2020 Pulmonary Rehabilitation Network Meeting Minutes

Date: Tuesday 31st March 2020

Time: 1.30 pm – 2.30 pm AEDT

Location: Via Zoom videoconferencing

Attendees: 104 Pulmonary Rehabilitation Network Members

Meeting Chair: Professor Jennifer Alison (JA)

LFA Reps: Kelcie Herrmann(KH), Emma Gainer (EG)

(Additional LFA attendees included: Brigitta Rose, Juliet Brown, Toni Hammond)

1. Welcome & Acknowledgement of Country

1.1 Pulmonary Rehabilitation (PR) Network State Representatives & Network Members- Jennifer Alison.

- Acknowledgement of the testing times we are currently in for both clinicians and patients. Patients are incredibly anxious due to being 'high risk' during this pandemic.
- Although this is the regular annual meeting scheduled to occur at TSANZ, In light of the current situation the meeting will focus on the management of our PR patients during COVID-19.
- Overview of PR Network in Australia: Now 464 members, an increase of 20 since last year. Since our last meeting we have a new VIC state rep, Janet Bondarenko. Thank you to state representatives who continue their roles: Allison Eastman NSW, Lissa Spencer NSW, Mary Roberts NSW, Coralie Brannelly NT, Simon Halloran QLD, Helen Seale QLD, James Walsh QLD, Paul Cafarella SA, Nola Cecins WA. Still looking for reps in ACT and TAS – Please email Emma Gainer if interested in state rep role. Please refer to pre reading for more information.

ACTION: ALL – email Emma Gainer (emma@lungfoundation.com.au) if interested in state rep role, or if you are not yet a PR Network member and wish to be on the network to obtain updates, meeting invites and minutes etc.

2. LFA PR Priorities, Resources, Advocacy & Projects

2.1 LFA Clinical Programs, Research & Innovations General Manager update – Kelcie Herrmann.

- We would like to use this PR Network forum to find out how LFA and other organisations can support the PR community.
- LFA 's main focus currently is on supporting its patient community during this crisis – LFA sees its role helping patients with Lung disease to better understand all the information around COVID-19.
- Developed an expert working group with some of the leading respiratory experts in the country and working with them around the information which is a priority for this consumer population - Working to dispel myths and using Social media channels to reassure people and answer questions and connect them to experts where we can.

2.2 Lungs in Action Program Update – Emma Gainer – Pulmonary Exercise Manager

- Due to the developments around COVID-19, on the advice of Lung Foundation Australia's Board of Directors, all Lungs in Action classes have been cancelled for a period of three months, effective, from 16 March 2020. This includes all practical face to face components of the training.
- PR providers are still encouraged to refer appropriate patients to their local LIA providers during this closure so that the patient can commence with the group immediately upon re-commencement.
- LFA are currently working on a package of supportive resources for instructors and those patients currently enrolled in LIA classes to keep them active during this time. This includes a home exercise video series called "Maintaining Movement' launched today by the LFA which aims at keeping this group (in addition to PR patients) stay active in the home during closures. The series of short videos can be found via the following page: **https://lungfoundation.com.au/physical-health/**.
- LFA has obtained the support of the University of Canberra to do a formal program evaluation of LIA. In the face of COVID-19 we will be seeking an extension on the project. Further information can be found within the pre reading.

2.3 PR Toolkit and PR for Lung Cancer survey - Lara Edbrooke

- Project between Melbourne Uni and LFA involving a survey aiming to gather info around current rehab that exist with Lung Cancer referrals and what resources are currently available and utilised. The data that are gathered will provide an understanding of the current services, the gaps and how we can better support the clinical community with providing a rehabilitation service for Lung Cancer patients. In addition, the survey also is gathering information on how the PR community are currently accessing the PR Toolkit. The survey is currently open. Press here to complete: https://www.surveymonkey.com/r/38JQK8M

Action: ALL: All network members encouraged to complete the survey via above link.

State Rep Updates – How is your service/state dealing with COVID-19?

Please see pre reading for information on the research projects that are currently underway in each state.

State reps were asked to report on the PR situation in their state in relation to COVID-19.

