trial?** (n=14+5=19) | **Number of responses** | **Percentage of responses** |
| Have an interest | 10+3=13 | 68.4 |
| Currently taking part | 3+2=5 | 26.3 |
| Previously took part | 1+0=1 | 5.2 |
| Total | **19** | 100 |

A greater proportion of patients were currently taking part in clinical trials in GP practice 3 than in the other two GP practices: 2 out of 5 (40%) instead of 3 out of 14 (21.4%). (See table 13).

Patient satisfaction with the booking process (n=24)

All patients who responded to this question were very satisfied (83.3%) or satisfied (16.6%) with the booking process, the information given and the team that welcomed them A slightly smaller proportion of patients from GP practice 3 were ‘very satisfied’ with the booking process (75%) compared to GP practices 1 and 2 (87.5%). (See table 14a)

***Table 14a: Patient satisfaction with the booking process***

|  |  |  |
| --- | --- | --- |
| **How satisfied were you with the booking process?** (n=16+8=24) | **Number of responses** | **Percentage of responses** |
| Very satisfied | 14+6=20 | 83.3 |
| Satisfied | 2+2=4 | 16.6 |
| No opinion | 0 | 0 |
| Unsatisfied | 0 | 0 |
| Very unsatisfied | 0 | 0 |
| Total | **24** | 100 |

Information given to them (n=23)

A total of 21 patients were very satisfied with the information given to them (91.3%) and 2 were satisfied (8.6%). GP practice 3 had a slightly higher proportion of very satisfied patients, 100% of 7, instead of 87.5% of 23 (See table 14b).

***Table 14b: Patient satisfaction with the information given***

|  |  |  |
| --- | --- | --- |
| **How satisfied were you with the information you were given?** (n=16+7=23) | **Number of responses** | **Percentage of responses** |
| Very satisfied | 14+7=21 | 91.3 |
| Satisfied | 2 | 8.6 |
| No opinion | 0 | 0 |
| Unsatisfied | 0 | 0 |
| Very unsatisfied | 0 | 0 |
| Total | **23** | 100 |

Satisfaction with the team that welcomed them (n=23)

All 23 patients were very satisfied with the team that welcomed them (See table 14c).

***Table 14c: Patient satisfaction with the team that welcomed them***

|  |  |  |
| --- | --- | --- |
| **How satisfied were you with the team that welcomed you?** (n=16+7=23) | **Number of responses** | **Percentage of responses** |
| Very satisfied | 16+7=23 | 100 |
| Satisfied | 0 | 0 |
| No opinion | 0 | 0 |
| Unsatisfied | 0 | 0 |
| Very unsatisfied | 0 | 0 |
| Total | **23** | 100 |

Confidence in managing breathing symptoms (n=24)

A total of 24 patients answered the question about confidence in managing breathing symptoms before and after the HLCCs (See table 15a).

***Table 15a: Confidence in managing breathing symptoms before the HLCC***

|  |  |  |
| --- | --- | --- |
| **Currently how confident do you feel managing your breathing symptoms? (n=16+8=24)** | **Number of responses** | **Percentage of responses** |
| Very confident | 3 +0=3 | 12.5 |
| Confident | 9+6=15 | 62.5 |
| No opinion | 0+1=1 | 4.1 |
| Un-confident | 4+1=5 | 20.8 |
| Very un-confident | 0+0 | 0 |
| Total | **24** | 100 |

***Table 15b: Confidence in managing breathing symptoms after the HLCC***

|  |  |  |
| --- | --- | --- |
| **Following your appointment how confident do you feel managing your breathing problems? (n=16+7= 23)** | **Number of responses** | **Percentage of responses** |
| Very confident | 10+5=15 | 65.2 |
| Confident | 6+2=8 | 34.7 |
| No opinion | 0+1=1 | 4.3 |
| Un-confident | 0 | 0 |
| Very un-confident | 0 | 0 |
| Total | **24** | 100 |

Before the 60 minutes HLCC appointment only 12.5% (n=3) were very confident in managing their breathing problems, 62.5% (n=15) were confident and 20.8% (n=5 out of 24) were unconfident and one had no opinion (4.1%) (See table 15a and 15b).

***Table 15c: Overview of change in confidence level in managing breathing symptoms before and after the HLCCs***

|  |  |  |
| --- | --- | --- |
| **Levels of confidence** | **Before** | **After** |
| Very confident | 12.5% (n=3) | 65.2% (n=15) |
| Confident | 62.5% (n=15) | 34.7% (n=8) |
| No opinion | 4.1% (n=1) | 4.3% (n=1) |
| Unconfident | 20.8% (n=4) | 0% |
| Very unconfident | 0% | 0% |

After the 60 minutes HLCC, no patient was unconfident, one patient had no opinion (4.3%) but 34.7% (n=8 out of 23) were confident while 65.2% (n=15 out of 23) were very confident. (See table 15c).

Recommending the breathlessness case finding service to friends and family (n=23)

All of those who responded [22 out of 23 who responded to this question or 95.6%) said they would recommend the clinic to family and friends (See table 16).

***Table 16: Recommending the breathlessness service to friends and family***

|  |  |  |
| --- | --- | --- |
| **Would you recommend this service to friends and family? (n=15+8=23)** | **Number of responses** | **Percentage of responses** |
| **Yes** | 15+7=22 | 95.6 |
| **No** | 0+1 | 4.4 |
| **Total** | **23** | 100 |

A total of 22 out of 23 patients who responded to the question said they would recommend the service to family and friends (95.6%). All 15 patients that attended Clinic 1 and 2 (100%) said yes to this question, but 7 out of 8 that attended Clinic 3 (87.5%) said yes to this question.

Overall, the great majority of patients who completed the written questionnaire survey were highly satisfied with the service, from booking process (83.3%) to information given (91.3%) and the team that welcomed them (100%) and to recommending the service to family and friends (95.6%).

**Qualitative data (n=15)**

Every patient was given the opportunity to provide open-ended qualitative written feedback on their experience and views of any aspect of the service provided.

Of the 19 patients seen across both Clinics 1 and 2, 16 provided quantitative data and 12 out of 16 (75%) provided open-ended written comments or qualitative data, which is 63% of total number of patients seen.Of the 23 patients seen at Clinic 3, 8 provided quantitative data and 3 out of 8 (37.5%) wrote open-ended comments and thus provided qualitative data, which is 13% of the total number of patients seen.

All, but one comment (out the 33), were positive. They can be divided into five categories or themes: praising the team (39.3%); overall experience very helpful (21.2%); information received very good (15.1%); given me a firm diagnosis/treatment (9%); and would recommend (12.1%).

The only non-positive comment was ensuring that patients were aware of the duration of the clinic (See table 17). However, this had been made clear in the letter of invitation and this had been reiterated verbally on the telephone to make sure patients understood that this was going to be a comprehensive diagnostic process and that assessment including completing questionnaires and diagnostic tests to assess heart and/or lung function would take about one hour.

