

## Working together to support and engage the respiratory community in the North East and North Cumbria (NENC)

Nationally, lung disease has a huge impact on the health of the population, accounting for over 700,000 hospital admissions each year. Around 1 in 5 people in the UK will develop some form of lung disease during their lifetime. In the NENC area there are over 115,000 people living with chronic obstructive pulmonary disease (COPD). The Academic Health Science Network (AHSN) NENC and the British Lung Foundation (BLF) are working together to inform and connect people in the region who live with a lung condition. The aim is to empower patients and their carers to be effectively involved in managing their own care and in the future development of health services.

The AHSN and BLF aim to provide training and support to people living with a lung condition in the NENC area, helping them understand how to influence their own care as well as respiratory service improvements at a local and regional level.

### Outcomes

The BLF and the AHSN Respiratory Programme have been working closely on several patient-focussed initiatives including: **Patient Education; Patient Carer Networks**, and the **Pulmonary Rehabilitation (PR)** promotion campaign. A series of events and workshops around these themes have been held over the last 18 months:

As part of the **Patient Education** project, a "Meet the Experts" conference was held in Newcastle upon Tyne. Two "Winter Wellness" workshops, designed to help patients self-manage their COPD were also held in Gateshead Health Centres. In addition, a series of videos to promote the benefits of PR have been created.

The **Patient Carer Network**, established to support individuals in representing the views of people affected by lung disease held its first meeting in July 2016. Two further meetings have since been held. The programme aims to bring together individuals who are willing to represent the views of people affected by lung disease at a local / regional level.

The **Pulmonary Rehabilitation** 'Changing Lives - Breathing Better' promotional campaign involved the development of a series of videos to promote the benefits of PR directly from a patient's perspective. These videos can be accessed from the AHSN website or via You Tube <http://www.ahsn-nenc.org.uk/programmes/respiratory-care/pulmonary-rehab/>

### Impact

- The Patient Education project - feedback from the "Meet the Experts" conference and Winter Wellness Workshops was excellent. Attendees said they had learned more about lung disease, where to find support and felt encouraged to get involved. All attendees said it was useful information, delivered clearly. All felt more confident in recognising and managing their symptoms.
- The Patient Carer Network - 30 participants from 8 CCGs have attended these meetings. Participants are currently developing campaigns to promote the importance of pulmonary rehabilitation, the correct use of inhalers and to reduce the myths and stigma surrounding COPD.

- The Pulmonary Rehabilitation promotional videos have been viewed over 700 times on YouTube and have been adopted into numerous GP surgeries' Care Pathways and hospital clinics to assist when explaining the concept of PR to patients. They have also been adapted into an App, which supports the "Hospital at Home" project developed by Northumbria Healthcare NHS Foundation Trust.

*"What a breath of fresh air! This was great from start to finish. Please have more of them. It has given me a lot of hope & confidence."*

*A "Meet the Experts" conference delegate*

## Background Summary

The BLF is a UK charity, which aims to prevent, treat and cure lung disease, provide support and to improve respiratory care. It encourages patient engagement and involvement in the development of local services. The AHSN Respiratory Programme and the BLF have worked closely on several successful, patient-focussed initiatives. These include: Patient Education and Patient Carer Networks.

### Patient Education:

A "Meet the Experts" Conference was held in September 2015; it provided clear information about lung conditions, how to manage them and how to get involved with developing care in your region.

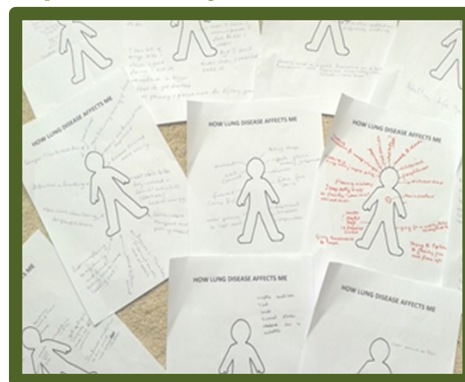
The Winter Wellness Workshops were a patient education initiative agreed with Newcastle Gateshead CCG. A small number of the most 'at risk' patients were selected by GPs to attend a 3-hour educational workshop, aiming to help them to manage their condition more effectively.

The **Patient Carer Network** enables people to share experiences and learn more about how and what they can influence. The forum aims to inform patients and their carers of the care they should receive and how services are prioritised and commissioned within the NHS. It aims to equip representatives with the knowledge and skills required to influence these processes and to lobby for change where appropriate. Members are encouraged to develop proposals for improvement, and supportive guidance is given to assist with their delivery.

## Pulmonary Rehabilitation Promotional Campaign:

PR is accepted as one of the most cost-effective treatments for COPD yet in some parts of our region referral to PR is as low as 4.2%, and completion rates are less than 2%. The video "Changing Lives – Breathing Better" and accompanying case studies were created to promote the value of PR. The aim is to provide insight directly from a patient's perspective into the benefits of PR; they can be used as an educational tool for both patients and clinicians.

## Support provided by AHSN



The AHSN NENC has provided the funding for these events. The educational events have been developed and delivered jointly by the two organisations.

## Benefits

- For patients: More knowledge of their condition and its management. More confidence to ensure the right treatment for their condition. Peer support and the opportunity to get involved with and to influence local and regional care.
- For healthcare professionals and the NHS: A more involved, engaged and aware respiratory community has significant advantages to commissioners and providers of respiratory healthcare.

## Next steps and plans for the future

The AHSN is keen to continue its partnership working with the BLF to help to achieve the goal of reducing the burden of COPD for patients, healthcare practitioners and the NHS.

Contacts - AHSN Respiratory Programme Lead: Sue Hart ([sue.hart@ahsn-nenc.org.uk](mailto:sue.hart@ahsn-nenc.org.uk)).

[www.blf.org.uk](http://www.blf.org.uk)