

## PR Network Meeting July 2022 Minutes

### Research and Innovation – Shaping the Future of Pulmonary Rehabilitation

- Date:** Tuesday 19<sup>th</sup> July 2022
- Time:** 12:30pm to 1:30pm AEST
- Location:** Via Video or Teleconference only using Zoom details below
- Invitees:** All Pulmonary Rehabilitation Network Members
- Meeting Chair:** Professor Jennifer Alison
- LFA Reps:** Emma Halloran
- Video Recording:** <https://youtu.be/eCTIIIEatsM>

#### Meeting Minutes

##### Welcome and acknowledgement to country – Prof Jennifer Alison

Jennifer Alison opened the meeting with an acknowledgement to country and a summary of the meeting agenda.

##### Perx m-PR platform – A/Prof Zoe McKeough

- Zoe presented a new mobile PR platform that has been developed to support patients with exercise and education in their home environment through technology such as iPhones and iPads.
- Access to centre-based PR has always been an issue, and researchers have been working on alternative solutions for some time.

- Zoe's team found there is a high use (85%) of mobile phone technology with people who have COPD.
- Zoe and her team have been working on the project since 2018, developing a collaborative research agreement between stakeholders, sourcing funding to evaluate the platform and working with a commercial partner (Perx Health) to develop the platform.
- The platform has now been developed and is currently being trialed with participants who undergo a face-to-face assessment and then use the m-PR app for their PR program. Participants are contacted by phone on a weekly basis to check how they are going.
- The app provides a unique exercise program tailored to the individual's needs and has a daily symptoms score, education and exercise videos and sends out motivational text messages.
- The app is currently being evaluated in a research project and Zoe is expecting to get outcomes from this study by 2024. The team are directly comparing patients' outcomes to those attending a centre-based program.

**Would you use the Perx m-PR platform? Let Zoe know [here](#).**

Paper of interest related to the Perx Platform: [\*Effect of a smartphone application \(Perx\) on medication adherence and clinical outcomes: a 12-month randomised controlled trial\*](#)

A full copy of Zoe's presentation can be viewed [here](#).

### **PR in Tasmania - Jessica Beaman**

- Despite the lack of lockdowns, Tasmania has still been significantly impacted by the pandemic.
- Services moved to a new home-based model during service shutdowns in 2020 and 2021.
- Since the Tasmanian borders have re-opened, they are back to running a modified Home-Based service with only high-risk patients attending face-to-face services.
- Patients are still nervous about attending a hospital environment and some patients do not want to do a home-based model. Many patients in Tasmania do not have internet access which has been an additional challenge. There are long waiting lists for services which means patients conditions are often worsened by the time they are seen.
- Clinicians are looking at continuing to operate with a hybrid model.

A full copy of Jessica's slides can be viewed [here](#).

### **Lung Foundation Update – Emma Halloran**

#### **PR Audit Results:**

- Emma thanked the network for a great response to the PR audit and shared some of the findings.
- 53% of services responded to the PR audit out of 324 services.

- Full results will be published on the new PR Toolkit in the next few months.
- Highlights included:
  - 89% of programs now accept patients with any type of lung condition, including lung cancer, compared to 52% in 2017
  - 59% of programs supporting patients with Long Covid
  - 69% of programs supporting patients who have been in hospital due to Covid
  - 87% of programs involve a physiotherapist, 62% involve a nurse and 33% involve an AEP
  - 88% of services offering a hospital outpatient or community health program. 23% offer a homebase program and 15% offer an online service.

#### Service Directory:

- The new service directory is due to launch within a week. Emma will send out a link to all services once it is fully functional so they can check their details and see how it works.

#### PR Toolkit:

- The PR Toolkit has undergone a major clinical review and redesign. The new site is expected to launch mid-August and can be accessed via the same URL (<https://pulmonaryrehab.com.au/>).

#### Workplace:

- The Workplace Community of practice forum now has over 120 members.
- Network members can register to join [here](#).

Emma's presentation slides can be viewed [here](#).

### Pitch your project – Research and innovation in rehabilitation

A panel of researchers shared details of research projects that are currently in progress.

