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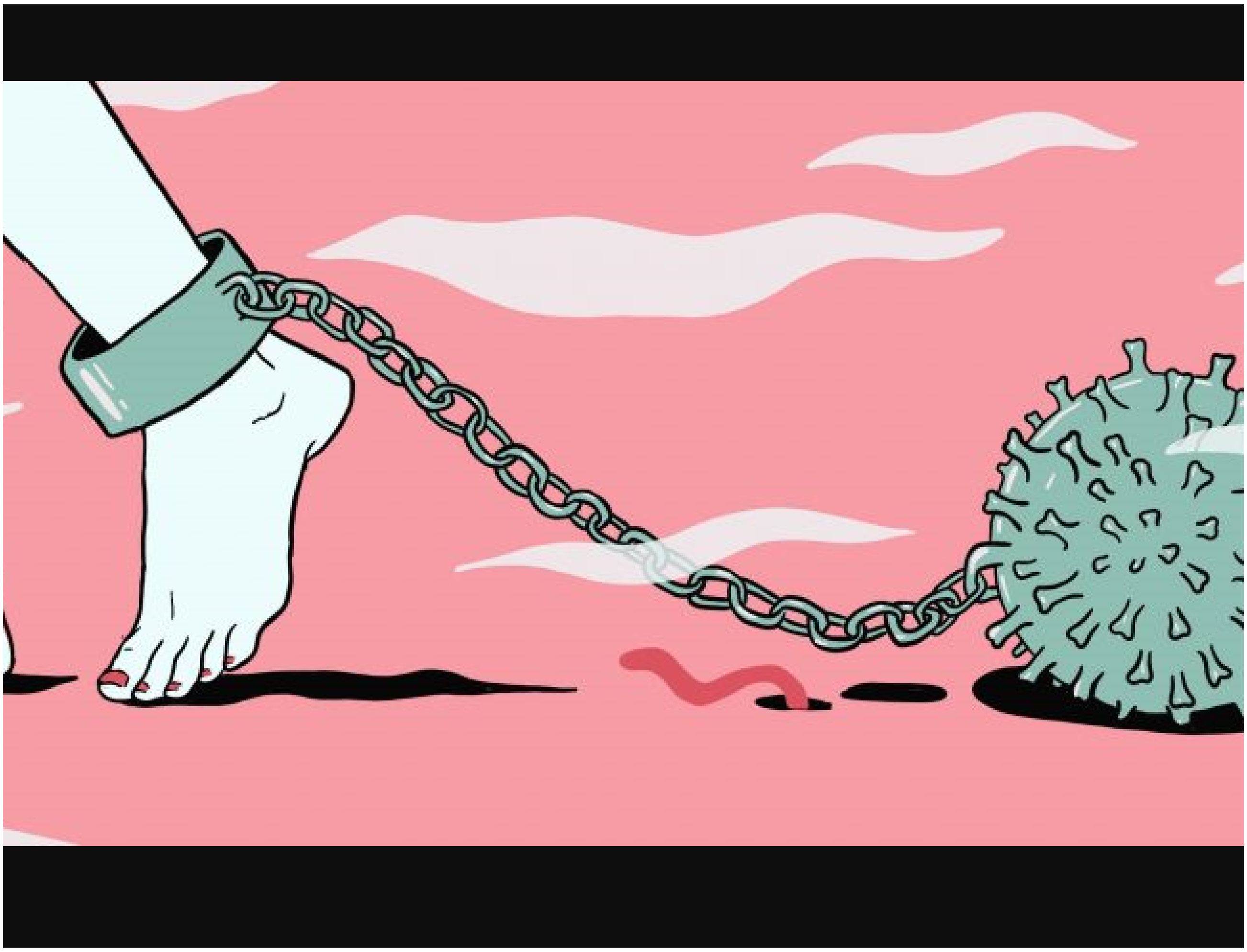

Establishing Long COVID services in Aotearoa NZ – what can we learn from overseas?

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Long COVID (LC) is becoming a substantial issue internationally and many countries are establishing dedicated health services to support people with the condition. In this blog, we discuss what LC services look like overseas and identify key components and considerations for the development of high quality and culturally appropriate LC services in Aotearoa New Zealand (NZ).

The need to establish Long COVID services

Long COVID (described in an earlier blog), is defined as highly variable symptoms in individuals with previous SARS-CoV-2 infection, usually three months from the onset of COVID-19 and lasting for at least two months.[1] The most common symptoms include fatigue, headaches, cough, shortness of breath, anosmia (loss of the sense of smell), sore throat, chest pain and cognitive dysfunction ("brain fog"), and a general decline in everyday functioning.[2] Further up-to-date information on Long COVID (LC) can be read here.

Internationally, the prevalence of LC has been variably reported at 10-30% of people with COVID-19 and higher in those who were acutely hospitalised.[3-6] The number of people with LC in Aotearoa NZ is not known and predictions are difficult due to our unique context to date, our population demographics and high vaccination rates, and the unknowns about the impact of the Omicron variant. As far as we are aware, there are no specific services for people with LC in the country despite growing concerns.[7-10] Therefore, we have explored what public LC services look like overseas and identified key components and considerations for the development of a LC service here.