***Table 17: Emergent categories and items (n=12+3=15 patients)***

|  |  |  |
| --- | --- | --- |
| **Themes** | **Number** | **% of total items** |
| **Praising the team**  Well organised and thorough  Very efficient and friendly and helpful  Taking care of people so well  All staff very professional  Very welcoming, friendly and professional  Everyone has been most helpful and understanding  Lovely group  Excellent, knowledgeable team  Very professional  I am so very pleased with what they have done  A very helpful and useful clinic  The clinic was run with excellent bedside manner  Initial mix up in the booking but rescued well in advance | 9+4=13 | 39.3 |
| **Overall experience very helpful**  Very good idea  Very worthwhile visit  An excellent day - well worth my time  Learnt from my visit and I very grateful  I am very satisfied with everything today  Very satisfied and impressed  Taught me things about myself I didn't know | 6+1=7 | 21.2 |
| **Information received very good**  Pleased with all the information  More information than GP  Very informative  Very informative  Explain and check inhaler technique | 5 | 15.1 |
| **Given me a firm diagnosis/treatment**  Reassured me having all the tests done  Hopefully symptoms will improve from now on  My primary reason for taking part in the clinic was to increase confidence in diagnosis | 2+1=3 | 9 |
| **Would recommend**  Would recommendx2  Could help a lot of people  Thank you | 2+2=4 | 12.1 |
| **Ensure duration of clinic is flagged up to manage expectations**  Worth ensuring participants are aware of duration of clinic - length is fine and efficient as can be, but just takes time | 1 | 3 |
| **Total** | **33** | 100 |

**Illustrative comments**

*I am extremely pleased I was invited to attend this clinic as it has given me a firm diagnosis of my condition as I have been suffering symptoms for some time now and never knew I had asthma. Hopefully I will feel better and not have the phlegm and catarrh I am suffering.*

*I enjoyed the experience today although I wasn’t aware that this was a pilot scheme/project, but something my doctor had advised me to attend for health purposes. I thought everyone was very informative and professional, I even had an allergy testing done which was interesting. It was also useful having someone explain why I’m taking inhalers, how it works properly and how to take it correctly. Would recommend :)*

*It reassured me having all the tests done and I am so very pleased with what they have done. I am very satisfied and impressed. Thank you!*

*This breathlessness project was very well organised and thorough and could help a lot of people*

*My primary reason for taking part in the clinic was to increase confidence in diagnosis. This was fully achieved. The clinic was run with excellent bedside manner. There was an initial mix up in the booking but this was rescued well in advance. Worth ensuring participants are aware of duration of clinic - length is fine and efficient as can be, but just takes time*

*A very helpful and useful clinic which taught me things about myself I didn't know; I would definitely recommend it to other people.*

These illustrative comments offered a brief snapshot of the very positive comments written by the 19 patients out of a total of 42 who attended the HLCCs (45.2%).

* 1. **Initial Health Economics**

NICE guidelines make recommendations for early diagnosis on the basis of lesser costs in secondary care (NICE 2010a, 2010b). This includes various outcome measures (A&E visits, emergency hospital admissions, exacerbations requiring ICS or AOB, OOH visits, emergency visits to GP, medication usage in the 12 months before and four and six months after intervention timeframe *i.e* when HLCCs took place.

The data sets for the comparison were collected by the RQI nurse who entered into them into an Excel spread sheet. The results were then analysed using simple descriptive statistics and simple comparison statistics. The tables and charts were created through Excel.

The unit costs were collected from various sources e.g. Unit Costs of Health and Social Care 2013 (See Curtis, 2013), British National Formulary (BNF), NHS Reference Costs 2014-2015 (average unit cost to the NHS of providing secondary healthcare to NHS patients), GP Earnings and Expenses 2008/2009 and ITV News 2014.

***Table 18: Health Economics Costs Incurred for HLCCs***

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **HLCCs** | **Hrs** | **Cost p/hrs** | **O/T Rate** | **Total cost** |
| **Clinic** |  |  |  |  |
| Consultant | 7.5 | £83.81 | 1 | £628.57 |
| Clinical Fellow | 7.5 | £31.02 | 1 | £341.22 |
| RQI nurse and physiologist nurse | 15 | £21.00 | 1 | 157.50 |
| Admin | 7.5 | £14.38 | 1 | £158.18 |
| Consumables (including PRIMIS?) | 11 | £7.50 | 1 | £82.50 |
|  |  |  |  | £1,392,97 |
| Clinic x4 |  |  |  | **£5,571.88** |
|  |  |  |  |  |
| Electronic/manual searches RQI nurse: 5 hrs x3 (excluding cost of PRIMIS suite to tools) | 15 | £21.00 |  | £315.00 |
| Preparation for clinic  RQI nurse: 3hrs x4 | 12 | £21.00 | 1 | £252.00 |
| Follow-up clinic with RQI nurse: 19x0.5hrs | 9.5 | £21.00 |  | £263.40 |
|  |  |  |  | **£830.40** |
| Secondary care referrals  (6 respiratory and 1 cardiac) |  |  |  | **£1,635** |
|  |  |  |  |  |
| **Overall total** |  |  |  | **£8,037.28** |
|  |  |  |  |  |
| Cost per patient (n=42) without electronic/manual searches |  |  |  | £183.86 |
| Cost per patient (n=42) |  |  |  | £191.36 |

**Costs or costs incurred**

Initial health economics suggest that the total cost of the HLCCs was £8,037.28 which when divided by the number of patients to give a cost of £191.36 per patient. This includes GRASP identification, manual search, medical, nursing and administrative staff and consumables for the HLCCs (See table 18). [The cost for RAACs [Rapid Access Asthma Clinics] was quoted by Winker (2015) as £84 per patient and £456 per patient for SAACs [Special Access Asthma Clinic]. However, it is unclear whether this was only the cost of the SAACs and RAACs on the day or taking into account all costs incurred in preparation for RAACs and SAACs.]

The national tariff for new patient outpatient appointment is £241 for respiratory multi professional and £189 for cardiology multi professional. Six patients had respiratory referrals and one patient had a cardiology multi-professional referral giving a total cost £1,635 for referrals to specialist secondary care (See table 18).

***Table 19: Health Economics Benefits Costs Saved or Benefits***

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Items** | **12 months before** | **Costs** | **4 + 6 mths+**  **n=23 + 17** | **Costs** | **% reduction/**  **increase** | **Costs saved or benefit** |
| ICS [oral steroids] | 13 | £590.07 | 39 | £1,770.21 | +66.6% | +£1,180.14 |
| SABA | 80 | £191.20 | 37 | £88.43 | 62.5% | £102.77 |
| GP non-elective visits | 92 | £3.312.00 | 15 | £540.00 | 83.6% | £2,772.00 |
| A&E visits | 4 | £494.64 | 0 |  | 100% | £494.64 |
| OOH visits | 2 | £228.00 | 0 |  | 100% | £228.00 |
| Hospital admissions | 2 | £4,378.00 | 0 |  | 100% | £4,378.00 |
| New diagnosis |  |  | 41 |  |  | £1,845 |
| **TOTAL** |  |  |  |  |  | **£8,640.27** |

**Benefits or costs saved**

In 2015 the cost per emergency hospital admission is £2,189, cost per visit to A&E is £123.66, cost per OOH visit is £114, cost per emergency or non-elective visit to GP is £36\*, cost of SABA is £2.39, cost of ICS is £45.39. A saving/bonus of £45 per patient is made by the GP practice for a new diagnosis. The total costs saved of benefits incurred consequent to the HLCCs are/is £8,640.27. As the total costs incurred for the HLCCs were £8,037.28, a net benefit of **£602.99** has been generated in savings from the reduction in A&E visits, emergency hospital admissions, OOH visits, emergency or non-elective visits to GPs and SABA use. If the reduction in emergency non-elective visits to GPs is costed at £74, the benefit would be an additional £5,800 *i.e.* £6,402.99.

