NHS
North West
Respiratory Clinical Pathway Team

A passport to successful patient engagement

Demonstrating meaningful involvement and shared decision making with patients and the public is a real challenge for commissioners in the NHS, but essential to improving quality, innovation and productivity. NHS North West developed a COPD passport and Patient Leader Programme to empower respiratory patients and ensure that they receive the NICE standards of care for COPD when visiting respiratory services in the North West.

Empowering patients

The North West currently spends in the region of £700 million on COPD and asthma services. The majority of this spend is still heavily reliant on secondary services and not on prevention, self-care and rehabilitation.

In September 2011, a North West regional patient listening event was attended by patient representatives from each of the 24 PCT localities. Personal reflections of experience and feelings were captured and shared in group discussions to identify common themes and differences.

This data - mapped to the NICE COPD guideline and quality standard - formed the basis for developing a COPD patient passport outlining 7 steps for quality COPD care. The passport is a simple credit-card size document that provides patients with key self-care interventions and links to the British Lung Foundation (BLF) helpline for on-going support.

A total of 100,000 copies were printed and distributed across the North West using the Respiratory Network and BLF's patient network.

A Patient Leader Programme was also established to provide ongoing patient engagement to CCGs and providers. Patient Leaders should explain the needs of respiratory patients and help identify best practice examples.

7 steps to high-quality COPD care

An audit of adherence to the 7 steps in the COPD passport is on-going and will provide local respiratory services with relevant data to inform service development and improvement.

NHS North West conducted a pilot survey involving 305 members from the BLF online community to find out how frequently the 7 steps were being met.

Results show a variation in the offer of basic standards of care provided to COPD patients completing the survey. For example, 90% of patients received a COPD diagnosis via spirometry, but only 46% of patients were offered support in self-management. The findings demonstrate significant room for improvement, but show real promise for the use of the passport which is now being adopted by other regions in England.

Following the training and embedding of the first 11 patient leaders, further investment will ensure that there is one patient leader for each of the 32 CCGs in the North West.

Patients as change champions

Patients can be change champions to drive improvement at a local level if their views are listened to and taken on board. Listening to patients and carers experience and feelings about the care they received was fundamental to the creation of the COPD patient passport.

Most patient leaders do not feel engaged because they do not understand the language of the NHS, so it is important to provide them with training. This programme is being led by the North West Clinical Pathway team and BLF and has been successful in harnessing the patient voice and engaging NHS organisations to work collaboratively with patient leaders.

Feedback from patient leaders following the training has been excellent. They are highly motivated, committed and appreciative for the investment in their training. Feedback from NHS management and clinicians has recognised the positive changes in engagement.

Combining the patient perspective with that of local clinicians ensured that the COPD passport is evidence based.

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