NSW - Renae McNamara

- No current directive from NSW Health regarding PR services (Non essential services)
- All directives are based on the Local Health district decisions – all health services around the state now seem to have closed PR classes, but there are some still doing individual face to face PR and home visits.
- A group of expert PR clinicians are working with the Agency of Clinical Innovation Respiratory Network to develop an organisational model of PR via telehealth that will serve as a guideline for PR clinicians.

VIC - Janet Bonderenko

- Directives coming from local health services only – indicating that Non essential outpatients should be ceased and encouraged to provide telephone and telehealth support to patients.
- Within own service at the Alfred Health are taking on Anne Holland's 'Home Base' pulmonary Rehabilitation model, but without the home visits.
- Currently investigating how to move the model forward in the absence of face to face contact.
- Looking at developing a group model on telehealth if hospital platform will support that – for exercise as well as social or educational as well.

QLD – James Walsh

- Similar to NSW and Vic in terms of looking at the other options for Telehealth and Home Based.
- Metro North - Transitioning across to Pulmonary Support – focusing hospital on avoidance - Target the frequent presenters / Post acute exacerbation and provide support. Don't know the structure yet.
- Continuing to manage the lung transplant cohort with exercise – all home based.

SA – Paul Cafarella

- Local Health Network – suspended PR -non essential.
- Local tele rehab options being reviewed.
- SA health has provided 'health direct' platform for clinicians to use – will go live next week.
- Downfall - can only have 4 participants and one presenter - but it is one option that is being developed, with weekly physio calls and health coaching in between.

TAS - Sophie Mummery

- Feedback from south of Tasmania only.
- Last two weeks PR has ceased from directive of respiratory physicians.
- Currently looking at what options are feasible in terms of home visits and telehealth etc.
- And essential services – looking at what that means.

WA – Nola Cecins (Was unable to provide the update during the meeting, but provided the information below proceeding)

- This is our current practice at SCGH:
- New referrals to PR: Doctors and inpatient physios are still being encouraged to refer suitable patients to pulmonary rehab. When we receive a referral we are sending a letter explaining that the program is temporarily closed and that we will contact them when it is running again. We also include a brochure on the benefits of exercise and activity in lung disease (this was fairly quickly put together and I am happy for it to be shared / improved). Patients are also provided with a telephone contact. So at this stage no phone call for this group. (both docs attached). This group could contacted by phone at some point to monitor their activity levels and be provided with general advice.
- Existing patients in PR: had assessment and perhaps attended some classes. This group all have a home exercise booklet with diary card. They are being contacted once per week for a telephone consult (and recorded as a service event for ABF purposes). This is done at the roughly same time as the group session once per week. We are doing a subjective assessment and update of diary card entries and following a simple script based on the Homebase Rehab program. Exercises are progressed as indicated (breathlessness, leg fatigue). Small education topics are discussed (5 min – set topics used in usual program). Also self-isolation suggestions, flu-vax reminders, and 'what to do if I get symptoms'. Trouble-shooting. We expect that we will discharge them at the end of the 8 week program and perhaps send out (or email) a CAT assessment.
- Maintenance: we have groups with severe IPF/COPD / high risk group – similar strategy to the above. Ongoing weekly telephone consults to trouble shoot and ensure adherence to home exercise program (all have been provided with extra diary cards).
- Other programs in WA are doing similar to above where they are able including community programs.
- Rehab in the Home: there is a service in metro WA that goes into people's homes and supervises a home-based exercise program post-hospital admission if they are unable to manage an outpatient based program – as a bridge to usual PR. The aim is either early discharge or prevention of readmission. It is hoped that this service might be able to increase their ability to go into the home and assess but this remains to be seen.

Alternative models of Pulmonary Rehabilitation & Support systems – Working amidst COVID-19

Tele Rehab – Renae McNamara

- 'BEYOND TRADITIONAL PULMONARY REHABILITATION: EXPLORING TELEREHABILITATION' See accompanying slides provided by Renae as attachment to these minutes.
- Been running Tele rehab model for 7 years

