

CONFERENCE ABSTRACT

Respiratory Patients Breathing Life into the Canterbury Integrated Respiratory Service

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A group of past pulmonary rehabilitation participants have joined together to form the Pulmonary Rehabilitation Consumer Group. They have been actively engaged in Canterbury's respiratory service design and innovation since 2013.

Telling their Story: Members of the Consumer Group meet monthly to give their opinion on how pulmonary rehabilitation and the wider respiratory service support patients to look after their own health.

They discuss their own positive and negative experiences to a wide range of audiences and report to governance and working groups. They present their stories at regional and national conferences and workshops for clinicians, such as the South Island Respiratory Educators Forum (SIREF) and GP Continuing Medical Education.

They attend and promote community exercise groups and have just started a weekly coffee group to provide support for all patients and carers who have an interest in respiratory issues. They led a walking train of people through the Christchurch Botanical Gardens for World COPD Day in 2014. The Chair of the group has won the Asthma and Respiratory Foundation Achiever Award for COPD 2016.

They are advocates outside the clinical meetings they attend by joining every session of the community-based pulmonary rehabilitation programmes to support participants new to pulmonary rehabilitation.

Aim: We've previously identified that a large proportion of our referred patients to pulmonary rehabilitation are not attending, or are not completing the programme. In 2015 the service received 604 referrals from health practitioners, of which 268 attended (>1 sessions) and 175 completed (attended >8 sessions) the programme. The governance group agreed to investigate issues of non-attendance.

Highlights: Specialist and primary health care services typically lack direct feedback from patients. The Integrated Respiratory Service in Canterbury has found that by actively supporting a group of patients, increasing their health literacy and engagement in service design and delivery, we have achieved a higher level of understanding.

We have become more focussed on outcomes, defining and measuring what we are delivering and reducing barriers to attendance. Through working with our consumer group and undertaking relevant research we have identified key issues facing community-based programmes.

Lessons Learned: The Integrated Respiratory Service and its governance infrastructure are supportive and open to consumer input at every level. We only wish we had organised a group like this earlier in the community-based programme establishment.

The benefits to the consumers, the respiratory nurse facilitator, the wider community respiratory team and Integrated Respiratory Service, and people in Canterbury with respiratory conditions, have been profound. The consumers feel they are contributing to their communities, as well as the health sector. They feel valued, because they are.

“I read that lovely Maori woman’s story, and I thought, if she can do it, then so can I!”

Pulmonary Rehabilitation Participant 2016

Keywords: respiratory; pulmonary rehabilitation; consumer group; integrated service; empowering people
