Wednesday 8 December, 2021
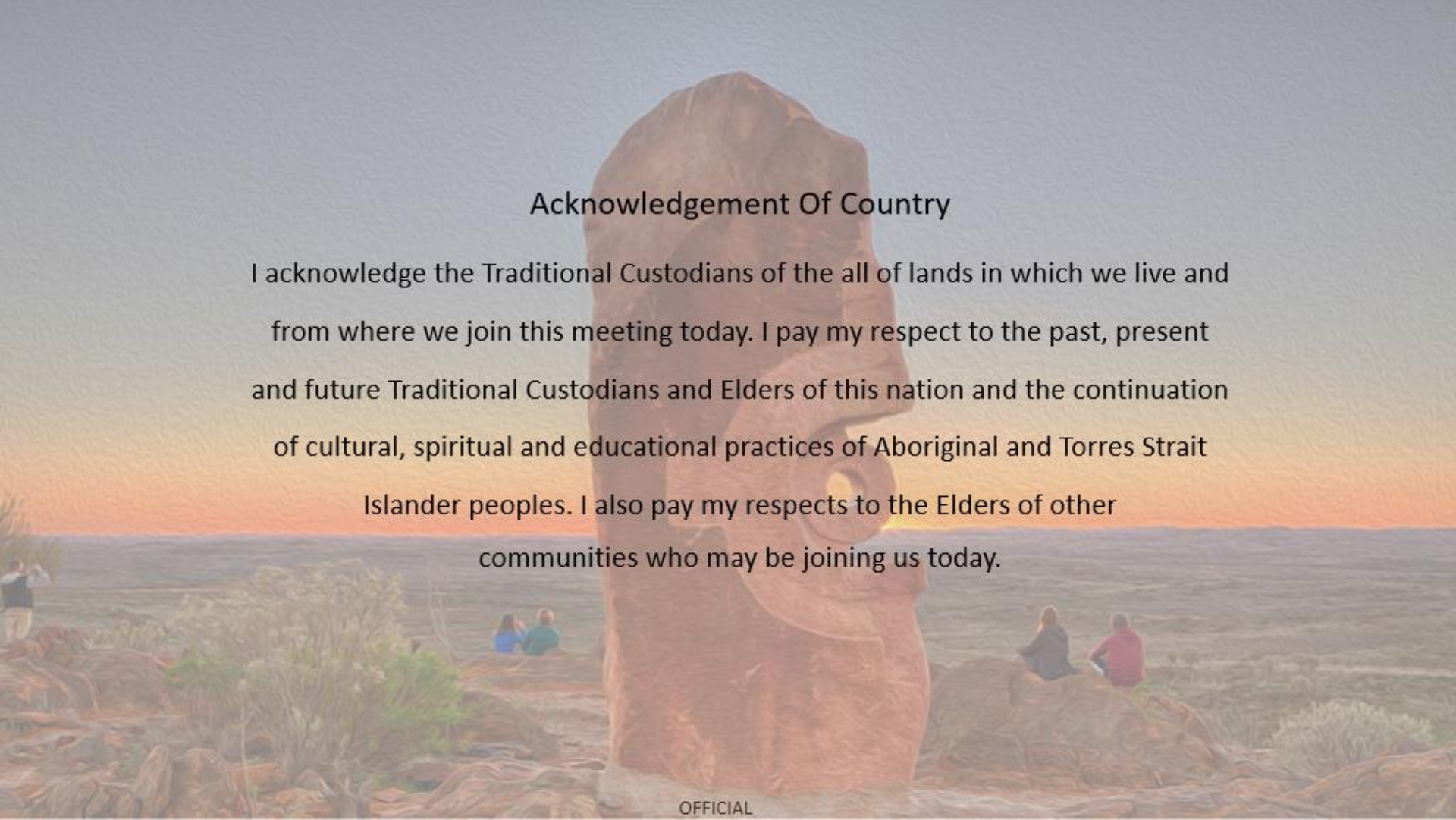
COVID + Pathway Learning Network webinar series

Webinar 11: Care after the wave: Caring for patients with long COVID

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Acknowledgement Of Country

I acknowledge the Traditional Custodians of the all of lands in which we live and from where we join this meeting today. I pay my respect to the past, present and future Traditional Custodians and Elders of this nation and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples. I also pay my respects to the Elders of other communities who may be joining us today.