- *What is it*: Delivery of Rehab at a distance using technology. The model uses simple technology – things clinicians and patients generally would already have access to e.g computer/iPad.
- A recent study showed that 60% of people who were currently attending Pulmonary Rehab would be willing to undertake Telerehab (Seidman, Z et al. Link: https://www.ncbi.nlm.nih.gov/pubmed/28652080)
- This percentage likely to increase over time as our older patients get increasingly technology savvy. Also in the face of this current pandemic there is likely to be a higher uptake as our patients experience longer time in isolation and seeking ways to stay connected.
- Trials in Australia and Canada have demonstrated that Telerehab models are safe and feasible.
- The Australian telerehab study was part of Ling Ling Tsai's PhD. (Tsai, L et al. 2016). See attached to minutes. The study showed improvement in endurance exercise capacity and a small improvement in quality of life. Additionally, some qualitative work found that patient satisfaction was very high with this program. The study did involve face to face assessment in the hospital environment which is not possible now.
- Tele rehab is not without problems. There can be technical problems usually related to the data network capabilities.
- Prior to COVID-19 the model of telerehab was: Deliver an exercise bike, pulse oximeter, iPad and hand weights to the home and help set-up.
- Model during COVID-19: patients provide their own technology and internet. Exercise will use minimal equipment that is available in the person's home. Since there will be no face to face assessments, telephone or videoconference will be used for assessments which will be limited to questionnaires only (if only telephone contact) and probably the 5 sit-to-stand test for lower limb strength if videoconferencing is available.
- For more information please contact via the following email: Renae.Mcnamara@health.nsw.gov.au

HomeBase Pulmonary Rehabilitation - Anne Holland (https://homebaserehab.net)

- HomeBase rehab model has been running for some time alongside traditional PR.
- HomeBase is a low cost, low equipment telephone coaching model.
  Patients are assessed in the home and provided an exercise prescription with weekly follow-up calls for goal setting and coaching.
- During COVID-19: Transitioning all patients to home based option however not doing a home visit at this time. Encourage clinicians involved to have some Health coaching / Motivational interviewing training.
- Downloadable Resources are available on the website for use and implementation of the service: https://homebaserehab.net/.
- There is also a contact form on the website – so if you wanted to find out more or have specific questions please use this to get in contact. Link here: https://homebaserehab.net/covid-19-rehabilitation-program/.

mPR App- (JA)

- m-PR – Mobile Pulmonary Rehabilitation through an App.
- Developed in conjunction with Tech support from CSRIO

- Lead by Zoe McKeough and Sally Wootton
- In current format the patient would come in for a face-to-face assessment and then go home with the app which includes exercise videos specific to their individual program.
- Monitoring is done from home using a pulse oximeter for SpO2 and heart rate and a symptom score of breathlessness
- Same issues would apply to this app as the others above regarding assessment - how do we assess when not in person?
- App would be ideal for this period, but is approx. one month away from being ready.

NSW Agency of Clinical Innovation (ACI), Respiratory Network guidelines for PR during COVID-19 – (JA)

- ACI and the NSW Ministry of Health are developing a document that will provide information on the Management of patients using telehealth technology – either phone or videoconferencing to support PR at home.
- The document will provide guidance for clinicians managing patients who already had commenced a PR program, those who were on a waiting list or newly referred during COVID-19 pandemic, as well as those who are admitted to hospital with an exacerbation and then referred to PR.
- The document is being prepared at the moment and once it is endorsed by the NSW Ministry of Health it will become available to all – even those outside of the state.

ATS – New Resource: Pulmonary Rehab resources in a complex and rapidly changing world (JA)

- In breaking news for support in this area the ATS Pulmonary Rehab Assembly (Lead by Anne Holland) has prepared a document called Pulmonary Rehab resources in a complex and rapidly changing world: Link to document here.

Direct Patient text messages (JA)

- Prof Julie Redfern is a physiotherapist who has been researching the use of text messaging to support people with chronic conditions. and has just completed a project on text messaging to support people with COPD.
- Through this system the patients would receive a combination of messages targeting general COPD knowledge, symptom management, physical activity, medication adherence in addition to new COVID-19 specific support messages that have been developed.
- The text messages are sent from a secure centralized web based platform, and Julie has advised that this platform s could be available free for the next six months.
- This could prove to be an additional support mechanism for patients who are home and isolated. The system requires the patient to register themselves or a clinician or family member can complete the registration for the patient with their consent.
- The text message system will be reviewed by LFA and if approved will be available on the LFA website.

