

PR Network Meeting October 2020 Minutes: Reflection and progress through a pandemic

- Date:** Tuesday 20th October
- Time:** 12.30 pm – 1.30 pm AEDT (VIC, NSW, ACT, TAS)
- Location:** Via Video or Teleconference only using Zoom details below
- Invitees:** All PR Network Members (137 attendees recorded)
- Meeting Chair:** Professor Jennifer Alison (JA)
- LFA Reps:** Kelcie Herrmann(KH), Emma Gainer (EG)

Link to recording:

https://www.dropbox.com/s/syp86e0gleqattv/PR_Network_Meeting_20_10_20.m_p4?dl=0

Minutes

1. a. Welcome & Recap (JA)

- Positive feedback coming from the previous meeting – particularly in the information presented on the COVID rehab.
- Please continue to visit the PR Toolkit (and click on COVID-19 Support tab) where we are loading all the relevant documents and resources to support you in this area. The link is as follows:
<https://pulmonaryrehab.com.au/covid-19-useful-links/>

New resources (which are on the Toolkit site) are below:

- *New resource since the previous meeting & in line with this main agenda points in our last PR Network meeting - NSW Health Agency for Clinical Innovation (ACI) Respiratory Network: Rehabilitation following COVID-19 in the pulmonary rehabilitation setting. Link available on the Toolkit website. https://pulmonaryrehab.com.au/wp-content/uploads/2020/09/0474-Respiratory-Rehab-Following-COVID-19_v04.pdf*

- Since the previous meeting the 'Rapid Review' around homebased and remote exercise testing (lead by Anne Holland and team) has become available. Direct link in the toolkit: <https://journals.sagepub.com/doi/full/10.1177/1479973120952418>
- Case series by Sally Wootton – describing virtual rehabilitation of the first three patients with COVID-19 managed by their Northern Sydney program: <https://onlinelibrary.wiley.com/doi/pdf/10.1002/rcr2.669>

b. LFA Updates (EG)

LIA recommencement process –

- From October 22nd 2020 LIA instructors will be provided an online process to apply to recommence LIA classes. There will be compliance process that providers must abide by in line with LFA's COVID-19 Expert Working Group, state health departments, and recognised Australian pulmonary exercise professionals.
- This will be an online COVID Safe LIA Instructor Acknowledgement form.
- I would therefore suggest that PR programs regularly referring / or having contact with LIA to make contact with your local provider.
- The recommencement of Lungs in Action community classes - Position Statement is now available via the PR Toolkit here: <https://pulmonaryrehab.com.au/wp-content/uploads/2020/10/LIA-Recommencement-Position-Statement-V2-OCT-FINAL-2020.pdf>

Free - World COPD day Webinar

- To celebrate World COPD day this year we are hosting a free webinar called: An update on COPD-X Guidelines and COPD quality improvement tools for primary care
- Date: Wednesday 18 November 2020.
- Although the webinar is aimed at the primary care health professional workforce, specialists and secondary/tertiary care nurses and allied health staff are also welcome to attend.
- Speakers include Prof Ian Yang, Dr Kerry Hancock, Dr Eli Dabschack and Katrina Otto.
- Link to register and/or find out more here: <https://event.on24.com/eventRegistration/EventLobbyServlet?target=reg20.jsp&referrer=https%3A%2F%2Fflungfoundationaustralia.secure.force.com%2F&eventid=2764692&sessionId=1&key=4B78E1673F181AA9B636704364DCEC70®Tag=&sourcepage=register>

Survey open regarding the PR Toolkit upgrade to include rehabilitation for people with Lung Cancer

- The survey is aimed at gathering information around current rehab that exist for people with Lung Cancer including referral, and what resources are currently available and utilised.
- The data that is 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.
- The survey also is gathering information on how the PR community are currently accessing the PR Toolkit and will be used in its upgrade.
- We know the PR Toolkit is a well used site, and we want to ensure it continues to meet your needs!
- Link to survey here: <https://www.surveymonkey.com/r/38JQK8M> - **Will be opened until the end of the year.**

ACTION:

All – complete survey here: <https://www.surveymonkey.com/r/38JQK8M>

National Health and Medical Research Council (NHMRC) Funding: [GO4446](#) – 3 focus areas, including Exercise and nutrition.