Webinar series purpose

- Showcase local clinicians who will share their experiences delivering the COVID + Pathways model

- Provide a forum for sharing and collaboration to support the delivery of best practice

  * To share your services' experiences, innovations and learnings in delivering the COVID+ Pathway at an upcoming webinar email centresofclinicalexcellence@safercare.vic.gov.au

Before we start

Throughout the webinar you can ask questions by typing your question into the chat.
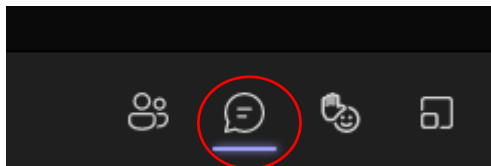
There will also be a dedicated time for questions and discussions.

The presenters will do their best to answer your questions at the end of the presentation.

This session will be recorded and made available on the SCV website
https://www.bettersafercare.vic.gov.au/support-training/learning-networks/covid-pathways

Overview

Topic	Presenter
Long COVID update	**Louise Galloway** Executive Director, Community Based Health service, Policy Improvement, Department of Health
Questions	
Lived experience of COVID-19	**Angela Franzone** Consumer, lived experience COVID-19
Life after COVID-19 – What do we know and what do we want to know?	**Dr Danielle Hitch** Allied Health Research and Translation Lead Allied Health Strategy, Planning, Innovation, Research and Education (ASPIRE) Unit
Long COVID Model of care	**Janet Bondarenko** Senior Respiratory Physiotherapist Alfred Health
Questions	

Supporting long-COVID-19 recovery

Louise Galloway – Executive Director Community Based

Health Service, Policy Improvement

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VICTORIA State Government | Department of Health

In Victoria to date there have been over 111,000 cases of COVID-19

- Most people recover from COVID, however a smaller (10-35%) proportion of people go on to have long-COVID. Returned travellers and people who may have not tested for COVID may also be among those who go on to have long-COVID.

- Long-COVID has debilitating and long-term effects putting pressure on the health system and preventing people from returning to their usual lives with significant social and economic costs.

Long-COVID work to date has fallen under three areas:

1. **Research -** data collection to inform implementation of optimal models of care and service arrangements to maximise treatment outcomes and quality of life for Victorians diagnosed with long COVID.

2. **Clinical Care -** with a focus on primary care and referral pathways to specialist advice.

3. **Community engagement -** ensuring people who have had COVID are aware that they may experience long-COVID sequalae and that it is important for them to raise with their GP that they have had a diagnosis of COVID.

Work to date:

- Safer Care Victoria's Clinical Leadership Expert Group informed the development of long-COVID clinical guidelines for clinicians as well as an information factsheet for consumers.

- The department is represented on the external Victorian post-acute COVID-19 study group (VPACS) of Victorian researchers with an interest in the patient management of long-COVID (chaired by Prof David Watters).

- The Victorian Agency for Health Information (VAHI) is investigating the development of a COVID Health Survey of COVID positive Victorians. This would form the basis of a Victorian long COVID data asset, which could be used for surveillance, system planning, models of care development and evaluation, research and clinical improvement.

Work to date

A time limited primary care long-COVID advisory group was established to support people experiencing long-COVID-19 sequalae to access responsive primary health care including a timely interface with allied and acute specialist systems as required.

The group included senior clinicians, allied health and consumer representation
who has experienced long-COVID.

Focus has been on primary care and referral pathways to specialist advice:

- Ensuring treating primary care clinicians are aware of long-COVID and the need to consider if patients present with post-viral type symptoms and to ask patients if they have had a diagnosis of COVID. Most patients with long-COVID will present to GPs in the first instance.

- Ensuring clinicians have contemporary clinical guidelines for the diagnosis and treatment of long COVID.

- Ensuring primary care clinicians have access to specialist advice as required, and referral pathways if patients need specialist care.

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Work to date

- SMS sent to all past COVID patients notifying them of long-COVID supports through primary health.

