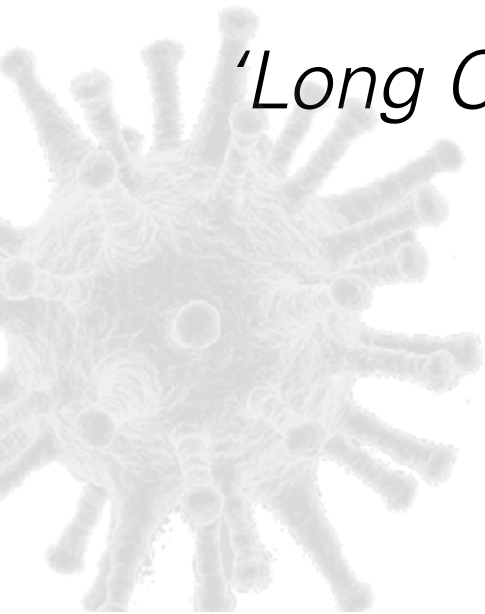


Long Covid Nurse Group Meeting

SUMMARY

'Long Covid research development projects'

Thursday 25 May 2023
12.30pm - 2pm, via Zoom



1. Welcome and Introductions

Helen Donovan, QN, Long Covid Programme Lead, The QNI, @HelenDon_RN

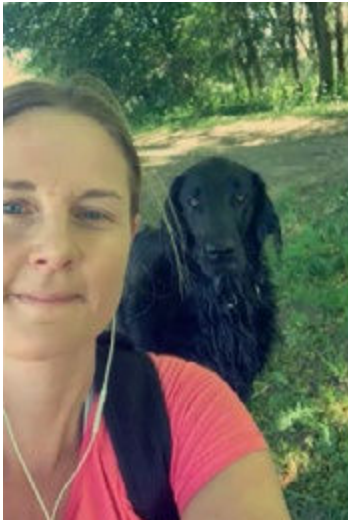
- Welcome everybody to this meeting.
- According to Office for National Statistics (ONS): an estimated 2.0 million people living in private households in the UK - 3.1% of the population - are living with Long Covid.
- The Long Covid Nurse Group (LCNG) is a community of practice for nurses in the community to improve care and increase understanding about the physical, mental and emotional effects of Long Covid.
- The network was created in 2021 commissioned by NHS England and offers an online network of nursing colleagues; bimonthly meetings with expert speakers; regular newsletters; dedicated pages on the QNI website; Long Covid resources.
- Contact me at helen.donovan@qni.org.uk
- To find out more or join the network, go to: <https://qni.org.uk/nursing-in-the-community/long-covid-nurse-group/> or scan the QR code below:



2. Long Covid - Expert by Experience

Expert by experience Kerry Davies

- I have been a nurse for 20 years and I have lived with Long Covid for 3 years.
- A film was created of my experience by Lesley Goodburn.
- It was made at that time, because after 20 minutes of talking, I ended up with slurred speech so the video of me can be used for educational purposes. It tries to get across 3 years of my journey.



- I used to be very fit, I'd run 3 times a week, I was very busy.
- I have two wonderful teenagers and a very supportive husband, I couldn't have gone through this without him.
- I got Covid very mildly, the infection lasted 2 weeks, brain fog was mild, I got a temperature and headaches but not badly and went back to work and seemed fine.

- 6 weeks later the symptoms came back, and I also started with new ones : shortness of breath, rashes, headaches, strange neuropathic pains, joint pains, strange sensations in the left side my head, low oxygen saturation, heat intolerance, rashes after food, temperature,

strange bruising started to appear, muscles twitching, tinnitus. They would go after an hour and then come back.

- The most debilitating symptoms started to appear: I started to not be able to speak properly, I'd suddenly start slurring words, using nonsense words, getting stuck on words, stammering.