- The objectives include: *improve health outcomes for Australians living with chronic and complex disease through innovative public health approaches, particularly for Aboriginal and Torres Strait Islander peoples and for disadvantaged regional and rural and culturally and linguistically diverse communities.*
- Closes FEB 2021 link: <https://www.grants.gov.au/Go/Show?GoUuid=db65f66d-95a4-7e4c-97b5-e39585bafc61>

2. A tale of two towns.

An insight into COVID's effect on regional PR – then, now, and into the future.

Megan Smithers, Chronic Disease Care Coordinator, Sunraysia Community Health Service VIC.

Background Respiratory Services

- Located in Mildura in North-west VIC
- Started 2 years ago with a program named 'Lung and the breathless Pulmonary Rehab' obtained funding from the PHN
- Have since extended to include cardiac rehab
- PR runs for 8 weeks and also run LIA for maintenance exercise
- Includes Exercise training, Education and Self-management.

How have the last 8 months Affected the Program?

- Ceased all F2F groups initially
- Initially weekly and fortnightly checks
- Now developed pathways to replicate the face to face via Telehealth and/or Home exercise program
- Huge decrease in referrals into program during COVID period

Changes required to succeed:

- Moving from F2F to Telehealth or Home base
- IT set up and support that goes with this
- Education packs sent to clients
- Telehealth checklists sent to clients to ensure safety at home in line with LFA LIA guidelines

Perceived issues:

- Clients seeking f2f for motivation and interaction socially
- Clients who don't have access to technology are not able to utilise Telehealth option
- Clients completing HEP aren't supervised closely so completion and quality of exercises can't be assured.
- Barriers can be IT issues

- Number of reports that the clients feel deconditioned as they aren't doing as much as they would in a face to face class.

Strategies Implemented to future proof PR programs

- The change has made PR more accessible by allowing Home based programs – so will continue along side centre-based program once f2f groups recommence.

Perceived Benefits and or disadvantages of being regional/Rural in this type of circumstance.

- Low COVID cases - yet still restrictions
- Clients access IT options for the first time has given them confidence to choose Telehealth options – and therefore decreasing need to go to Adelaide or Melbourne

Robyn Paton, Respiratory Clinical Nurse Consultant, Murrumbidgee Local Health District (MLHD)NSW

Background Respiratory Services

- Rural and Remote areas with 33 public Hospitals & 12 Community Health Centres.
- We have had asthma & Respiratory Services for over 30 years commencing with Asthma Education & then having Pulmonary Rehabilitation groups from about 2008.
- Prior to Covid-19 We had Face to face PR twice a week, for 8 weeks, which included 2 one hour Exercise sessions and a one hour Education session.
- In the smaller sites there may be Cardiac & respiratory Patients doing rehabilitation groups together.

Changes required to improve

- Now we are doing face to face assessments where possible prior to commencement of the telehealth program.
- We need to have Physiotherapy involvement to do an exercise prescription that can be achieved at home or as part of a group.
- Include Face to face with some of the group whilst others do virtual using a big screen.

Strategies Implemented to future prove PR programs

- These programs are now commencing each two weeks & going for 8 weeks led by Respiratory Care Coordinators taking their turn from different towns within MLHD.
- Whilst we do not have an exercise component yet, we are recommending that clients visit their physio or go to the Lung Foundation resources for their exercise ideas.
- We have encouraged GP's and specialists to continue to refer clients.
- A mix of Face to face for those with difficulties exercising at home & larger screen virtual people using Pulse oximeters & the BORG scale would keep clients safe and provide Service flexibility.

Perceived Benefits and or disadvantages of being regional/Rural in this type of circumstance.

- A benefit is defiantly having less exposure to the COVID-19.
- However there are less resources available including physical resources, as well as allied health, Nursing specialty staff etc.
- Distances to assistance are greater and take more time.

- There are gaps in technical services as well as difficulties in the older patients ability to use technology.

