CareSearch Project Research Studies Register: Registration Proforma	0149

Study Title: Developing self management strategies to reduce avoidable Emergency Department presentations for chronic refractory breathlessness: a strengths based approach using qualitative methods

Brief description of the study: This project aims to inform development of self management strategies for reducing avoidable breathlessness related Emergency Department (ED) presentations via a better understanding of the natural history of such presentations and strategies patients and families have found useful in avoiding them. Chronic breathlessness is a distressing symptom that occurs in around 1% of the population, especially in people with chronic obstructive pulmonary disease (COPD), heart failure, cancer and neurological diseases. A recent UK study found 20% of presentations to the trolley area of an ED were due to chronic breathlessness, and about half of these patients were not admitted to hospital or discharged within one day, suggesting their visit may have been avoidable. Avoidable ED presentations and hospitalisations are associated with substantial personal and economic burden, making their prevention a priority for action. People living in the community with chronic breathlessness are often provided with self management strategies by Pulmonary Rehabilitation services that include action plans, breathing techniques and exercises. It seems likely that some 'expert' patients will also develop their own strategies for self managing breathlessness and successfully avoiding unnecessary Emergency presentations. The proposed study will take a qualitative approach in which patients who have experience of avoiding one or more Emergency presentation for breathlessness will be interviewed to learn how they did so. Interviews are expected to take up to 45 minutes and will include questions on decision making about whether or not to go to Emergency, perceptions of what helped avoid presentation, and use of self management strategies more generally. As well as patients, we will also be interested to interview family who were involved in decision making to learn their perspectives. Where patients are too unwell to participate, we will interview family alone provided the patient gives informed consent for this to happen. Interviews will be conducted either face to face at a place of the participant's choosing or over the telephone. Interviews will be transcribed for qualitative analysis, which will look for patterns or 'themes' in each interview and develop theory about what self management strategies have worked to be tested in future interviews. We will keep conducting interviews until no new themes emerge. Based on rules of thumb and previous experience, it is estimated that 15 interviews may be sufficient for this to occur.

Study Methodology: (Please mark with an x which type of study methodology)

	Epidemiology
	Health Services / Health Economics / Quality Improvement
X	Qualitative, Observational or Descriptive
	Mixed Method
	Systematic Review
	Intervention: RCT
	Intervention: Comparative or cohort study

	Intervention: Case series					
Project details:						
Funding source (Optional): UTS Faculty of Health						
Has the study received ethics approval?	**X**	Yes		No		Not applicable
Project starting date: September 29 2015						
Project completion date: December 31 2015						
Multi site:	**NA**	Yes		No		Not applicable
Researchers						
Principal Investigator (name)	**Dr Tim Luckett**					
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Investigator B (Name)						
Investigator C (Name)						
Investigator D (Name)						
Investigator E (Name)						
Associated publications / reports:						
Topics (Admin only): dyspnoea, respiratory						