- Where available, letter sent to GPs of COVID positive patients to remind them to recall patients who had COVID and to screen for long-COVID. (in progress)

- Distribution and promotion of Safer Care Victoria long-COVID guidelines for clinicians through Primary Health Networks and RACGP and allied health networks.

- Working with RACGP to explore training and education for GPs to support better practice long-COVID care.

- Long-COVID webinar delivered with RACGP to Victorian general practitioners.

- Review and feedback on Primary Health Network Health educational pathways for GPs on long-COVID including guidance on recall, asymptomatic COVID-19 patients, social/psycho support.

- Long-COVID guidance developed by SCV for patients provided to: COVID positive pathways program participants; hotel quarantine participants; Study Melbourne for international students.

- Long-COVID education and information for culturally diverse communities.

Next steps:

- The department is keen to ensure the health care needs of long-COVID patients are effectively managed in primary health care settings with secondary health service supports through statewide health services and research and data collection.

- Contingent on resources planning is underway to develop:
  - resources and training for primary care workforce to support long-COVID care in primary health care;
  - targeted education and resources about long-COVID for patients and close contacts who have had COVID-19;
  - resourcing for long-COVID data collection and research;
  - mapping of existing long-COVID clinics in health services.

Questions

Please type your question in the chat

Lived experience of COVID-19

Angela Franzone - Consumer, lived experience COVID-19

Western Health COVID19 Recovery Collaboration

Life after Covid19 – What do we know and what do we want to know?

Life After COVID – Australian evidence

- Not a lot of local evidence available yet ….

- Liu et al. (2021)

  - Telephone interviews (n=2904)
  - Original NSW wave
  - 80% full recovery within 4 weeks, but 5% will have symptoms at 3 months

Longitudinal Study

To describe how people diagnosed with Covid-19 describe their health, disability and recovery in the months following diagnosis (3, 6, 9, 12, 18 & 24 months)

Research Questions

- Are there any significant differences between recovery outcomes for people diagnosed with Covid-19 and matched controls after 6 months?

- How do people recovering from Covid-19 describe their profile of fatigue and functional outcomes?

Longitudinal Study – Preliminary Findings

WHODAS @ 6 months

Chart: Stacked bar chart showing WHODAS disability categories for Australian Norms, Matched Controls, and People with COVID19. Y-axis 0% to 100%. Legend: No Disability (blue), Mild Disability (red), Moderate Disability (green), Significant Disability (purple).
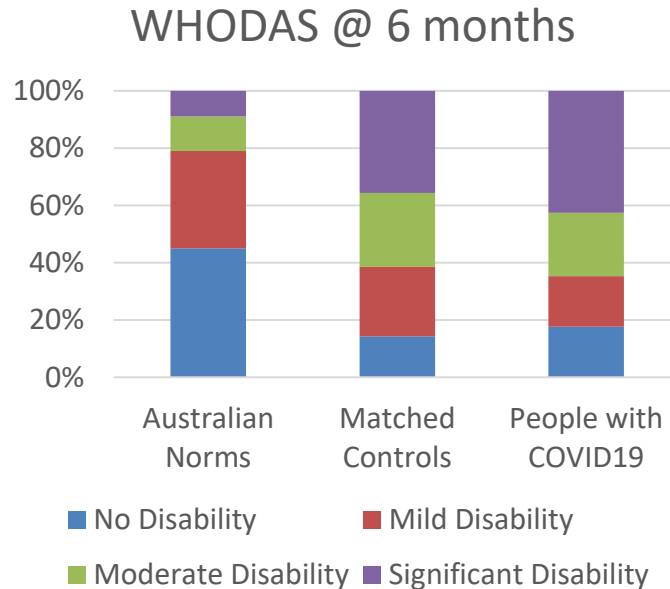
- No significant differences in recovery outcomes between people recovering from Covid-19 and matched controls.