Findings from overseas

The overall aim of LC services is to provide an integrated, multidisciplinary service with seamless treatment pathways that ensure individualised recovery plans for people with LC. The UK is seen as leading the way for LC initiatives given their nationally funded establishment of 90 LC assessment clinics alongside published NICE guidelines on managing the long-term effects of COVID-19. Several other countries, such as Italy and Canada, have been aligning their initiatives with UK developments.[11-12] The UK system relies heavily on general practice (GP) services to carry out the initial LC assessments, as is the case for other countries.[2,11-14] UK GP practices are able to sign up to a NHS Enhanced service specification. This requires education of staff about the condition, development of pathways for self-management, and local clinical pathways for signposting or referring into appropriate pathways such as the post COVID assessment clinics or other local rehabilitation/support services. Some services have utilised existing infrastructure while others have created new facilities, depending on different local resources.[13,15] However, it is important to note that differences in the set-up of LC clinics in the UK have created significant variation in access and level of assessment provided[16] (which is problematic from a health equity perspective).

The standard process for LC services involves an initial assessment/evaluation done in person, or via telemedicine, and treatment plans are designed based on specific on-going symptoms. Multidisciplinary teams (MDTs) appear to be essential for LC services and the core clinicians involved are respiratory physicians, nurses, physiotherapists, occupational therapists, sports therapists, psychologists, speech and language therapists, dietitians, and social workers. However, other services offer further specialist support from cardiologists, ENT/otorhinolaryngologists, infectious diseases specialists, neurologists, nephrologists, rheumatologists, sleep medicine specialists, psychiatrists, and immunologists.[3,12-13,17-19] Several LC services involve virtual clinics which refer patients directly to existing appropriate services/specialists.[20-21]

Several LC services in Canada[22] and Scotland[23] are led by allied health, and a few regional NHS (UK) Trusts involve a dedicated team of allied health professionals who provide single, but coordinated, treatment plans.[20] Research embedded services (including having research assistants based within the clinics) also exist where patients can participate in LC studies (Austria, US, Canada, and Spain).[11-12,24,27]

To date there is little published evidence on the outcomes of these services. A recent evaluation of the Leeds community LC Rehabilitation Service, treating over 750 adults with LC, revealed significant improvement in various symptoms and overall health-related quality of life. But of concern, a 12-month service evaluation of a specialist LC service in London assessing 1325 patients identified signs of inequitable access to care in their cohort, particularly with ethnic minorities.[25] They also mention that non-hospitalised patients had delayed referral and consideration should be given to proactive follow-up of patients managed in the community.

Potential key components of LC services

Based on our review of international services, along with discussions with several service leads particularly in the UK, we propose the following as key components of any LC service:

- **Education of patients, whānau, and health professionals** regarding LC and up-to-date LC information provided through respected sources (e.g. public website).
- **Referrals:** Services should accept referrals from existing health services (e.g. primary care, hospital services), and a process for self-referrals[26,28-29] would minimise access barriers.
- **Standardised definition:** Nationally agreed LC criteria for providing a diagnosis.
- **An initial assessment:** A standard initial assessment process conducted as much as possible remotely (questionnaires, telehealth etc) by allied health or nursing professionals to identify areas of specific concern for further investigation and needs for ongoing services/support.
- **Self-management support:** An easily accessible way for patients to get information/support for patients with LC related queries/concerns (e.g. help line, online information hub), especially as people wait for further treatment.[30] Translated materials and interpreter services are also necessary.[28,31]
- **MDT:** A dedicated MDT should be responsible for developing care plans following initial assessment and for referring patients to specialist or community services where needed.
- **Patient/peer support:** Mechanisms for enabling people to support each other, and share information has been appreciated overseas.[32-33]
- **Service delivery:** Prioritising remote methods (e.g. telehealth, remote monitoring) for patient assessments and follow up services is beneficial. Culturally appropriate services will be critically important in our context.
- **Measures:** Agreed measures should be adopted to determine patient progress, discharge criteria, and for evaluation of the effectiveness of the LC service.

Further considerations for developing LC services in Aotearoa NZ include:

- Establishing a person and whānau-centred approach for LC service delivery is critical for acknowledging the significant impact and developing an understanding of the needs of individuals with LC and their whānau in NZ.
- Involving those with experience of LC in the design and development of new services is essential and will be particularly important due to our different experience of COVID-19 in Aotearoa NZ. This could even include health workers who have had LC.

- COVID-19 has had a disproportionately negative impact on Māori and Pasifika communities. As little is known about the experience of LC in Māori and Pasifika, proactive engagement with these communities is needed to ensure experiences of LC are accommodated by the service and that support and treatment is prioritised to prevent worsening inequities.
- Multidisciplinary input and engagement are essential, not just within the medical system but across social and community services. This includes clear communication between relevant professionals across all sectors and professions. Lessons may be learned from other recent examples, such as COVID care in the community in Auckland, or cancer care coordinators/navigators across the country.
- Acknowledging the limited evidence for LC treatment options, and the lack of information on the NZ population, on-going research will be important to understand LC better and to continue to refine and improve LC services.[34-35] Embedding research within services will be beneficial for understanding patient experiences, enabling data collection, measuring the effectiveness of services, and providing access to new knowledge to patients and providers.
- Ongoing active collaboration with international LC services and research networks will be important in sharing and adding to the body of knowledge about LC as the COVID-19 pandemic progresses.
- Flexibility in being able to adapt to the changing context of COVID-19, LC and how the NZ population is responding to LC is paramount. Preparation for scale-up/down and involvement of other existing services such as social support services is needed.

Conclusions

Numbers of people with LC around the world are high, but the likely size and scope of the impact of LC in Aotearoa New Zealand is still uncertain. Furthermore, future LC numbers may not be proportionate to our official case numbers of COVID once our borders reopen with kiwis returning from overseas (a proportion of whom will also have LC). While much about the scale and scope of LC services needed in Aotearoa NZ is unclear, it is without a doubt important that research and services are established sooner than later and that these are continuously evaluated and refined to ensure delivery of high quality and culturally appropriate services.

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