\*According to ITV News (2014) and Curtis (2013), a 11.7-minute visit to a GP costs the NHS £45. IC (2010, 2010a) suggests that including direct care staff costs, a GP face to face appointment lasting 11.7 minutes can be costed at between £28 and £36.

1. **Discussion**

The evaluation focussed on the extent to which the aims and objectives were met and the extent of which the new case finding breathlessness pathway was effective at both organisational and patient level and including the health economics impact.

**5.1. Increased access to early accurate diagnosis of breathlessness**

**Identifying patients with undiagnosed breathlessness and diagnostic yield**

The main aim of this intervention was to identify patients with symptoms of breathlessness but no diagnosis in order to test a new model of care to facilitate early and accurate diagnosis in an efficient and effective way.

Using inclusion and exclusion criteria, electronic GRASP-COPD/GRASP-HF/Asthma audit tool (AAT) identified suitable patients which had to be manually filtered by the RQI nurse using additional inclusion and exclusion criteria. The approach enabled to save time, money and inconvenience to patients in the long term as otherwise too many patients would have been invited that would may have been diagnosed with a respiratory or cardiac condition. It also highlighted the need for GP practices to develop consistency of coding for breathlessness.

Out of 87 patients identified (68 for COPD and asthma; 6 for asthma and HF and 13 for HF and COPD) in GP practices 1 and 1, 53 (61%) were eliminated by RQI nurse led manual search. Out of the 24 patients invited, 19 booked appointments and 19 attended the HLCCs.

In GP practice 3 a total of 313 patients were identified electronically. As the number were smaller, all of them were manually reviewed by the RQI Nurse: 35 were selected but 7 were excluded after further review. Out of 313 patients 284 (90.7%) were eliminated by RQI nurse led manual search, leaving 29 patients to be invited to attend the HLCC. A total of 23 patients were booked for appointments and all attended.

In the case of GP practices 1 and 2, 19 out of 34 patients invited to attend booked an appointment (55.8 %) while for GP practice 3 a total of 23 out of 35 (65.7%) did so. All 42 patients (100%) who had been booked for appointments attended the HLCCs. However, OPM who were commissioned by NHS IQ to undertake an evaluation of all three pilot sights that had received pump priming funding, indicated that only two patients did not attend after confirming their attendance, which is different from information received from the RQI nurse by the evaluator (See Roberts et al, 2016, p21)

In WAHSN, NIHR CLARHC Wessex/WHCCG (2015, pp9-12) a total of 58 undiagnosed patients were booked for the 60-minute diagnostic clinic run by RQIP nurses, of which 54 attended (93.1%). Of these 54 patients, 48% were referred to primary care for follow-up and further investigation and 6% referred to secondary care. The diagnostic yield was 59% (n=32) compared to 97.6% in the present intervention. In WAHSN, NIHR CLARHC Wessex/WHCCG (2015) 6% were referred to and diagnosed in secondary care compared to 21% in the present intervention. In WAHSN, NIHR CLARHC Wessex/WHCCG (2015) the case finding clinics were run by RQI nurses instead of a multi-disciplinary team including specialist respiratory medical consultant and patients were not diagnosed, but received a suggestion of a diagnosis and were asked to contact their GP for further testing and management.

**Reduction in secondary and primary care usage**

The present intervention demonstrated that specialist secondary care case-finding breathlessness clinics in primary care can identify at risk patients and accurately confirm diagnosis and optimise treatment and improve management. It led to reduction in A&E attendance (100%), emergency hospital admissions (100%), OOH visits (100%), exacerbations requiring ICS or AOB (89.1%), emergency non-elective visits to GPs (83.6%) well as a reduction in SABA (62.5%), leading to reduced NHS costs (£8,640.27).

The cost per patient was £191.36 instead of £241 for a secondary care respiratory appointment, leading to a net benefit of between £602.99 to £6,402.99 depending on the allocated cost of emergency non-elective visits to GPs (£36 or £74). The high percentage of respiratory diagnoses (97.2%) and the compliance with treatment (76%) of as well as the lifestyle advice are likely to have resulted in improved Quality of Life (QOL). Based on materials provided by Wessex AHSN and interviews with RQI nurse, clinical team members, project lead, the NHS IQ evaluation of the three breathlessness pilot tests undertaken by OPM indicated 70% compliance (See Roberts et al, 2016, p23).

**Views of patients**

The survey of patients (n=24) showed that patients were very satisfied (83.3%) or satisfied (16.6%) with the booking process, very satisfied (91.3%) or satisfied (8.6%) with the information given to them, very satisfied (100%) with the team that welcomed them and 93.7% would recommend the clinic to family and friends. Before the 60-minute HLCC appointment only 12.5% were very confident in managing their breathing problems, 62.5% were confident and 20.8% were unconfident. After the 60 minutes HLCC, no patient was unconfident, 34.7% were confident while 65.2% were very confident. Qualitative comments can be divided into five categories: praising the team (39.3%); overall experience very helpful (21.2%); information received very good (15.1%); given me a firm diagnosis/treatment (9%); and would recommend (12.1%).

**5.2. Partnerships primary and secondary care, increased skills of HCPs and improved patient experience, education and quality of life**

NICE guidelines make recommendations for early diagnosis on the basis of lesser costs in secondary care (NICE 2010a, 2010b). NHS England (2014) and the King's Fund (Robertson et al, 2014) have suggested that ensuring specialist expertise is used to support the delivery of care outside hospital has the potential of improving patient experience and access to care. The new model of care for early diagnosis was possible because of an effective partnership between primary and secondary care across Wessex. Efficiencies were created through inter-organisational working and collaboration of resources and skills across primary and secondary care.

A key objective was to increase the education and skills and practices of HCPs in GP practices in delivering respiratory care by way of bespoke training sessions by a specialist secondary care team including the RQI nurse and to thereby help them identify training needs as part of continued professional development staff offered and upskilling by RQI nurse who mentioned setting up and managing education training for practices and mentorship clinics. Surveying and/or interviewing of healthcare and medical staff about the ease of use and functionality of the newly created pathway/model of care was not undertaken despite this being part of the objectives and framework and despite suggestions from the evaluator. The reason given was that NHS IQ was commissioning an evaluation of all three pilot tests that had each received £15,000 funding. OPM gained feedback from the project lead, the RQI nurse who co-ordinated the intervention, a GP and a nurse from GP practice 2 as well as from a members of the specialist respiratory clinical team.

develop education for the GP practice to leave a legacy [as well as the GRASP electronic tools which are free to use] p20 Someone from the GP practice said there had been ‘lots of learning’ and more awareness of the breathlessness symptoms and have been taught ‘better procedures, like inhaler techniques’ p23

The use of multidisciplinary team meetings [MDTs] was part of the objectives. MDTs were key in diagnosis and management plan for each patient and were an opportunity to provide educaiton and training for HCPs. However, there is no feedback from HCPs about learning they might have acquired from MDTs.

Observations in the field from project team were referred in the objectives and outcome measures. However, none were provided despite a PDSA approach to the intervention. The views and experience of the RQI nurse were gathered by the evaluator during several meetings. However, apart from being more efficient with electronic searches and writing better letters of invitation to patients gathered from dicussion with the RQI nurse, it was difficult to find out what exactly she had learnt and how her learning or that of others during the intervention informed the delivery of the intervention.

