

PATIENT LEADERS FINDING VOICE

THE BACKGROUND

We worked with The British Lung Foundation (BLF) and the NHS North West Respiratory Board on a Project to identify, train, and put in place Patient Leads to support and help with the communication of patient experiences, to help lead to better patient understanding and improve service provision and to share best practice.

The primary focus of the Patient Leader role is that of a volunteer representing the BLF working in collaboration with Clinical Commissioning Groups (CCG) and other NHS bodies/interested parties, with the Patient Lead explaining the needs of respiratory patients and identifying best practice examples (and providing a much needed, articulate patient voice). Their role is to work in partnership with the NHS/ CCG's to improve patient experience, and patient outcomes.

Oakridge Training and Consulting worked with the BLF and NHS North West in designing and delivering training for the initial pilot of 11 volunteers. The training consisted of an incident event outlining the role of the Patient Lead and the changes to NHS. This was followed by two days of skills training, covering topics such as:

- How to communicate clearly
- How to be assertive (not passive or aggressive)
- How to influence others
- How to work in teams
- How to play a positive role in meetings
- How to be confident.

The outcome being to ensure Patient Leads were competent in their role.

Representatives of the BLF from London attended the training and commissioned training in London, the South East, and South Central. Patient Leader Training was also commissioned in the Midlands. Within 9 months 52 Patient Leaders were trained, who attended NHS meetings, and worked to ensure that Chronic Obstructive Pulmonary Disease (COPD) and Asthma patient's experiences were communicated to service providers.

The training was very well received with Patient Leaders showing high their levels of commitment and enthusiasm for their role.

"Following the training I was so motivated I have attended more meetings in the last 10 weeks, than I did in the previous 10 years."

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OUR APPROACH

The primary benefits of this project being:

1. **To improve communication between patients with COPD and Asthma, and the service providers (NHS/ CCG's)**
2. **To improve service provision (addressing areas of poor service provision and sharing best practice, ensuring CCG's have the opportunity to hear and understand clear key messages of patients experience's)**
3. **Improved quality of life for patients with COPD and Asthma**
4. **Reduce admissions and cost of provision of health care to COPD and Asthma**

THE OUTCOMES

Patient Leader training has been completed in the North West for 11 Patient Leads. The BLF, NHS and CCG's now have a trained group of patients

to represent the BLF, and patients by attending meetings and sharing best practice (and experiences that need to be addressed and improved on).

Patient Leaders now attend NHS meetings regarding service provision and BLF meetings to gather patient experience information, communicate news, and share best practice in how to communicate and influence others.

As a direct result of the success of the pilot in the North West, Patient Lead training was commissioned in the South, the South East and the Midlands (a further 41 Patient Leaders have been trained).

RESULTS

The early feedback from the Patient Leaders attending NHS meetings has been excellent.

With Patient Leads being much more motivated, confident and competent at putting forward "patients experiences".

Feedback from NHS management and clinicians have recognised the positive changes in Patient Leaders behaviour in that they are being more effective and adopting a more collaborative/more effective approach to working together to identify and address issues.

NEXT STEPS

- **Further development and improvement of communication of COPD and asthma patient experiences**
- **Further improvement of service provision**
- **Support and further development of Patient Leaders**
- **The BLF and the NHS are keen to secure funding to roll out this programme nationally.**
- **Evaluation and sharing of best practices (case studies)**

"In over 25 years this project has been the most rewarding project. The commitment of patients with chronic conditions who want to make a difference (and who are keen to learn) has been inspiring."