

Summary of Tackling Long Covid Westminster Policy Forum webinar on 20th April 2023

LCAI have added notes below to give some insight into the discussion that took place, you will see LCAI below each speaker where our notes are added.

Note: quotes are taken from the transcript, an effort has been made to replace obvious mistakes in the picking up of certain words with the correct word. Efforts have been made to ensure no speaker's statements have been quoted without the necessary context

Attendees and Agenda

Denis Naughten TD, Independent TD for the Roscommon-Galway constituency Long COVID in Ireland - assessing the progress made so far, and developing an integrated and multi-disciplinary approach to the further development of specialist services

LCAI - Denis has been advocating for the Long Covid community for some time, since 2020. Denis flagged that for yrs now long covid patients have reported not being believed by healthcare professionals, and highlighted the lack of any attempt by the government to measure LC prevalence in Ireland

'what's not measured is not managed' - Denis Naughten

In the 4 month period between two polls carried out to measure the prevalence of long covid in Ireland, there was 4% increase in those reporting LC symptoms, this is concerning

Dr Siobhán Ní Bhriain, Consultant Psychiatrist; and National Clinical Director, Integrated Care, HSE Questions and comments from the floor

'we worked on developing the long COVID model of care, which was signed off as an interim model in September 2021'

'So we were keen that it will be an interim model as (it) will need further progression down the road. The aim of the model of care is to provide follow up services and support for those who experienced persistent symptoms of COVID 19. And it sets out a framework for how these services should be - 5 - designed and delivered, spanning general practice community services, the acute hospital setting and mental health services'

LCAI - Dr Ni Bhriain discussed the background of the HSEs response to LC and their interim model of care for LC

Developing the Model of Care - options for ensuring timely access to long COVID services including for children, developing the patient pathway, options for a central hub, and integrating services to provide minimal disruption

Professor Seamus Linnane, Deputy Medical Director and Consultant in Respiratory & General Internal Medicine, Beacon Hospital

'I think (it) does serve as a model for how we support patients who have very disabling symptoms and don't fit in to meet diagnostic labels and categories. And we find that very important going forward. I think this concept of having a shared learning and extrapolating that to a national level'

'And we are struck that this as a cohort tends to challenge existing medical processes in in that the pathophysiology, or the reasons behind their presentations remain poorly understood. And that challenge asks questions of the service that we provide and and is provided, I think nationally, and, and I think does serve as a model for how we support patients who have very disabling symptoms and don't fit in to meet diagnostic labels and categories. And we find that very important going forward'

LCAI - Dr Linnane discussed the approach he and his colleagues are taking at the Beacon private Long Covid clinic

He flagged that their service has had to evolve as they have learnt more about LC from their patients, and that they found regular team meetings to share learnings essential in helping refine their service

Dr Stefano Savinelli, Consultant Physician in Infectious Diseases, St Vincent's Hospital

'And we were able to identify three different clusters of symptoms of muscular skeletal cluster, where there's a prevalence of fatigue and aches and pains mostly as prevalent symptoms, rather than a cardio respiratory cluster, where people would report mostly shortness of breath, palpitations and other cardio respiratory symptoms. And finally, what we call the recovering cluster, where people would mostly complain of fatigue and not any other centres with fatigue and cognition being the main issues there. Now, the question is do Are there different pathogenetic mechanisms behind this different clusters? And this is something that we don't know yet'

' what we actually know is that first of all, long call COVID is not a single entity. And it is not only our experience here and our publication from symptoms clusters, but that has been replicated in

other centres as well. And there is a need for a personalised approach to each patient, each patient is different and needs to be approached in a personalised manner. We need to exclude other medical conditions because not every symptom can be associated with long COVID'

LCAI -Dr Savinelli highlighted that LC prevalence may be as high as 20% and his clinic uses the WHO definition of LC which is symptoms 12 wks post infection. He also mentioned the importance of treating each patient as an individual, as there is no one size fits all approach, and the importance of ruling out other diseases but to also be aware of subjecting the patient to unnecessary investigations

He cautioned about the use of unproven treatments, mentioning ppl travelling to Germany for tests that are do not have scientific justification

Tanja Buwalda, Founder, Long Covid Advocacy Ireland

LCAI - this is a full transcript of Tanja's presentation shared with her permission

Thank you. Good morning. I shouldn't actually be here. I shouldn't have to co found an advocacy group to be a part of the diagnosis and treatment of long COVID. My name is Tanja Buwalda and I'm representing 1000s of others. Like me in Ireland..