  - *HCW participants reported feeling significantly more 'worn out' at 6 months*

- **HOWEVER,** fatigue and function for both groups (people with COVID19 and controls) were markedly worse than previously established population norms.
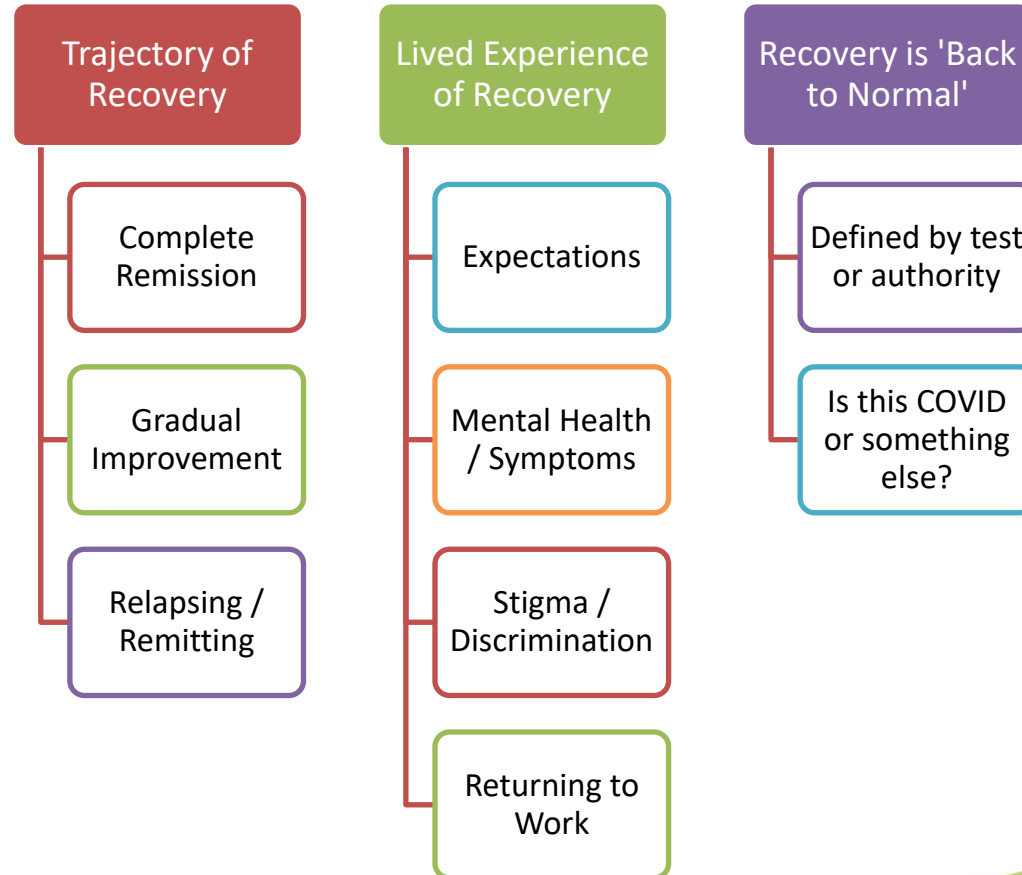
Functional Profiles @ Recovery Stage
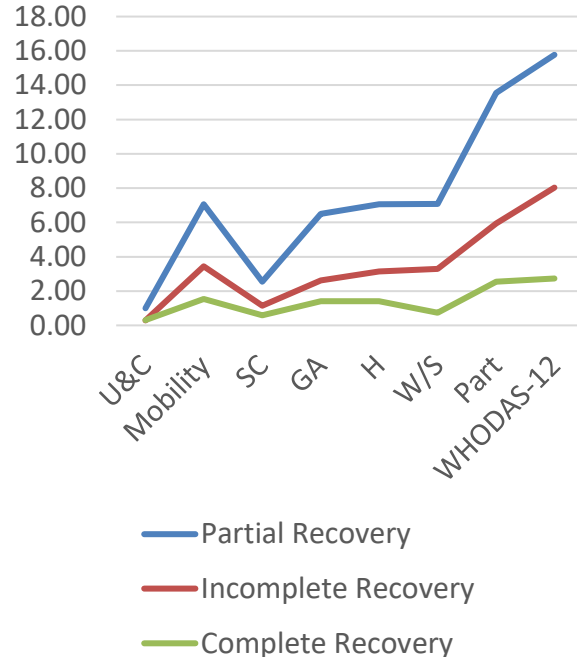
- Only one third patient reported full recovery at 6 months