2. Long Covid - Expert by Experience

Expert by experience Kerry Davies

- I called 111 as I thought I might have experienced a stroke or a brain injury. They sent me to A&E and I was referred to neurology. The speech and language expert said I needed to rest before and after every single activity and I had to pace my life from now on: I had no idea what pacing meant, I had lived a very busy life! But now I had to rest before I had a conversation, and then after the conversation. I came off social media, I couldn't watch much TV, everything was an activity: chopping a carrot, having a shower.
- I saw tiny improvements over 2 or 3 months, it was ridiculously slow.
- In October 2020 I was referred to my occupational health consultant, he understood and was empathic and not just for 5 minutes.
- In January 2021 I was assessed by a professor of clinical linguistics and she is studying, cognitive linguistic difficulties in Long Covid and to have a professional listening to you and validating what you're going through - you can't be fixed - but it makes you more comfortable in terms of being heard.
- About brain fog and fatigue: people think I'm just tired, but it's debilitating! I don't function. For example, I've been talking for 13 minutes now, I'm slowing down, words are coming out harder, what I'm feeling is drunk or concussed. People going through this need support. I hope my experience helps others.
- Just because you have a normal MRI, or normal bloods, doesn't mean something's not wrong: symptoms are far more complex.
- I have 4 wishes: more investment, more research, more treatment options, more support.

2. Long Covid - Expert by Experience

Expert by experience Kerry Davies

COMMENTS FROM DELEGATES:

- “I have had hyperbaric oxygen treatment and vagus nerve stimulation. I think the vagus nerve stimulation was a game changer.”
- “I am getting my head into the cold water now when I am swimming and it is defo helping with fatigue - feel much more alert afterwards. cold water = stimulation of the vagus nerve. ”
- “We run critical care follow up clinic for patients who had intensive care stay and it is difficult to differentiate whether the symptoms associated with Long COVID is related to this or intensive care stay. It is still unclear where to refer patients to.”
- This is a helpful link:
<https://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-conserving-energy>

3. Long Covid research development projects

Louise Brady RN Primary Care Nursing Lead, NHSE, Nursing Directorate, @louisebrady17

- With a small pot of money, we wanted to make a difference to patients with Long Covid. So we created a group consultation model.
- Groups clinics are an alternative way of consulting with people, delivered in a supportive peer group setting. Usually 6-8 people for online meetings and 10-12 for face to face meetings.
- A consultation brings together a group of people with a similar condition or set of clinical problems.
- It's managed by a facilitator and also has a clinician and administrator present. It generally lasts around 60-90 minutes with the clinical present for around half the meeting.
- We're talking about a lot of patients with complex long term conditions and they can't see their community nurse or their GP because of lack of staff / workforce pressures etc.
- So we know this model isn't for everyone, it's not suitable for complexity for severe mental health problems in Long Covid for example.
- But there are significant impacts, we've seen this in cardiovascular and multi morbidity. It's an important tool in the tool box.
- The unintended consequences have been: retaining nursing staff, it improves the cohesion in the primary care community teams, it promotes new roles. GPs are not viewing Long Covid as mission critical and we need as nurses to create that headspace for patients and families and this is one way we can do it.



3. Long Covid research development projects

Louise Brady RN Primary Care Nursing Lead, NHSE, Nursing Directorate, @louisebrady17

- It creates peer support, makes you feel you're not alone with your symptoms. And we can measure the difference it makes.
- Long Covid will be seen as an established Long Term Condition and group consultations restore relationships which is crucial.
- We saw patient activation measures go up, decrease in blood pressure.

Improved Health outcomes and wait times: Qualitative & Quantitative impacts

Key outcomes so far: Long Covid

- A Nurse & Therapist integrated Group Clinic Model
- 'Covid lives in the Community' Primary & Community teams supporting timely access and outcomes
- (Policy Drivers example: Fuller report 2022)
- 'The group is powerful' Sarah Fowler Respiratory Lead
- VGC is NOT a webinar or group education- unintended consequence of additional peer support to communities living with Long Covid
- The Group clinic creates time & space for deep listening which benefits whole communities.
- VGC can provide high quality clinical intervention that maximises clinician time and reduces waiting lists
- Prior to implementation of Assessment VGC in Nov 30% of patients were seen within 6 weeks.
- Post Video Group clinic implementation 75% seen within 6 weeks.
 - Respiratory VGC – Able to clear 6 month waiting list and keep ongoing wait to 8 weeks. Key

'Smokers welcome'



'Reducing Health Inequalities is about restoring relationships'
Louise Brady 2022

3. Long Covid research development projects ?

Jason Westwood NHS England, Senior Manager, Primary Care Nursing & Next Gen Nurse Programmes, @NHSjwestwood