Reflections

- MLHD had a dynamic Respiratory team which now has three vacancies to be filled.
- The virtual Pulmonary education is, at first glance, initially more cost effective, but this form of delivery is not evidence-based.
- The concern is that the new model may be implemented without adequate research.
- A blend of the two virtual and face to face including exercise prescription, would give clients & clinicians an option to service the remote areas.

3. Promoting (re)engagement with PR and supporting mental health in the context of COVID-19. Strategies on how PR clinicians can support patients to engage in face to face programs and services.

Paul Cafarella, Health Psychologist/Manager Respiratory Ambulatory Services, Flinders Medical Centre/Flinders University

To see the full PowerPoint Presentation here: <https://pulmonaryrehab.com.au/wp-content/uploads/2020/11/Paul-Cafarella-ALF-PR-Net-meeting-20-10-2020-PDF.pdf>

Mental Health

- Well-known consequences of disease outbreaks:
 - Anxiety & panic
 - Depression
 - Anger
 - Confusion and uncertainty
 - Financial stress
 - Estimates of between 25% to 33% of the community experiencing high levels of worry and anxiety during pandemics

Butts et al., 2015 Disaster Med Public Health Prep

Impact of COVID19 on MH of Australians

Survey (27/3/20 – 7/4/20: 'peak' of 1st wave) of 5,070 adults

- 1/3 were "very or extremely concerned about an outbreak"
- Perceived risk of infection was 70%
- 61% felt they would get moderate to severe covid19 symptoms
- 78% reported their MH problems worsened. Those already with a MH Dx had higher levels of anxiety regarding health and fear of COVID-19
- Nearly half "worried" re loneliness, financial troubles & uncertainty
- Psychological distress levels higher: Raised levels of depression 62%, anxiety 50%, health anxiety 24% & stress 64%.

Newby et al., 2020 PLOS ONE

Populations groups of increased risk of MH problems

- **Physically vulnerable** (pre-existing physical problems esp. cardio, lungs, compromised immune function, elderly etc.)
- **Pre-existing** anxiety disorders, substance disorders and other mental health problems
- **Those living or receiving care in congregate settings**
- **Being placed in quarantine, extended quarantine**
- Unemployed/reduced hours/casualised workforce
- Extroverts
- People living in dysfunctional or dangerous relationships
- Health care workers (HCW)
 - Front-line HCW experience higher anxiety than the general community about contracting viruses during pandemics
 - Ongoing survey of >10,000 general Aus HCW: 58% 'burnout', 61% anxiety, 28% depression (as of 16/10/20)

Pfefferbaum et al., 2020 New Eng J Med; Black Dog Institute 2020; Smallwood et al., 2020

Our role

- **Understand the –'ve psychological impacts** of COVID-19 & mass quarantine
- In past pandemics, patients who experienced severe illnesses were at risk of PTSD & depression, **months to years** following their illness
- Recognise/assess/provide **mental health screening** support for COVID-19 patients
 - e.g. DASS, K10, GHQ9 etc.
 - NB these screening questionnaires are not diagnostic but are a good guide
 - Trauma increasingly common (e.g. Impact of Events Revised Scale)
- Offer **technology** enabled mental health and PR services
 - e.g. mobile apps, telehealth, online treatment
- Don't assume that if someone has a MH hx that a dyspnoea presentation is entirely due to anxiety
- **Information, motivation and hope**
- Encourage and facilitate **help-seeking** behaviour (and links)

(Re)engagement with Pulmonary Rehab

- Identify barriers
 - Known PR barriers, covid-19 related barriers, mental health barriers
- Assessing and addressing relevant help-seeking determinants:
 - e.g. low health literacy, perception of treatment efficacy, mental health
- Mental health status of people with respiratory illnesses is a predictor of nonadherence as well as health outcome
- Be prepared for and pre-empt responses to questions that potential PR participants will have:
 - Do I really need this?
 - Does it really help? Will it really make any difference? Is there any point?
 - Is it safe? Especially now during covid19? Is exercise dangerous? Is the hospital/centre etc. safe or will I catch covid19 attending? Is exercise via tele-health (without a physiotherapist 'in-person') safe?
 - Can it wait till all the covid19 drama is over? Should I wait?
 - I don't feel fit enough to begin PR so should I wait?
 - I'm not sick enough. I'm too sick.
 - Should I wait till the stress in my life is over? What about my mental health?