- Significant differences in functional profile related to patients self-reported stage of progress

  - *WHODAS could be a good tool to stage or monitor recovery over time, which is essential to delivering person centered care.*

Narrative Interviews

- Temporal Characteristics

  - *Acute – Not everyone has 'classic' symptoms, significant weight loss*
  - *Post Acute – Varied incl. fatigue, dyspnea, chest pain, cognitive impairment, altered smell & taste, allergies and speech & language problems.*

- Complex Needs

  - *Impacts on multiple body systems & diverse illness trajectories*
  - *Return to work, stigma & discrimination, trauma, CALD, doubt & dismissal*

- Lived Experience Expertise

  - *Assistance needed to navigate & connect with the health system*
  - *Variable access to & experience of follow up care*

Western Health

Trajectory of Recovery
- Complete Remission
- Gradual Improvement
- Relapsing / Remitting

Lived Experience of Recovery
- Expectations
- Mental Health / Symptoms
- Stigma / Discrimination
- Returning to Work

Recovery is 'Back to Normal'
- Defined by test or authority
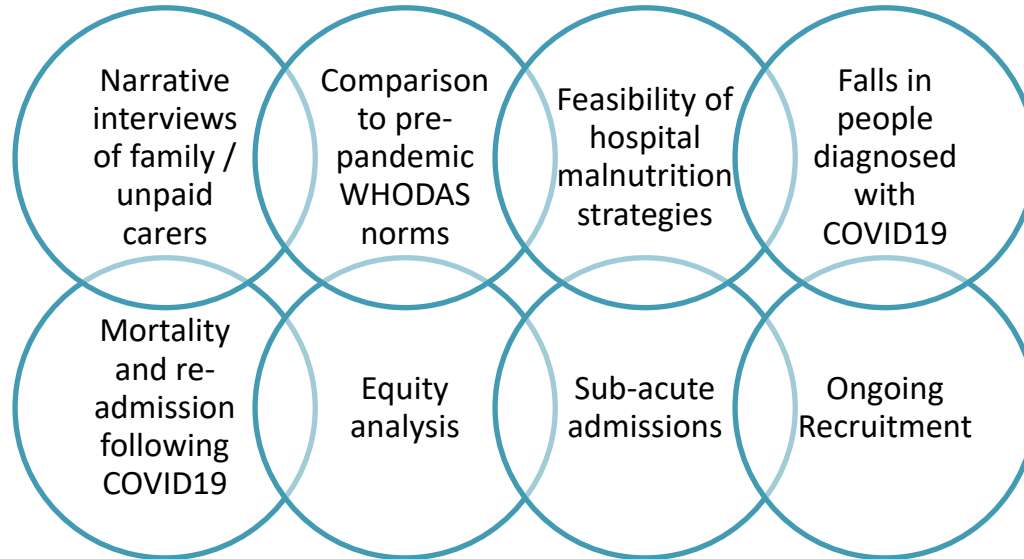- Is this COVID or something else?

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Healthcare Worker Survey

- Allied Health 84.1% - more medicine and nursing needed!

- Majority had <u>not</u> directly treated anyone with COVID

- HCWs recognize the diverse impacts Long COVID has on health.
    - Variable recovery trajectories. Prolonged symptoms (93.9%), relapsing / remitting (53.7%), emergence of new symptoms (46.3%).

- Generally rated their knowledge and skills for Long COVID as non-existent or limited.

- Long COVID will have a minimal (57.3%) to moderate (32.9% impact on their practice.

- Resources: Guidelines, algorithms and documentation templates.

- Information: Identification of Long COVID and evidence-based practices.

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What happened

- Pausing some of the activities I had returned to after realizing I wasn't ready / up to them
- Re-emergence of some symptoms (i.e. chest pains, breathlessness)
- Noticing new symptoms or issues that weren't there before COVID (i.e. cognitive problems, hair loss)

What I wished had happened

- Knowing who to speak to or which pathways to follow
- One stop shop for information and care - Not having to chase it
- Care and advice based on the most up to date evidence
- Empathy and support from care providers in response to the distress and uncertainty I feel

Week 5-8

ACUTE PHASE (?)