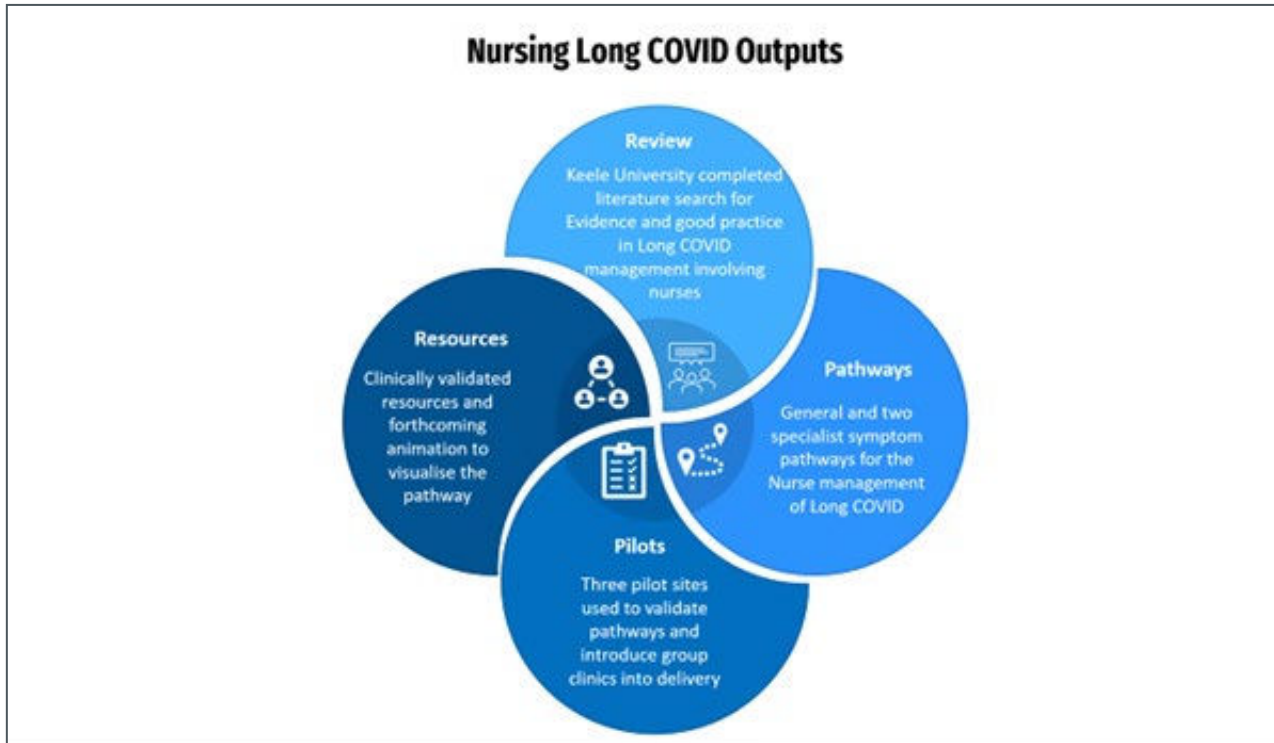
- Main thing we're aware of is that nurses are the primary element of condition management.
- We're about to do a call to action via the RCNi where nurses can help in Long Covid management in the future.
- We wanted to look at delivery pathways, we worked with a GP with clinical expertise who helped support 3 pathways. 3 pilot sites have looked through pathways, then also allowed us to have a look at how functionally they were interacting with community and primary care. We trained them into video consultation.
- Local engagement was very important.



3. Long Covid research development projects ?

Jason Westwood NHS England, Senior Manager, Primary Care Nursing & Next Gen Nurse Programmes, @NHSjwestwood

- We would like the group members on this call and in the network to give input on this, we'll post the pack and you can comment before we publish.



Future meeting dates:

- 18th July 2023, 2.00 – 3.30 pm
– focus on Occupational Health challenges
- 22nd September 2023, 10.00 – 11.30 am
– focus on Women's Health and Menopause
- 23rd November 2023, 1.00 – 2.30 pm
– focus on Community Rehabilitation Alliance Standards

To book your free place on the next meeting, please go to:

<https://qni.org.uk/news-and-events/events/long-covid-nurse-group-meeting/>



Thank you to all delegates who attended today's meeting.

FEEDBACK:

Thanks all really enjoy these meetings and gain from them.

Thanks Kerry, really powerful, moving.

Thank-you so much

Thank you very much for today extremely relevant to me as a community matron.

Thank-you - really useful meeting - so helpful for nurses in more remote regions.

Every day I have been in this job I thank my lucky stars that I do not have long covid I have been overwhelmed by how it has devastated my patients.

Thank you both really look forward to having opportunity to view the pack.