At patient level, a key objective was to improve patient experience of care by creating links and relationships with various health care providers. Patient feedback indicates a very high level of satisfaction. OPM reported 100% satisfied with the experience (Roberts et al, 2016, p24) which is misleading as only satisfaction with the team that welcomed them scored 100%. Satisfaction with the booking process scored 83.3%, satisfaction with the information given 91.3% and 95.6% of those who responded to the question would recommend the service to family and friends. The sample of patients surveyed was limited with 24 out of 42 providing quantitative data but not all respondents answered all the questions and only 16 providing qualitative comments. OPM reported that a specialist clinical team member had explained that they had ‘done a lot of assessment of patient experience in clinics and 100% appreciated the experience’, which is not congruent with data provided for this evaluation. This specialist clinical team member also underlined that they ‘captured the feedback with a mix of quantitative and qualitative – some semi-structured interviews and questionnaires’. (Roberts et al, 2016, p25) The only material made available to the evaluator for this evaluation were satisfaction questionnaires completed by the patients themselves rather than patients being interviewed and their comments recorded verbally or in writing by someone else.

Another patient level key objective was to improve patient education leading to effective self-management. This was assessed by the RQI nurse of the GP practice nurse during the one-month follow-up mentorship clinics and by the patient satisfaction survey questionnaire that indicate that those who felt unconfident decreased from 20.8% (n=4) to 0%, that those who felt confident decreased from 62.5% (n=15) to 34.7% (n=8) and that those who felt very confident increased from 12.5% (n=3) to 65.2% (n=15). It is rather different from the claim that 96% of patients were more confident in managing breathlessness symptoms (Roberts et al, 2016, p23). Lack of confidence decreased by 20.8%, confidence decreased 47% and high confidence only increased by 80%.

A third patient level objective was to improve patients’ quality of life by providing accurate, relevant and timely information. This was not assessed, only inferred because of early diagnosis, management plan and education during HLCCs and one-month follow-up mentorship clinic with RQI nurse or GP practice nurse. Patients were not followed-up after the HLCCs about their experience, quality of life or the education received. However, quality of Life questionnaires used in other respiratory interventions before and after the intervention were not used in this intervention.

1. **Conclusion**

**6.1. Strengths**

* Accurate earlier diagnosis for patients and adequate treatment management plan, hence better experience and better education and better self-management.
* Longitudinal element with patients followed at 1, 4 and 6 months
* Value-added for cost effectiveness because of substantial reduction in exacerbations requiring ICS [oral steroids], A&E visits and emergency hospital admissions, OOH visits and emergency non-elective visits to GPs.[[15]](#footnote-15)
* Partnership primary care and secondary care based on multi-disciplinary and inter-professional intervention and use of MDTs to agree a diagnosis and treatment management plan.[[16]](#footnote-16)
* Compared to Wessex AHSN, NIHR CLARHC Wessex/WHCCG (2015) that also used the same GRASP-COPD and Asthma audit tool (AAT) for case finding, a greater percentage of patients invited to attend the diagnostic HLCCs were given a respiratory diagnosis: 97.6% compared to 59%. This suggests a more efficient manual filtering system following the electronic case finding searches of patient records and that a case finding approach based on symptoms rather than a specific condition may be more cost effective and a case-finding clinic run my multi-professional team is better than one run by RQI nurses only.
* Not only was joined up care provided, but there was an opportunity for HCP education and mentorship
* The intervention successfully identified three supportive and energetic GP practices to pilot the new model of care and thus built trust and a common history that could be further built upon before it could be rolled out across the local health economy (Naylor et al, 2015)
* GP practices 2 and 3 are part of 11 Vanguards developing new model of care in Wessex. South East Hampshire counts 10 GP surgeries interested in rolling out this new model of care to larger cohorts over 2 years for MISSION ABC [Asthma, Breathlessness, COPD] which will continue case finding for breathlessness, asthma and COPD and also focus on better control and management of asthma, breathlessness and COPD.

**6.2. Limitations**

* On-going project monitoring was meant to be informed by a PDSA approach and observations in the field were included under methods/framework/design. However, despite the evaluator’s attempt to eliciting such retrospectively, no evidence was provided except in the most general terms of increased efficiency in electronic searches and manual filtering and writing better letters of invitation to patients for GP practice 3. In fact, all the results of electronic searches were reviewed manually in GP practice 3 because it was a small GP practice (rather than only reviewing patients who had come up in at least two types of electronic searches *i.e.* asthma, COPD and heart failure) and not because of previous learning subsequent to filtering manually the results of the electronic searches in GP practices 1 and 2.
* Even though this was a specified objective of the intervention no data was collected about the experience and views of healthcare and medical staff involved and in particular about their views on the ease of use and functionality and sustainablility of the new model of care. The evaluator suggested this be carried out, which was rejected. The reason was that NHS IQ had commissioned OPM to undertake the evaluation of the 3 pilot projects that had received pump priming funding of £15,000. The very positive views of staff involved are articulated in the OPM report which includes views of the Project Manager, Lead RQI nurse, specialist clinical team and GP practice. However, out of 15 quotes provided, only two were from the GP practice. All the other quotes were from the project lead, the RQI nurse and members of the specialist clinical team.
* No data was collected about education and training from those involved in the intervention. The evaluator suggested this be carried out, which was rejected as OPM would evaluate the three national pilot sites on behalf of NHS IQ. In the OPM evaluation report, the Lead RQI nurse refers to providing education and training and the Clinical QI Research Fellow said that ‘by going out and doing the education side of things you hopefully have a knock on effect for the rest of the GP practice as well as all the patients even if you haven’t seen them’. (Roberts et al, 2016, p27 and p59). Someone from GP practice 2 (assumed to be a GP practice nurse) is quoted as describing the intervention having led to ‘lots of learning’ and being more aware of breathlessness and having ‘been taught better procedures, like inhaler techniques’ (Roberts et al, 2016, p23)
* Apart from the opportunity to use the GRASP suite of electronic tools that was left behind as a legacy, no system was set up to enable the GP practice to continue identify patients in order to diagnose them earlier. It is not known whether using GRASP electronic tools was something that HCPs or GPs were taught to do and could replicate and whether this learning could be further applied or transferred to others.
* The sample of patients surveyed was limited with only 57.% taking part in the survey and only 34.7% partipation from patients GP practice 3 (Avis, 1997; Cook, Heath, and Thompson, 2000). The survey questionnaire was only a basic satisfaction survey and it did not specifically seek suggestions for improvement. The evaluator’s suggestion that patients be surveyed at the one -month follow-up clinic was rejected, missing a valuable opportunity to collect valuable feedback.