What else will we be able to tell you?

- Narrative interviews of family / unpaid carers
- Comparison to pre-pandemic WHODAS norms
- Feasibility of hospital malnutrition strategies
- Falls in people diagnosed with COVID19
- Mortality and re-admission following COVID19
- Equity analysis
- Sub-acute admissions
- Ongoing Recruitment

Western Health

POST COVID FOLLOW UP
Alfred Health Model of Care

Janet Bondarenko
Senior Respiratory Physiotherapist

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Part of **AlfredHealth**

COVID: Pathway to recovery

- Growing population of COVID survivors report prolonged symptoms and delayed recovery
- Symptoms are heterogenic: neurological, psychological, physical and cognitive.
- Little information on the care of ambulatory/outpatient management of post COVID – most research describes hospitalised patients with moderate to severe disease.
- Models of Long COVID care emerging internationally -> recommend integrated multidisciplinary care, use of standardised screening tools for symptom assessment and appropriate clinical rehabilitation pathway

theAlfred

Post COVID service model recommendations

Principles:

- Multidisciplinary teams
- Integrated care
- Self-management
- Coordination of care
- Evidence based care

Components:

- Standardised symptom assessment
- Referral system
- Follow-up system
- Virtual & home-based care

Decary S, Dugas M, Stefan T, Langlois L, Skidmore B, Bhéreur A, and LeBlanc A. (2021).
Care Models for Long COVID – A Rapid Systematic Review. SPOR Evidence Alliance, COVID-END Network

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Care Models for Long COVID – A Rapid Systematic Review. SPOR Evidence Alliance, COVID-END Network

Referral system to Alfred service:

People with Alfred hospital admission or on medium risk community pathway

People managed by GP/hotels or had COVID care out of Alfred catchment

- Blanket referral
- Contact with patient at 6-8 weeks post discharge and provide opportunity for follow up assessment -> helps to focus on those most likely to require follow-up

- Self referral
- GP or specialist referral

postcovidfollowup@alfred.org.au

Part of **AlfredHealth**

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Systematic Assessment and Triage

Standardised symptom assessment via phone or REDCap:

- Ongoing symptoms or limitations
- Modified Medical Research Council scale
- HRQOL: EQ-5D
- Hospital Anxiety and Depression scale
- Impact of Events Scale-Revised – PTSD
- Fatigue Assessment Scale
- Weight Loss
- Return to work / study
- Cognitive functioning
- General comments

Physical assessment:
- 6MWT (oximetry)
- 30 sec sit-stand

Feedback to patients
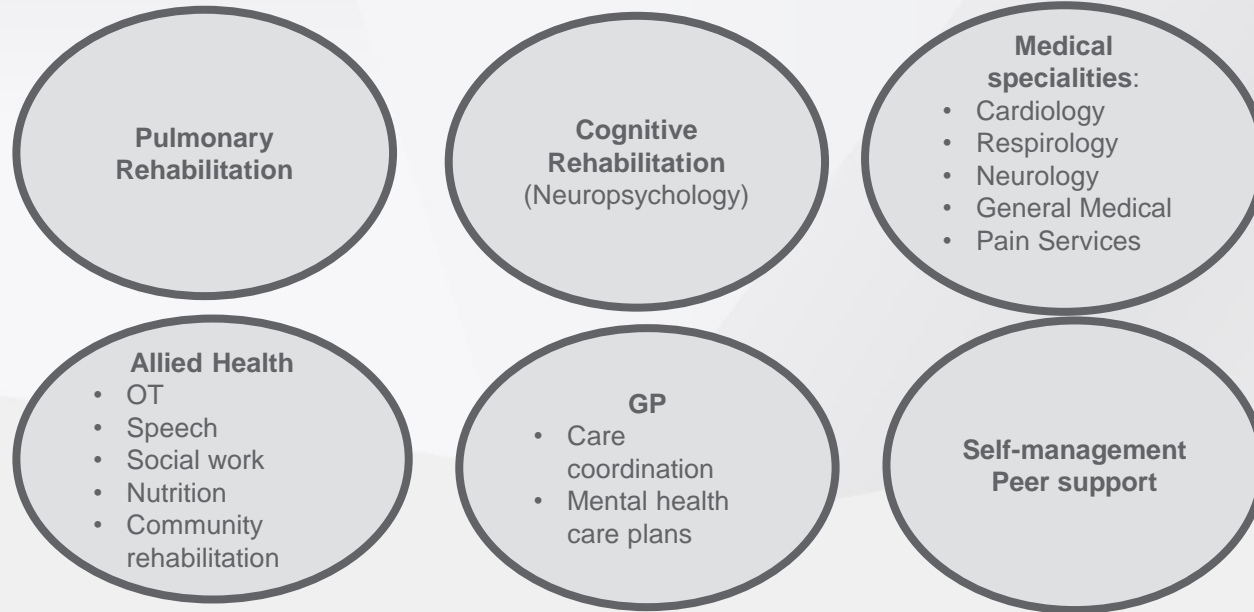
MDT meeting fortnightly