Barriers, safety thoughts & behaviours

- "What ifs"?
- Risk vs reward/ costs vs benefits (explain/'sell' the benefits of PR)
- Perception of risk
- Maladaptive illness perceptions (including those related to covid-19)
 - **Perceptions can be modified by interactions w HCWs, restructuring personal models of illness – influencing adherence, PR uptake & adherence**
- The 'cost' of waiting
- Opportunities for "back on track" discussion post-deconditioning
- Motivational interviewing
- Strengthen 'enablers'

4. Invigoration of Peer Support through Lung Foundation Australia's Mighty Network''.

A look into the benefits of peer support, current LFA options available, and a review of 'Mighty Networks'

Chanelle Moar, Peer Support Coordinator LFA

Peer Support options at LFA - 3 forms of Peer support

- Telephone support for Lung Cancer – open group and a young lung specific group:
<https://lungfoundation.com.au/patients-carers/support-services/peer-support/lung-cancer-support/>
- Peer to Peer matching service – Peer connect. People living with IPF or PF for patients and careers.
<https://lungfoundation.com.au/patients-carers/support-services/peer-support/peer-connect/>
- Peer Support Group model – Online and Face to Face options:
<https://lungfoundation.com.au/patients-carers/support-services/peer-support/peer-support-groups/>
 - Online Peer Support Group model - utilising Mighty Networks

- LFA have introduced this online peer support network to provide a place where peer support groups can still meet during COVID and other barriers that may arise.
 - LFA has purchased a license for this program making it free for our users and group members whilst being private and safe as possible.
 - The online program allows Video chat , general text chatting – one on one or group , online events, face to face events, sharing resources etc
 - Available for existing peer support groups or anyone who wants to create one
 - For those interested the first step is talking to the peer support coordinator about the needs of the group and then allow Chanelle to feedback on how the program can be set up to tailor these needs.
 - Can be used on a smart phone, computer or tablet.
 - It is private and secure – new members can only come onto the system if invited.
 - LFA aim to make this process as easy as possible.
 - LFA are available at every step to support new and existing groups and their members; with no experience necessary.
 - There is a full induction, welcome guide and ongoing support from Chanelle – Peer support coordinator.
- Now LFA have launched the online network:
 - Will begin Share group stories
 - Grow peer support groups
 - Build online community
 - Evaluation and review
- Now opening up the opportunity for Lungs in Action groups or Pulmonary Rehabilitation groups to use this platform to connect with their own group members – or encourage patients/clients to otherwise take the lead and develop groups.

If anyone is interested in a virtual tour, Chanelle will be holding a zoom event on the following day:

Topic: Online network tour
Time: Nov 25, 2020 01:30 PM Brisbane

Join Zoom Meeting
<https://zoom.us/j/96514639703?pwd=UG8yUnVvSHFNOFhwSS9RaU1WRIJFdz09>
Passcode: 788102

1800 893 423 Australia Toll-free
Meeting ID: 965 1463 9703
Passcode: 788102

Questions through chat:

Q. *Is there a cost to using Mighty Networks within our Lung Foundation portal?*

A. No cost. LFA has a paid subscription, but as a user and group member you are not required to pay any of this cost.

Q. Does mighty networks chew up a lot of data i.e. patients would need a good data plan?

A. Data to use such an app is comparable to Facebook. General forum discussions within the app create minimal data usage.

5. PR Network- Where to next? (JA)

Role of the Network moving forward? What do you want to get out of the network?

Possible options are:

- Continuing meetings and providing presentations relevant for the time
- Developing as a group a minimum data set useful across all programs nationally
- 'Year in review' event - yearly review of new PR research and implications of this information to clinical practice for PR.

We look forward to receiving feedback from network members on this item. Please respond to the minutes email and update Emma on **your thoughts about what you would like the PR Network to provide for 2021 and Beyond.**

ACTION:

- o Email emma@lungfoundation.com.au with feedback on the future of the PR Network.