1. **Recommendations**

* Development of accessible integrated respiratory services should include representation from primary and secondary care, including both physicians and nurses, and ideally organisations that promote innovation across both.
* Ensure that the skill mix of the specialist clinical team reflects the broad nature of respiratory and cardiac conditions to account for all presenting patients and their potential diagnosis.
* Build in evaluation, monitoring sustainability and potential spread from the start, not just expect that cost savings in the first year may be reinvested to fund a second year
* Collect data on the experience views of healthcare and medical staff especially HCPs and GPs in GP practices about the ease of use and functionality of the newly created pathway/model of care as well as suggestions for improvement
* Continue to build education, training and mentorship in GP practices
* Encourage and train GP practices to use GRASP suite of tools and manual filtering to identify patients with breathlessness symptoms but no diagnosis
* Collect data about education electronically or otherwise, training and mentorship given and especially received to provide evidence of the extent to which skills have been increased and of the transferability of the newly acquired skills
* Using validated questionnaires and/ or open-ended questions, collect evidence beyond basic satisfaction i.e. about the views and experience of patients, including the opportunity to provide suggestions for improvement
* Using interviews (telephone or otherwise) and/or focus group collect data on the experience and views of patients
* Using validated questionnaires collect data on the quality of life and education of patients after HLCCs – the one-month follow-up clinic is a good opportunity to do this
* Further mentorship and education clinics should be planned between the practice staff and the clinical project team to consolidate learning and make this new model of care or new pathway sustainable in the long term.
* Work with GP practices and CCGs to encourage more standardised and more consistent coding of breathlessness
* Involve patients and carers and all levels of staff, including patient groups, in co-designing and evaluating the service and piloting surveys (Lockett et al 2012; Hayes et al, 2014; Bevan and Fairman, 2014)
* More marketing and awareness raising would have been beneficial
* The outstanding benefits to patients and GP practices and to CCGs need to be better disseminated, including in peer refereed academic publications

**References**

Academy of Royal Medical Colleges. *Measuring up the medical profession's prescription for the nation's obesity crisis?* 2013. London: AoRMC

Barwell J, Arnold F and Berry H. How inter-professional learning improves care. 2013. *Nursing Times*; 109: 21, 14-16 Available at <http://www.nursingtimes.net/roles/nurse-educators/how-interprofessional-learning-improves-care/5059052.fullarticle> [Accessed 21 May 2016]

Baxter, N. *Detecting breathlessness and structured assessment in primary care*. 2014. Southwark Clinical Commissioning Group and Lambeth Clinical Commissioning Group. Available at <http://www.slideshare.net/NHSIQ/detecting-breathlessness-and-structured-assessment-in-primary-care> [Accessed 4 April 2016]

Bellamy D, Booker, R, Stephen Connellan S, and Halpin D. *Spirometry in Practice: a practical guide to using spirometry in primary care*. [2nd ed.] London: British Thoracic Society (BTS) COPD Consortium

Borton C, Tidy C and Cox J. *Breathlessness.* Patient Trusted Medical Information and Support] 2014. Available at [www.patient.co.uk/doctor/breathlessness.htm](http://www.patient.co.uk/doctor/breathlessness.htm) [Accessed 2 February 2016]

British National Formulary (BNF). *BNF Online*. 2016. Available at <https://www.bnf.org/> [Accessed 21 June 2016]

British Lung Foundation (BLF). *Invisible Lives Report*. 2014. BLF: London. Available at <http://www.impressresp.com/index.php?option=com_content&view=article&id=20&Itemid=19> [Accessed 9 March 2016]

Brown V*. Specification for Services to be Commissioned for Research to inform NHSIQ Work. Scoping Research on Models* *of Care to Support Earlier Diagnosis of Diseases related to Breathlessness as a Symptom* LLL01.2014. NHS Improving Quality

Cook, Heath, and Thompson (2000) Cook C, Heath F and Thompson, RL. 2000. A meta-analysis of response rates in web- or Internet-based surveys. *Educational and Psychological Measurement* 60, 6, 821–836

Crisafulli E. Measures of dyspnea in pulmonary rehabilitation. Multidisciplinary Respiratory Medicine 2010, 5:202-210 doi:10.1186/2049-6958-5-3-202

Deloitte UK Centre for Health Solutions. *Working differently to provide early diagnosis - Improving access to diagnostics*. 2013.

Department of Health. *An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in Englan*d. 2011. London: Department of Health.

Department of Health. *Consultation on a strategy for services for chronic obstructive pulmonary disease (COPD) in England*. 2010. Available at <http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_113279.pdf> [Accessed on 02/03/16]

Department of Health. *The NHS Outcomes Framework 2015-2016.* 2015. London: DH. Available at <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/385749/NHS_Outcomes_Framework.pdf> [Accessed 07/08/15]

Department of Health. 2015. *NHS Reference Costs 2014-2015*. Available at <https://www.gov.uk/government/publications/nhs-reference-costs-2014-to-2015> and <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/477919/2014-15_Reference_costs_publication.pdf> [Accessed 25 June 2016]

Curtis, L. 2013. *Unit Costs of Health and Social Care 2013*. Personal Social Services Research Unit. University of Kent Canterbury. Available at <http://www.pssru.ac.uk/project-pages/unit-costs/2013/> [Accessed 21 June 2016]

Dominey R. *Background on the Project*. NHS IQ meeting with Heather Heathfield from OPM 1pm-3pm and Jayne Longstaff WAHSN, Caroline Powell CIS, Catherine Matheson CIS, Frank Radcliff WAHSN, 6 January 2016

Durham University. *The Life of Breath : a new project on breathlessness and COPD*. 2015. Available at <http://centreformedicalhumanities.org/the-life-of-breath-a-new-project-on-breathlessness-and-copd/> and <https://www.dur.ac.uk/cmh/lifeofbreath/> and <http://www.bristol.ac.uk/arts/research/projects/life-of-breath/> [Accessed 15 December 2015]

Evans R. *Developing the model of pulmonary rehabilitation for chronic heart failure. Chronic Respiratory Disease*. 2011. 8(4) 259–269. Doi:10.1177/1479972311423111. Available at <http://crd.sagepub.com/content/8/4/259.short> [Accesses 5 January 2016]

Evans RA, Singh SJ, Collier R, Loke I, Steiner MC, Morgan MD. Generic, symptom based, exercise rehabilitation; integrating patients with COPD and heart failure, *Respir Med*. 2010;104(10):1473-81. doi: 10.1016/j.rmed.2010.04.024 [Accessed 5 January 2016]

Haroon S; Jordan R, O’Beirne-Elliman J, Adab, P *Screening Test Accuracy Of Case Finding Interventions For Chronic Obstructive Pulmonary Disease In Primary Care: A Systematic Review*. 2014. Poster Presentation at American Thoracic Society, May 19, 2014. Available at http://www.atsjournals.org/doi/abs/10.1164/ajrccm-conference.2014.189.1\_MeetingAbstracts.A2955?src=recsys [Accessed on 12/12/15]

Health and Social Care Information Centre [HSCIC]. *READ Codes*. n.d. Available at <http://systems.hscic.gov.uk/data/uktc/readcodes> [Accessed 7 March 2016]

IMPRESS (Improving and integrating respiratory services). *About us*. 2014. Available at [http://www.impressresp.com](http://www.impressresp.com/#sthash.e77qTpCa.dpuf) [Accessed 5 January 2016]

ITV News (2014) *GPs to vote on charging patients for appointments. One visit to GP costs £45*. Available at <http://www.itv.com/news/update/2014-05-22/one-visit-to-gp-costs-45/>

Jones R, Price D, Ryan D., Sims E, Von Ziegenweidt J, Mascarenhas L, Burden,A, Halpin D, Winter R, Hill S, Kearney M, Holten, K, Moger A, Freeman D, Chisholm A, Bateman E. Opportunities to diagnose Chronic Obstructive Pulmonary Disease in routine care in the UK: A restrospective study of a clinical cohort. 2014. *The Lancet*. (14) 70008-6.

