**Royal Arch Mason Centennial Award Report.**

**March 2020**

Thank you to the Arch Masons for their support and assistance with my research.

**Research Aim:**

* **How can we make pulmonary rehabilitation more accessible for people living with a chronic respiratory condition in NZ.**

**Background**

For people living with a chronic respiratory condition, they experience shortness of breath, fatigue and difficulty completing their everyday tasks. The burden on the person, their family and the healthcare system is significant. Chronic respiratory disease (CRD) is incurable, but can be managed to minimize the burden. Pulmonary rehabilitation (PR) is a highly effective, evidence based intervention for people living with a chronic respiratory condition which has been shown to reduce symptoms, improve quality of life and increase independence. It has also shown to be associated with a reduction in hospital admissions.

Pulmonary rehabilitation involves; exercise, education and self-management strategies. Participants usually attend a center based programme twice per week for 6 – 8 weeks, with each session being 90 – 120 minutes in duration. Despite the proven efficacy, referral rates to PR, as well as attendance and completion rates are low. In NZ, It has been shown that less than 2% of the people who would receive benefit get referred to, or attend PR. Travel, transport, illness and lack of perceived benefit have been identified as barriers to attendance. Additionally, following completion of PR the benefits attenuate with time if participants do not continue to exercise. Alternative methods for delivering and supporting PR are important to increase opportunities for people with a chronic respiratory condition to achieve important health benefits and to maintain these benefits.

One global trend to improve access to PR is through the use of technology or telehealth. The use of technology in healthcare interventions is rapidly expanding, and has shown promise in assisting to manage other chronic health conditions. One form of telehealth that is rapidly developing is mobile health (mHealth) which is the delivery of health information or interventions through a mobile device, such as a phone or tablet. It has the potential to provide an alternative method for delivering PR programmes by increasing access for people who could not otherwise attend, and to support and encourage people to continue with self-management strategies for a longer duration.

This project is linked to a wider research project which aims to develop a mHealth intervention for people living with a chronic respiratory disease, and which is tailored to meet the needs of the NZ population. This PhD work is parallel and informs this work stream. The aim of this PhD thesis is to investigate the clinical utility of a mobile health PR application for people with CRD in NZ. Is it feasible and acceptable to deliver PR via mhealth and will this result in an increase in access to PR for people living with CRD?

**Research findings to date**;

Over the past year I have been involved in three research projects.

1. National Pulmonary Rehabilitation Survey
2. Formative studies of mPR
3. Pretesting of first prototype for mPR.
4. National PR survey

This study address objective one – **to identify the characteristics of current PR services in NZ.**

The information gathered from this research helps to form an understanding of the baseline of services and how this may contribute to the accessibility and feasibility of attending and completing pulmonary rehabilitation in NZ. It also serves to inform the research team of the distribution, structure, organisation and content of the services. This data highlights potential unmet need in service provision and opportunities to make services more accessible.

The current survey was not able to determine capacity of programme across NZ, nor was it aiming to estimate the uptake of PR services for people with COPD or other CRD.

The results from the national survey of PR services in NZ show the programmes are still predominantly reliant on public funding and resources. The survey identified there is a growing diversity in the chronic respiratory conditions being seen in the rehabilitation services. This is likely to further increase the demand on services, but also require programmes to become adaptable to the different exercise and educational requirements associated with the different conditions. The survey showed that the services offered across NZ were all similar in programme assessment measures used and content included in the programme. The greatest variability across services was seen in the site of PR delivery, with many moving away from hospital outpatient sites to community venues which were more accessible to participants including, community halls, gyms, marae and church facilities.

The results of the survey show PR services are adapting to different methods in a bid to make services more engaging for different cultures. There is a growing awareness of the importance of making meaningful connections and building relationships with participants to enhance engagement (8).

Technology is not currently routinely used in PR services, other than for appointment reminders. The referral to maintenance services identified a potential gap in the current service with many programmes reporting a lack of appropriate programmes to refer onto.

The current survey shows that PR services have adapted to advances in knowledge in PR through; an increase in number of services across NZ, attention to improving access through variation in venues offered, and adapting to make programme engaging for all participants. There appears to be opportunities for PR to further grow in New Zealand. The evidence is conclusive in COPD and growing for other respiratory conditions. A recent ERS statement declares the need to expand the provision of PR to suitable patients worldwide. (36) This includes expanding and advancing how we deliver programs traditional PR programs but also looking at alternative delivery methods which may assist people who would not be able to attend current models.

1. mPR Formative Studies

**mPR Stage 1 Formative Study. - Understanding end users perspectives of mobile pulmonary rehabilitation.**

**Study aim**

To understand the needs, preferences, and priorities of end users for the development of a mobile PR (mPR) support programme.

The survey identified some important considerations for the development of mPR. The study identified while these is an opportunity to utilise digital technology to widen the scope of reach of PR services, many challenges were identified from both groups, including; digital literacy, device access, safety concerns, lack of social connection. Many participants however, felt the advantage of overcoming the time and expense of travel and having the opportunity to access care in their own time with their family/whanau was a positive option.

1. mPR Pre testig

**mPR Stage 2 – Pre testing mPR**

**Study aim**

To assess the feasibility, acceptability and usability of an adaptive mobile PR program (mPR).

All participants reported that they would recommend the programme to other people with a chronic respiratory condition. When asked what they liked the most, the participants reported it was motivational and empowering, provided reminders and prompts, was supportive and increased awareness and knowledge. When asked what they liked least, they reported the exercises were too hard, progressed too quickly, unrealistic and not personal enough.

The results of the study highlighted the challenges associated with digital literacy and access to the App was difficult for many people and was therefore not used consistently.

The results reinforce the need for further development and testing of the exercise prescription and how this can be improved for future iterations. The stratifications may require adapting, along with the number, duration and difficulty of the exercises included.

**Research Next Steps for 2020 – 2021.**

1. Literature Review

The aim of this systematic review is to examine the literature relating to pulmonary rehabilitation, delivered by technology and, if this is able to improve accessibility for people with CRD.

1. Qualitative Study

**Discrete choice experiment (DCE)**

The study will identify patient trade-off preferences regarding the likely uptake or adherence to PR. It will involve development of a questionnaire based on the qualitative study. The questionnaire will include a sequence of hypothetical scenarios (choice sets) with two or more alternatives that vary along several attributes. Different levels for each attribute will be determined.

**Study Aim**

To examine the participant preference regarding the delivery of PR and investigate the factors which influence the ability to; attend, complete and maintain pulmonary rehabilitation (PR).

1. MPR next prototype development;

 

**Use of funds from centennial award;**

Funds used to far….

 1. Attend international conference

 Develop international links

 See what other countries are testing

 2. Membership to TSANZ

Access to online courses / webinars

Respirology Journal

Professional network

2020 Funds plan – to be revised considering current circumstances.

* NZ Travel / March – September
	+ Focus groups across New Zealand
	+ People living with a chronic respiratory disease
	+ People working in pulmonary rehabilitation
	+ People who would refer people to pulmonary rehabilitation
* ERS Conference – 2020?