Action - LFA to link in with Julie Redfern and investigate how the platform can be used and if possible to be added to the LFA website.

Please Note: Support Links and resources discussed in this section to be put on the Lung Foundation Webpage COVID-19 sections under Health professional tab: https://lungfoundation.com.au/patients-carers/lung-health/coronavirus-disease-covid-19/health-professionals-2/ as they become available.

Questions & Discussion

Q How do we safely prescribe exercise without assessing face to face? Is anyone assessing functional exercise capacity over video assessment?

RM: Our recommendation would be that we may need to bypass any physical assessment for the time being. If we can't see the patient (i.e no access to videoconferencing) and we haven't ever met the patient previously, as well as not knowing the home environment, from a safety point of view, any physical assessment should not be performed. For possible outcome measures pre and post any sort of home based program, you might just do quality of life questionnaires etc.

However if videoconferencing was available there may be an option to do some physical assessments such as:

- a remote six-minute walk test. This has been evaluated by Rita Hwang (Qld) for people with heart failure (Hwang R et al, Journal of Telemedicine & Telecare. 23(2):225-232, 2017)
- six-minute walk test apps using GPS type measurements to work out a distance.
- measuring laps and recording number of laps in 6 minutes - for example walked from the kitchen to their dining table and back again and using change in number of laps as an outcome measure. But for all of these you need to be able to visually see the patient via videoconferencing.
- You would need to do some risk screening of the patient and requesting that there is another person available in the home environment for safety.
- We are currently evaluating doing a 5 sit to stand test as a measure of lower limb strength and a 60 second sit to stand test as a measure of endurance. Again, the safety aspect of these tests being performed at home without the physical presence of a clinician has to be considered, even if there is videoconferencing available.

JA: During COVID-19 the most feasible measures are the quality of life questionnaires that could be used as the primary outcome for our programs for the time being.

AH: Noted that Sally Singh in the UK had developed a workbook based program SPACE for COPD: https://www.spaceforcopd.co.uk/. It is an unsupervised PR program where the patient engages in regular physical activity and work their way through the workbook over a period of three months. There is normally a cost associated with registering, but they are making it available free for the next three months and apparently it is available free to anybody who contacts them.

Q. Can anyone suggest a good valid physical activity survey that could be used in the PR space?

JA: The Australian Physical Activity Questionnaire is probably the best option, although it is not specific to PR.

Q. What QOL measures would we be using at this time?

AH: The SGRQ is s valid tool but may be too long. The CAT would be very appropriate during this time as the CAT is particularly amenable to this kind of situation because it should be fairly easy for people to complete independently or with a little bit of assistance over the telephone. The others QoL questionnaires may cause issues for people to do on their own.

Q. How do we assess safety if the patient significantly desaturated or has poor hemodynamic response to exercise?

AH: At this unusual time is going to call for all the great clinicians within this meeting to use their clinical judgment about the people who are going to be safe to exercise at home on their own. We've learned a lot from the population of patients with pulmonary hypertension in the last few years about that, about the importance of taking a really good exercise symptom history because those patients are often the ones we are a bit more concerned about their safety to exercise.

In a situation where we don't have the ability to directly supervise exercise, our history taking is going to have to be a lot better in addition to our training of patients to monitor their own symptoms is going to have to be better as well.

JA: If your PR programs are managing heart failure patients or people with pulmonary arterial hypertension, I think you will have to manage these patients differently from the COPD groups from the safety point of view.

Some messages to take away:

- The key is to keep patients out of hospital, and we all know PR helps do that.
- There will not be one model that works for every individual or region.
- Clinical judgement and taking a thorough exercise symptom history is vital for safety.
- Teaching patients how to monitor and report their own symptoms is also vital.
- Questionnaire outcomes for quality of life may need to be the measure of program effectiveness for the time being.
- ACI document on managing PR via telehealth will be coming soon and will be disseminated to the network when available.

Closing - JA

Thanked everyone for their involvement and their commitment to support their patients by providing PR in the best way possible during this time.

The meeting agreed that a follow-up meeting would be useful to hear about how clinicians are managing telehealth PR service provision within their own workplace.

> Chair to consult with the LFA and state representatives on what this follow up meeting would look like and an appropriate time and date. Likely to occur beginning of May. 2020.