Langley GL, Nolan KM, Nolan TW, Norman CL, Provost LP. *The Improvement Guide. A practical approach to enhancing organisational performance* (2nd edition). San Francisco: Jossey Bass

Winker M. *MISSION Asthma. Health Economic Evaluation on First Pilot*. 2015. Wessex AHSN, RQIP PPT [24 slides]

Murray, C et al. UK health performance: findings of the Global Burden of Disease Study 2010 *The Lancet*, 381, 9871m pp997-1020, 2013. DOI: <http://dx.doi.org/10.1016/S0140-6736(13)60355-4>. Available at <http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)60355-4/fulltext> [Accessed 6 December 2015]

National Institute for Health and Care Excellence [NICE]. *Chronic obstructive pulmonary disease in over 16s: diagnosis and management. NICE guidelines* [CG101]. 2010a. Available at <http://www.nice.org.uk/guidance/cg101/chapter/1-Guidance#diagnosing-copd> [Accessed 22 December 2015]

National Institute for Health and Care Excellence [NICE]. *Chronic heart failure. National clinical guideline for diagnosis and management in primary and secondary care*. Full version of NICE Clinical Guideline No 108. 2010b. Available at <https://www.nice.org.uk/guidance/cg108> [Accessed 02/02/2016]

National Institute of Mental Health (NIMH). *What are DALYs?* n.d. Available at <http://www.nimh.nih.gov/health/statistics/global/index.shtml> [Accessed 15 December 2015]

National Institute of Mental Health (NIMH). *What are YLDs?* n.d. Available at <http://www.nimh.nih.gov/health/statistics/global/what-are-ylds.shtml> [Accessed 15 December 2015]

NHS England. *The NHS Five Year Forward View*. 2014. Available at: http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf Accessed on: 22/04/2015

NHS Improving Quality*. First steps towards quality improvement: a simple guide to improving services*. 2015. Available at [http://www.nhsiq.nhs.uk/media/2591385/siguide.pdf Accessed 07/08/15](http://www.nhsiq.nhs.uk/media/2591385/siguide.pdf%20Accessed%2007/08/15)) pp28-29

NHS Improving Quality. [*NHSIQ Living Longer Lives*](http://www.nhsiq.nhs.uk/improvement-programmes/living-longer-lives.aspx)*.* n.d. Available at <http://www.nhsiq.nhs.uk/improvement-programmes/living-longer-lives.aspx> [Accesssed 5 December 2015]

NHS Institute for Innovation and Improvement. *Quality and Service Improvement Tools*. *Plan, Do, Study, Act (PDSA)*. 2013. Available eat <http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/plan_do_study_act.html> [Accessed 12 February 2016]

*NHS Networks.* [IMPRESS IMProving and Integrating RESpiratory Services in the NHS](https://www.networks.nhs.uk/nhs-networks/impress-improving-and-integrating-respiratory). *IMPRESS Breathlessness Resources*. 2014. Available at <https://www.networks.nhs.uk/nhs-networks/impress-improving-and-integrating-respiratory/news/impress-breathlessness-resources> [Accessed 15 December 2015]

Naylor C, Alderwick H and Honeyman M. *Acute Hospitals and Integrated Care: From hospitals to health systems*. 2015. London: King's Fund. Available at <http://www.kingsfund.org.uk/publications/acute-hospitals-and-integrated-care> [Accessed 2 December 2015]

Primary Care Respiratory Society UK (PCRS). *IMPRESS Breathlessness Tips (BITs) for researchers.* Impress Breathlessness Working Party LSE. 2014. Available at <https://www.networks.nhs.uk/nhs-networks/impress-improving-and-integrating-respiratory/documents/Breathlessness%20IMPRESS%20Tips%20for%20Researchers%20FINAL%202014-02-04.pdf> [Accessed 15 December 2015]

Public Health England. *Longer Lives: premature mortality*. n.d. Available at <http://healthierlives.phe.org.uk/topic/mortality> [Accessed 5 January 2016]

Rand Corporation. *RAND Europe Project: Living with Breathlessness*. n.d. Available at <http://www.rand.org/randeurope/research/projects/living-with-breathlessness.html> [Accessed 14 December 2015].

Roberts L, Macmillan C and Peach B. *Evaluation of the NHS Breathlessness Pilots. Report on the Evaluation Findings for NHS England.* 31 March 2016. London: OPM

Robertson R, Sonola L, Honeyman M, Brooke B, Kothari S. *Specialist in out of hospital settings*. 2014. London: King's Fund. Available at <http://www.kingsfund.org.uk/publications/specialists-out-hospital-settings> [Accessed 9 March 2016]

Royal College of Physicians. *Action on obesity: comprehensive care for all*. Report of a working party. 2013. London: RCP

Simon ST, Higginson IJ, Benalia H, Gysels M, Murtagh FE, Spicer J, Bausewein C. Episodic and continuous breathlessness: a new categorization of breathlessness. *J Pain Symptom Manage*. 2013 Jun;45(6):1019-29. doi: 10.1016/j.jpainsymman.2012.06.008.

Stenton C. The MRC breathlessness scale. *Oxford Journal of Occupational Medicine*. 2008. [58, 3](http://occmed.oxfordjournals.org/content/58/3.toc), pp. 226-227. Available at <http://occmed.oxfordjournals.org/content/58/3/226.full> [Accessed 03/03/2016]

Taylor MJ, McNicholas C, Nicolay C, Darzi A, Bell D, Reed JE. Systematic review of the application of the plan–do–study–act method to improve quality in healthcare. 2013. BMJ Qual Safdoi:10.1136/bmjqs-2013-001862. Available at <http://qualitysafety.bmj.com/content/early/2013/09/11/bmjqs-2013-001862.full.pdf%2Bhtml%20> [Accessed 10 January 2016]

The Health Foundation. *Star Methodology*. 2016. Available at <http://www.health.org.uk/star-methodology> [Accessed 2 February 2015]

The Information Centre (2010) *GP Earnings and Expenses 2008/09, Provisional Report Produced by the Technical Steering Committee,* *September 2010*, The Information Centre, Leeds. Available at <http://www.pssru.ac.uk/pdf/uc/uc2010/uc2010_s10.pdf> [Accessed 15 June 2016]

Troosters T, Remoortel HV. Pulmonary rehabilitation and cardiovascular disease, Semin *Respir Crit Care Med*. 2009.;30(6):675-83. doi: 10.1055/s-0029-1242637

WAHSN/ NIHR CLAHRC Wessex/WHCCG. *Evaluation of case finding for COPD/asthma and management of poorly controlled asthma/COPD project*. 2015. Southampton.

Wessex Academic Health Science Network (AHSN). *Respiratory Quality Improvement Programme*. *NHS Improving Quality (NHSIQ) Breathlessness Project.* 2015. Available at <http://wessexahsn.org.uk/projects/48/nhs-improving-quality-nhsiq-breathlessness-project> [Accessed 5 December 2015]

Wessex HIEC and AHSN Respiratory Scoping Group. *Academic Health Science Network Respiratory Quality Improvement Programme Purpose*. 2013.

Wessex AHSN. *Respiratory Programme Brief*. 2016. Available at <http://wessexahsn.org.uk/programmes/show/1/respiratory> [Accessed 19 May 2016]

Wessex AHSN. *Scoping Document. Final Document Submitted to Martin Stephens Interim Managing Director Wessex Academic Health Sciences Network on 25th June 2013. For the AHSN executive board meeting 4th July 2013*. Available at <http://wessexahsn.org.uk/programmes/show/1/respiratory> [Accessed 21 May 2016]

**APPENDICES**

**Appendix 1**

**NHSIQ Specification for services to be commissioned for research to inform NHSIQ work** (Brown, 2014)

The primary aim of the pilot work is

1. To explore the barriers to earlier diagnosis for people with the symptom ‘breathlessness’ and to test new models of care which address these barriers, facilitate rapid access to diagnostics and help to obtain an accurate diagnosis in an efficient and effective way.
2. To understand and apply ‘best practice’ in models of care from the UK and internationally for early diagnosis of disease both generally and with a focus on breathlessness as a symptom
3. To learn from past and present models of care (both successful and unsuccessful) relating to the above
4. To horizon scan/ consider how emerging trends and developments in this area might potentially affect the NHS IQ pilots, to help develop new insights and to think ‘outside the box.’