#### **Dr Lara Edbrooke from Melbourne University - Lung Cancer Rehabilitation: standardising evaluation and co-designing a program for people during immunotherapy for lung cancer.**

- Lara is running a study to develop a lung cancer rehabilitation core/minimum outcome set. Her goal is to reduce the burden on patients and clinicians of collecting less relevant outcomes. Her team ran a survey with clinicians and conducted focus groups to determine what outcomes of lung cancer rehab are important.
- The next stage of the project will involve a Delphi study which will be open to any Health Professionals offering rehabilitation for patients with lung cancer. The survey will be advertised on the PR Community of Practice once ethics approval has been granted and will take ten minutes to complete. The study will firstly look at what is important to measure and will then focus on the best instruments to measure these.

- The second part of the project will run next year and will involve codesigning a program for people having immunotherapy treatment for lung cancer.

Lara can be contacted on [larae@unimelb.edu.au](mailto:larae@unimelb.edu.au) and a copy of her full presentation can be viewed [here](#).

**Dr Hayley Lewthwaite from University of Newcastle. Pulmonary rehabilitation programme practices for prescribing exercise intensity for people with chronic obstructive pulmonary disease (COPD).**

- Hayley is running two surveys as part of her research including:
  - a survey for health professionals who work in PR prescribing exercise for people with COPD and
  - a patient survey for people with COPD who have completed PR in the last 2 years.
- For health professionals, Hayley is looking to find out how exercise is prescribed and at what intensity. She is interested in seeing if availability of resources influence current practices around prescription of exercise intensity. Hayley will compare what is idealist vs what is in clinical practice guidelines.
- For patients, Hayley is examining their perception of the exercise intensity prescribed. She is wanting to see if real life practice aligns with patient expectations.
- Hayley will post a copy of the survey for health professional on the Community of practice or you can access it [here](#).

Hayley can be contacted at [Hayley.Lewthwaite@Newcastle.edu.au](mailto:Hayley.Lewthwaite@Newcastle.edu.au) and her full presentation can be viewed [here](#).

**Dr Ling Ling Tsai – University of Sydney and SLHD - Minimal data set for pulmonary rehabilitation programs in NSW - A Delphi method.**

- There is no consensus in NSW around which outcome measures should be collected in PR to enable benchmarking of patient responses to PR.
- Ling Ling's study aims to gain a consensus from a multi-disciplinary panel as to what outcome measures should be collected.
- The process will aid improvement of PR programs through benchmarking.
- The team would like to hear from NSW PR Network on what they believe the outcome measures should be.
- The study is using a Delphi methodology and will involve three rounds of surveys. You can complete the first survey online [here](#).
- Ling Ling can be contacted at [ling-ling.tsai@health.nsw.gov.au](mailto:ling-ling.tsai@health.nsw.gov.au).

View Ling Ling's full presentation [here](#).

Jenny asked the network to provide feedback on this section to see if it is something that should be included in future network meetings. Please email [emmah@lungfoundation.com.au](mailto:emmah@lungfoundation.com.au) with any comments or feedback.

## Meeting close

Jenny thanked the speakers and advised the next PR Network meeting will be on Tuesday 1<sup>st</sup> November at 1pm AEDT.

Anyone wanting to present at the next meeting can complete the expression of interest form [here](#).

## Questions and Answers

### Perx m-PR platform

Q: Would there be a cost to the patient?

A: Typically the local health district negotiates a contract with Perx around the program involved so that there is no cost to the patient.

Q: Do you have any information on how client data is secured on these apps, or in which country this company has their server where the data is kept?

A: Client data is secured through Amazon Web Services and technology is also compliant with regulations and industry standards for privacy and security including the APPs, HIPAA and SOC2, plus a registered technology supplier to the NSW Government.

Q: What is the cost to a health service?

A: The cost is incurred by the sponsor which in the instance of a pulmonary rehab program would be the "health district" that manages the programs. Perx tend to set up "pilot programs" with new clients and they are flexible in negotiating the requirements of those services but it would be best to discuss each service's individual requirements before stating the overall cost. Needless to say there is value in the Perx offering as their costs are far lower than the costs associated with running a centre-based program or the cost associated with a patient having a hospital admission.

Q: Long term can patient data be pulled for research purposes? Is diagnosis recorded in the app?

A: Real world data on % enrolment, % active users and % engagement etc are pulled into monthly reports for the sponsor paying for the program by the data analysts at Perx. There is certain information collected from each participant that goes into the app and primary diagnosis is part of this.

Q: When patients finish with the program, are they still able to use the app to continue with their own self-management? Is there is subscription fee?

A: Yes - they can continue using the Perx App for ongoing self-management once the rehab program ends. There is then an ongoing cost to your health service for these active users.