- Medical reviews
- Referrals onwards
- Rehabilitation pathway

Virtual clinic staffing

- Allied health assistants – intake, screening assessments via phone or email
- PR Physiotherapists – review results of screening, conduct physical assessments, provide feedback to patients and organise outward referrals
- GENMED Physician
- Neuropsychologist – assessment and treatment of patients with ongoing cognitive symptoms
- Patients requiring specialist medical follow up seen in regular clinics

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Referral pathways and treatment

Pulmonary Rehabilitation

Cognitive Rehabilitation
(Neuropsychology)

Medical specialities:
- Cardiology
- Respirology
- Neurology
- General Medical
- Pain Services

Allied Health
- OT
- Speech
- Social work
- Nutrition
- Community rehabilitation

GP
- Care coordination
- Mental health care plans

Self-management Peer support

Goal is to maximise recovery with return to usual activities while managing symptoms

Demographics of patients followed up by Alfred

2020

- 95 patients eligible, 30% consented to follow up
- Mean age 63 (28-71)
- Gender 60% male
- 45% of respondents report at least one ongoing symptom (57 % female)

2021

- >500 eligible, 37% consented to follow up
- Mean age 49 (23-77)
- Gender 48% male
- 47% of respondents report at least one ongoing symptom (70% female) (excluding cognitive)

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Symptoms	2020	2021
Fatigue (FAS ≥35)	67%	57%
Dyspnoea (MMRC ≥2)	38%	27%
Depression (HADS D ≥11)	28%	9%
Anxiety (HADS A ≥11)	28%	32%
PTSD (IES-R ≥33)	22%	23%
Not returned to work/study	17%	7%
Returned in lower capacity	11%	25%
HRQOL (VAS EQ-5D)	Mean 67% (20-100)	Mean 50% (20-100)
Memory changes		62.5%
Concentration issues		62.5%
Slower thinking		59%
Heightened agitation		59%
Thinking difficulties		50%
Thinking difficulties affect everyday activities		81%
Desaturation on 6MWT	11%	

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Challenges and future directions

- Younger population

- Patients from NES backgrounds

- Patients feel unheard and unseen -> important to listen and validate their symptoms.

- Virtual recovery group and peer support

- Impact of vaccination on long Covid symptoms

- Long term follow up

- Understanding causes of persistent symptoms

- Treatment

Acknowledgements:

Prof Anne Holland

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Mel Chong

Dr Daniel Fineberg

Leonie Keall

Liz Webb

Jaycie Perryman

Questions

Please type your question in the chat

Resources

1. Learning Network webinar recordings and slides
    https://www.bettersafercare.vic.gov.au/support-training/learning-networks/covid-pathways

2. COVID Clinical Shared Resources SharePoint page - Secure site for sharing, with permission, health service developed COVID-19 resources.

   - To register for access and to share resources contact centresofclinicalexcellence@safercare.vic.gov.au

3. Department of Health COVID-19 clinical guidance and resources
https://www.health.vic.gov.au/covid-19/for-health-services-and-professionals-covid-19

Get in contact

- Please complete our short [survey](#)

- To register for future webinars email us: centresofclinicalexcellence@safercare.vic.gov.au

- If you have specific questions relating to the COVID+ Pathways please email the Department of Health at covid+pathways@health.vic.gov.au