The insight gathered by the successful provider for the scoping exercise, will be pivotal in NHS IQs development of a business case for any extension/expansion of the pilot work going forwards ()

The research questions are:

1. What evidence or good practice exists on early diagnosis and its impact on the quality of patient care (patient safety, outcomes and experience) and costs to the health service?
2. What evidence, evaluation and/or models are there for diagnosis of disease from a symptom-based perspective?
3. What models, standards, guidelines or good practice already exist for ‘rapid’ access to diagnostics generally, e.g. Rapid Access Chest Pain Clinics?
4. What evidence, evaluation and/or models are there for diagnosing disease by focusing on breathlessness in particular as a symptom? Are there any rapid access breathlessness clinics and/ or diagnostic pathways for breathlessness already in existence or in development?
5. The scoping research should include relevant evidence/ examples from the UK and internationally, both published/ unpublished, pertaining to any/ all healthcare settings, e.g. primary care, community, secondary care.

All models of care should be covered, but researchers should note that the primary focus of this work is diagnostic breathlessness clinics (Brown, 2014, p3)

Under ‘methodology’, it is specified that NHS IQ anticipated the use of secondary desk research to gather and analyse relevant information already available in print or published on the internet, as the core approach to meet the research objectives.

Having said that, we do not wish to constrain the design and methods used, but remain open to proposals which meet our requirements in other ways, particularly where these are innovative or build upon other relevant work. All proposals should explain the methodology recommended, how methods complement each other, how they are scheduled and how they will produce robust, relevant evidence against the relevant research objectives and questions.

Under ‘deliverables’, the expectation is that the primary output of this scoping research will be a thorough and fully referenced report:

1. Written in MS Word format to be published under NHSIQs name
2. To include an executive summary of no more than four pages and a one page ‘pull-out’ which highlights the key messages for NHSIQ
3. To address the research objectives and questions, the findings and recommendations for NHSIQ as well as any additional points agreed during the tendering or research process

It is anticipated that the successful provider will deliver the written report electronically to be discussed via teleconference / WebEx, removing the need for any travel for this project]

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| **Appendix 2** |
| Project Name: |
| **NHSIQ/WAHSN Breathlessness Pilot – “Using GRASP COPD and Asthma case-finding tools to find undiagnosed breathlessness** |
| Project Lead: |
| * Prof Anoop Chauhan (Clinical Lead) * Dr Andy Whittamore (Primary Care Lead) * Jayne Longstaff (Specialist Nurse Lead) * Frank Ratcliff (Project Manager) * Rachel Dominey (PMO) |
| What is it: |
| **Background:**  Breathlessness is a common symptom which can be caused by a number of potentially serious and life threatening conditions. Early diagnosis of the cause of breathlessness can improve outcomes for patients. However more needs to be done to develop and implement referral pathways and services which provide joined up care so that patients are not passed 'from pillar to post' through the system in order to undergo the necessary diagnostic tests and to receive the correct treatment.  NHS Improving Quality's Living Longer Lives team has designed a programme of work to pilot new models of care, which facilitate earlier diagnosis and treatment for people who experience breathlessness as a symptom. This involves supporting delivery partners in three pilot sites in 2015.  Shortness of breath, or breathing difficulty, is the most common reason for visiting a hospital accident and emergency department. It's also one of the most common reasons people dial 999 for an ambulance.  Unexpected breathlessness is most likely to be caused by one of the following health conditions, although this list is not exhaustive;   * Obesity or being unfit   Asthma that is not controlled properly   * Chronic obstructive pulmonary disease (COPD), which is permanent damage to the lungs usually caused by years of smoking * Anaemia, which is a low level of oxygen in the blood due to a lack of red blood cells or lack of haemoglobin * Heart failure, which means the heart is having trouble pumping enough blood around the body, usually because the heart muscle has become too weak or stiff to work properly * Problems with the heart rate or rhythm, such as atrial fibrillation (an irregular and fast heart rate) or supraventricular tachycardia (regular and fast heart rate). |
| Project Aim: |
| 1. To improve the quality of clinical care for patients with breathless symptoms across Wessex in Primary and Secondary Care 2. To improve the recruitment to respiratory studies to enhance our knowledge of the disease |
| Project Objectives: |
| * To form partnerships with primary care surgeries across the Wessex geography * To form partnerships with secondary care across the Wessex geography * To assist with the education of practice nurses delivering respiratory care * Recruit patients to clinical and commercial studies adopted by the NIHR CRN Wessex * Provide increased access to early accurate diagnosis of breathlessness * Increase patient education leading to effective self-management * Improve patient experience of care by creating the links and relationship with the various health care providers * Improve patients’ quality of life by providing accurate , relevant and timely information * To inform the development of effective breathlessness pathways |
| Benefits: |
| * A mixed commissioning model of care whereby an expert clinical service helps health care organisations across Wessex to deliver care for breathless patients * Improved recruitment to commercial studies |
| Project Methodology & Model: |
| This project will be strategically led by the Wessex Academic Health Science Network with additional support from NHSIQ.  A team consisting of an expert Respiratory Nurse, GP and Consultant will lead the delivery of this project within an identified locality in Wessex (Portsmouth, North Hants and West Hants).  Breathless patients without existing appropriate diagnoses will be identified using case finding modules of both GRASP COPD and the equivalent asthma audit tool. The two tools both exclude existing diagnosed patients, and can prioritise patients with a history suggesting breathlessness, for example by selecting those with prescriptions for short or long acting bronchodilators in the last 12 months. Further selections could be made on the basis of prescriptions suggesting chest infections (e.g. antibiotics and oral steroids) or on the basis of MRC breathlessness codes if they are present.  There is considerable experience, both within the team and within the local area in working with these tools, and early evidence suggests that over 1% of the population may be on inhalers without an existing diagnosis of either COPD or asthma. This represents a significant opportunity for medicines optimisation, and improvement of patient care.  Across Wessex, several CCGs have already incentivised use of some of the other audit tools in the suite made freely available by Primis (e.g. GRASP AF). There is therefore already a good level of acceptance and familiarity around the format of the audits which should be transferable to this respiratory project. Furthermore, should practices need more support in terms of installing or running the tools, help is freely available from Primis, and is likely also available from both the CSU and from local industry partners.  Once the two audit tools have been downloaded and run, initial selection will be carried out by one of the project team using the audit reports. A further round of selection will then take place in discussion with the HCPs in each area, to take into account their clinical knowledge of individual patients. Practice administrative staff will send a pre-formatted letter to greet patients, inviting them for a clinical review with a nurse from the project team. |
| Key Performance Indicators: |
| * Number of GP surgeries engaged * Number of patient case notes audited * Number of patients invited to attend * Number of patients attending screening clinic * Number of patients referred to secondary care * Number of patients attended a secondary care appointment * Number of differential diagnosis made * Number of new diagnosis made * Number of patients referred to smoking cessation services * Number of patients who report an improvement in their quality of life * Number of patients who have medication changed as a result of the service * Cost impact as a result of medication changes * Review of hospital admissions and exacerbation frequency of patient with breathlessness who have been reviewed * Patient and Healthcare Professional level satisfaction surveys |
| Project issues/risks: |
| * Non engagement of GP surgeries * Poor uptake of patients accessing the service * Lack of CCG support/interest * Access to data * Quality and quantity of data * Equipment and facilities availability |
| Stakeholders |
| * CCGs (proposed West Hants CCG; North Hants CCG; Portsmouth CCG) |
| Timeline: |
| **Definition of Service, resources required, key success criteria**  **Phase 1: Set-Up = April 2015 - June 2015**  Milestone 1: Set-up complete with buy-in from key stakeholders  Milestone 2: Literature designed and developed  **Phase 2: Implementation = July 2015 – Jan 2016**  Milestone 3: Determine rollout plan  Milestone 4: Project rolled out across participating practices across 3 CCGs  **Phase 3: Evaluation = Feb 2016 – Mar 2016**  Milestone 5: Patient and Healthcare Professional feedback collated and data collected and analysed  Milestone 6: Final outcomes presented to all stakeholders at NHSIQ dissemination event, final report for stakeholders and wider public circulated, outcomes published on website. |
| Costings: |
| **Summary of Costs:**     |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | | **Item** | **Description** | **Cost** | **Quantity** | **Total Cost** | **Source** | | Project Management | Management & delivery of the project | £250 per day | 1 day per week | £12000 | Boehringer-Ingleheim (matched) | | Equipment | Screening tools for specialist nurse clinic | Various | - | £5000 | NHSIQ | | Specialist Nurse | Patient data analysis and case-finding/ screening clinics | £250 per day | 48 days | £12000 | Wessex AHSN & NHSIQ | | Venue | Room hire | £300 | 6 practices | £2400 | NHSIQ | | Evaluation | Provision of independent evaluation by WAHSN/CIS  (Health Economic Analysis) with NHSIQ | £320/day | 10 days | £3200 | WASHN CIS & NHSIQ | |  | | | | £34,600 |  | |

