
COVID + Learning Network Webinar Questions

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Care after the wave: Caring for patients with long COVID

Questions and Answers

Q1: If you're trying to set up a clinic/service is there a place you can go to find the evidence for long COVID?

A: There are some websites where you can look at reviews, but they are not necessarily peer reviewed and can be a bit selective. One of the big issues with the evidence base is that most of the studies are descriptive so there are no matched controls which does impact on the quality but unfortunately there is not a one-stop-shop that you can go to for research. SCV will explore opportunities to enable evidence to be readily available in one location.

Q2: Does long COVID have any similarities to chronic fatigue brought on by GB virus?

A: The mechanism is not well known at this stage, but strategies for managing chronic pain and fatigue can be useful for patients who are experiencing those symptoms. It has been reported that in some patients with post COVID fatigue, exercise and physical activity can exacerbate symptoms, similar to ME/CFS, so assessment of post-exertional symptom exacerbation may be important.

Q3: Has there been any work done on a standardised battery of outcome measures being used in long term clinics?

A: We developed our battery of questionnaires based on symptoms and what we saw/heard from patients. There are a variety of questionnaires out there and there have been quite a few developed overseas but it is important to capture all those symptoms and do it in a very systematic way. There is also the COMET initiative which is trying to establish a core outcome set. See [here](#). Most of the outcomes are pre-existing and haven't necessarily been co-produced with people who have had COVID.

Q4: I was concerned when you (Angela) mentioned you were breathless. Where you at any time given access to a pulse oximeter to monitor your saturation in hotel quarantine?

A: No, we had nurses visit us every morning and they would measure our HR, RR, pulse and oxygen saturation levels but that was the extent of it. I could always call the nurses if I needed them. I had a physiotherapist call me who noticed I was struggling to breathe and finish a conversation. They wrote me a script and gave me Ventolin which was the first time I've ever had Ventolin. After quarantine, my GP referred me to a respiratory clinic and organised a chest x-ray.

Q5: What's the average age of people in your clinic?

A: The mean age of those being followed by the Alfred Clinic is 49 years (23-77) with 48% being male.