

This project was a collaboration between researchers from eHSRG, the School of Medicine at University of Tasmania, the School of Nursing at Griffith University, and the Royal Children's Hospital Brisbane. The project involved a randomized, controlled intervention pilot study of a program of education and behavioural adaptation in adolescents and adults with CF that is designed to enhance self-management. Individuals in the intervention arm will be supported by telephone mentoring and supplied with an IT system (modified mobile phone or use of home desktop) that allows electronic symptom monitoring.

Recent studies have suggested that encouraging patients with chronic disease to take a more active role in managing their own condition can be as effective as introducing new medications. Enhancing "self-efficacy" does not mean patients are left to their own devices, i.e. "DIY," but the development of self-efficacy is a process facilitated by experienced "mentors" who provide positive feedback and assist the patient to develop goals and then plan how they will achieve them. This is proving to be a very powerful process and may be particularly suited to people with CF, especially younger adults and adolescents who are transitioning from paediatric to adult care. Adherence drops off in this CF population with the risk that earlier gains in health outcomes may be lost.

This study recruited people with CF from clinics in Tasmania and Queensland. Individuals were randomised to continue with usual multidisciplinary care (n=30) or an intervention that involves a system of mentorship only (n=20), or mentorship plus or minus an IT tool. The IT tools will be either a customized mobile phone (n=20) or a desktop computer (n=20). Both IT systems involved a daily diary card that was sent by SMS or web to a central database. Patients were able to get feedback and view their own results with the anticipation that they would learn to recognize impending exacerbations for instance and act accordingly. The mentors contacted the patient on a weekly basis by phone initially until the patient feels increasingly comfortable with managing their own symptoms – at this point the need for such frequent phone calls diminished as the CF individual developed self-efficacy for self-management.

The study ran for one year and assessments occurred every three months. These included: lung function, exacerbation rate, self-efficacy questionnaire, six-minute walking distance, CF-related QoL questionnaire. At the end of the study, all participants (including the mentors) were interviewed and asked about the process and utility of the IT tools.