1. **Years of life lost (YLLs)**are years lost due to premature mortality. YLLs are calculated by subtracting the age at death from the longest possible life expectancy for a person at that age. For example, if the longest life expectancy for men in a given country is 75, but a man dies of cancer at 65, this would be 10 years of life lost due to cancer. See <http://www.healthdata.org/gbd/faq> and http://www.healthdata.org/gbd/faq#What is a YLL? [↑](#footnote-ref-1)
2. Years lived with disability (YLDs) are a measurement of the burden of disease that are calculated by multiplying the prevalence of a disorder by the short- or long-term loss of health associated with that disability (the disability weight). See <http://www.nimh.nih.gov/health/statistics/global/what-are-ylds.shtml>. When YLDs are added to the number of years of life lost for a certain disease or disorder, the overall disease burden or burden of disability associated with a disease or disorder can be reported in units called [disability-adjusted life years](http://www.nimh.nih.gov/health/statistics/global/index.shtml) (DALYs). See <http://www.nimh.nih.gov/health/statistics/global/index.shtml>. DALYs represent the total number of years lost to illness, disability, or premature death within a given population. DALYs are calculated by adding the number of years of life lost to the number of YLDs for a certain disease or disorder. [↑](#footnote-ref-2)
3. READ codes are a hierarchical clinical coding system or a coded thesaurus of clinical terms that have been used in the NHS since 1985 and which provide the standard vocabulary by which clinicians can record patient findings and procedures in health and social care IT systems across primary and secondary care (HSCIC, n.d.) [↑](#footnote-ref-3)
4. Breathlessness or dyspnoea is the subjective sensation of difficult, laboured or uncomfortable breathing (Borton et al 2014). [↑](#footnote-ref-4)
5. The ‘rapid access clinic’ model was popularised by the publication of the National Service

   Framework for Coronary Heart Disease in 2000 which resulted in widespread development of rapid access chest pain clinics (RACPC) to provide specialist assessment within two weeks of GP referral. [↑](#footnote-ref-5)
6. Wessex AHSN Centre for Implementation Science (CIS) supports provids analytical and knowledge mobilisation support to help evaluate respiratory innovations or to undertake independent evaluations.

   * Informing - providing baseline data for priority setting and measures the impact of projects over time.
   * Horizon Scanning and Evidence synthesis - identifying future needs, processing evidence from NICE (UK), and AHRQ (US) to provide recommendations for practice.
   * Adoption, Diffusion and Evaluating Change - supporting the adoption, diffusion, and evaluation of new interventions across the Wessex health economy. These processes involve complex analytical, organisational and psychological factors and our core expertise in this area, including Chairs in Healthcare Innovation and Health Systems Implementation is well placed to evaluate this innovation and also identify potential barriers to scaling up.
   * Writing up clear but thorough fully-referenced reports
   * Exploiting Research and Knowledge Transfer - communicating analyses and evidence to Wessex partners through a variety of media

   [↑](#footnote-ref-6)
7. Drafted and agreed (with Project Board and Practice Team) patient invitation letters for the HLCCs; agreed equipment needed and identified where this would be sourced and stored; booked dates, times and four rooms in each of the practices to host clinics; greed invitations to patients, booking patients into clinics and telephone reminders to patients *re* their time date of appointment; agreed paperwork for clinics and patient referral method back to the GP; ensured all members of the clinical project team had access to and were familiar with the electronic patient records in each surgery (EMIS Web); agreed dates and booked rooms for the Heart and Lung Check Clinics; agreed mentorship and education provision for practice; agreed GP support with patient identification [↑](#footnote-ref-7)
8. Epworth sleepiness scale. See http://www.britishsnoring.co.uk/sleep\_apnoea/epworth\_sleepiness\_scale.php [↑](#footnote-ref-8)
9. Gastroesophageal reflux disease. See http://www.gerdhelp.com/patient-resources/gerd-hrql-questionnaire/ [↑](#footnote-ref-9)
10. See Stenton C. The MRC breathlessness scale. *Oxford Journal of Occupational Medicine*. 2008. [58, 3](http://occmed.oxfordjournals.org/content/58/3.toc), pp. 226-227. Available at <http://occmed.oxfordjournals.org/content/58/3/226.full> [Accessed 03/03/2016] and also Appendix 9 [↑](#footnote-ref-10)
11. Three questions for asthma care. See <http://www.guidelinesinpractice.co.uk/nov_99_bucknall_asthma_nov99> [↑](#footnote-ref-11)
12. COPD Assessment Test. See <http://www.thoracic.org/members/assemblies/assemblies/srn/questionaires/copd.php> [↑](#footnote-ref-12)
13. Nijmegen hyperventilation questionnaire. See http://www.heartofengland.nhs.uk/wp-content/uploads/Nijmegen\_Questionnaire.pdf [↑](#footnote-ref-13)
14. Asthma Control Questionnaire. See https://www.qoltech.co.uk/acq.html [↑](#footnote-ref-14)
15. NICE guidelines make recommendations for early diagnosis on the basis of lesser costs in secondary care (NICE 2010a, 2010b) [↑](#footnote-ref-15)
16. Most other projects on breathlessness case finding take place in secondary care offering special clinics rather than hospital specialists coming to GP practices to offer case finding clinics working together with RQIP nurse. This Wessex AHSN RQIP model is more in line with multi-disciplinary collaboration and inter-professional learning (WHO, 2010; Barwell et al, 2013) and with ensuring specialist expertise is used to support the delivery of care outside hospital to improve patient experience and access to care (NHS England (2014; Robertson et al, 2014) [↑](#footnote-ref-16)