

Background

The patient involvement story...

Patient, carer and public involvement has been actively promoted by the Scottish Government since the initial comments in **Patient Focus Public Involvement (PFPI)** in 2001. "It is no longer good enough to simply do things to people; a modern healthcare service must do things with the people it serves."

In 2007, 'Better Health, Better Care: Action Plan' stated that the NHS was to... "move to a more mutual NHS where partners have real involvement, representation and a voice that is heard."

For those who are living with a respiratory long term condition, engaging with the NHS can be considerably challenging.



Chest Voices Pilot in Lanarkshire

Aim

The aim of the Chest Voices Project at CHSS was to develop a robust and sustainable patient involvement training package, applicable to all respiratory patients, to empower their voices in the development of respiratory services.

Methodology

The Long Term Conditions Unit at the Scottish Government funded CHSS to adapt the existing highly successful Hearty Voices Scotland patient and carer involvement training programme into an accessible format for respiratory patients. CHSS have been delivering Hearty Voices Scotland, in partnership with the British Heart Foundation for the last five years. The existing Voices Scotland team engaged with Respiratory Networks and Pulmonary Rehabilitation Teams across Scotland to establish what was required to ensure effective public involvement within respiratory services. CHSS also engaged with the British Lung Foundation to discuss how the training could benefit members of their Breathe Easy Groups across Scotland. Pilot areas were established and the Voices Scotland Team delivered Taster sessions to the CHSS Affiliated Chest Groups and BLF Breathe Easy Groups before carrying out the full Chest Voices training in these areas.

Respiratory MCN Engagement

Managed Clinical Networks (MCNs) for Respiratory Disease were slow in being established in all NHS Boards across Scotland, with some existing Respiratory Networks still discussing how to develop into an MCN. As CHSS have representation on these networks, it was decided to initially target them to provide an audience for Chest Voices, as this had proved to be successful with Hearty Voices Scotland.

As well as being new networks, the concept of Patient Involvement was very much in its infancy, with some networks looking to CHSS to guide them and 'kick-start' their work with patients and carers. The 'Mutual MCN' model developed by CHSS for the MCN 10 yrs on conference in 2008 proved a very valuable tool in helping to encourage their involvement.

NHS Lothian, Lanarkshire, Greater Glasgow & Clyde and Highland provided the Pilot sites and the Voices Scotland Team delivered taster sessions to the Breathe Easy Groups and some Pulmonary Rehabilitation groups in these areas to generate interest.

Results

The training programme

The final format of the Chest Voices training programme runs over two days and is presented in an accessible format for patients and carers to empower them to have their views heard and ultimately improve NHS respiratory services in Scotland.

It is presented over six hours on two non-consecutive days, starting later in the morning to suit the participants. The issues gathered at the training were fed back to the Respiratory MCNs who were then encouraged to form a patient involvement sub group to take them forward.

The evaluation

The pilot courses trained 27 people over the four NHS boards. The table below shows how participants scored the various elements of the day. (Scores are out of 5).

	Lothian	Lanarkshire	GGC	Highland	Mean
Content	5.0	4.43	4.6	4.8	4.71
Presentation	5.0	4.85	4.8	4.8	4.86
Training style	4.8	4.85	4.8	5.0	4.86
Venue	4.0	4.56	4.6	4.6	4.44



Chest Voices Pilot in Lanarkshire

Conclusions and recommendations

The Chest Voices Programme has demonstrated that it is possible to empower respiratory patients through accessible training and good quality support. Some of the main conclusions from the Pilot Report are detailed in the table below.

Conclusion	Recommendation
Poor health of the respiratory patients affects their ability to attend the training	Endeavour to offer Chest Voices training during the months of April-September, avoiding the winter months
Involving patients and carers within NHS Networks is still in its infancy	CHSS staff to use the Model of a Mutual MCN to encourage all parts of the NHS to set up effective ways for patients and carers to become involved. CHSS staff to work with the Respiratory Networks to encourage the setting up of patient/carer sub groups
Patients and Carers require further support to get involved with MCNs after Chest Voices	CHSS staff to encourage the networks to provide support. Where this is not available, CHSS will provide support for 6 months, post Chest Voices to keep the momentum going
Chest Voices delegates should be informed of any opportunities for involvement within the NHS	A Voices Scotland newsletter to be developed to provide information and opportunities to get involved
All respiratory networks across Scotland should have access to Chest Voices	All networks to be contacted and offered a 'taster' session or full Chest Voices day by the end of 2010

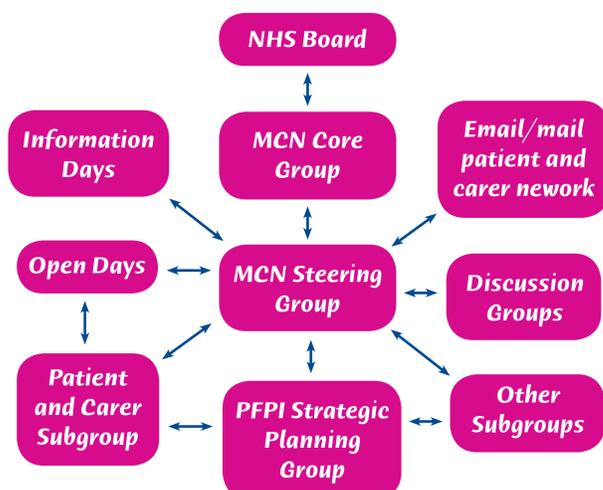
Further information is available on the CHSS website at www.chss.org.uk or email voicesscotland@chss.org.uk

References

Better Health, Better Care: Action Plan 2007 (Scottish Government)
Patient Focus, Public Involvement 2001 (Scottish Executive)

Chest Voices Project was funded by the Scottish Government

The Mutual Managed Clinical Network



'The training was presented in an informal, straight-forward way and has definitely increased my understanding'

'These 2 days were such a good use of our time and I hope to get much more involved with the NHS in the future'

'I really didn't know if I would get much out of this but it has opened my eyes up to what I am entitled to from the NHS'

Chest Voices participants evaluation