(if you) asked a random person on the street who they think gets long COVID. And their answer is likely to be the old, the infirm, the ones with previous health conditions. But they'd be wrong on all accounts, anyone can actually get long COVID. The public health messaging tells us that as long as you're vaccinated and otherwise healthy, you don't actually need to worry about COVID.

But that's not true by getting COVID and letting it currently rip through our society. We're creating new long COVID patients daily, we're seeing the steady uptick in numbers of patients joining the support groups. And we hear the stories of people who cannot understand why they still feel so unwell weeks and months or even years after their initial infection, non COVID severity ranges from people who are still able to work albeit while feeling awful most of the time, to those who are bed bound and completely dependent for care. There's a misconception...

There's a misconception that long COVID is simply a prolonged recovery from an acute event and that everybody eventually recovers. Again, this isn't true. A proportion of patients do require rehab from their ICU stay or have obvious organ damage picked up by standard tests. But it's ironic that these are actually the fortunate ones. There are treatment pathways in place. They're staffed by very experienced multidisciplinary teams, and they will improve but for many long COVID is something else for this group of patients. It's an ongoing fluctuating active neuro immune illness with a roller coaster of symptoms (that can) change day to day, week to week, month to month, it's a lot in common with other poorly understood viral illnesses. And unfortunately, it's often met with the same stigma and biases.

After (initially mild) infection when a long COVID patient eventually realises what's wrong with them. And remember, there's been no public health campaigns in Ireland to warn and educate people and GPs about the symptoms of long COVID. Then they look for help with their ongoing weird and baffling symptoms. And unfortunately, this as you see on screen is what they're frequently met with.

These are comments from our members of actual comments that were made to them. When visiting medical professionals. Personal favourite for me is you just need CBT because there isn't anything physically wrong with you. Or another doctor said, Oh, a heart rate of 180 BPM walking to the bathroom, that's fine, that's grand.

If it weren't for patients advocating globally since 2020, then we wouldn't actually know what long COVID was, or even have a term for it. But we're still having to advocate and advocate hard, because in many ways, the knowledge is still lacking. Because with this illness, if you do not rest, if you push through, it is likely that you will see a permanent lowering of your baseline level of function. If patients don't know to rest, if their GPs don't know that they should rest or worse suggests the opposite, that they should do a little more each day or work through on their fitness.

Not only are patients not helped while they wait for a Long COVID clinic appointment, they're actually actively harmed, and this to us is not acceptable. Patients were so excited when the HSE announced that they were setting up long COVID clinics in 2021. Many had been ill for over 12 months at that stage, and eagerly hoped help was in sight. It's now 18 long, slow months later. And from what we can gather, the entire model of care in the clinics has been set up with very little input from patients.

We've received a considerable amount of mixed feedback from patients attending these clinics. Now granted, some patients have been seen in a reasonably timely manner. Others are still waiting. It's a bit of an eircode lottery. Some have been seen by clinicians who genuinely are interested in the illness and who want to help. Unfortunately, the opposite has been the situation in some cases as well.

Many have had their illnesses psychologist, many more have been told -we need to wait for the research and have been sent on their way after some basic testing and referred to rehab programmes that often did more harm than good pushing the patient's outside their energy envelope and causing a crash.

Look, we accept there's no magic bullet for long COVID. But there are ways to help the disabling symptoms. There's an urgent need for foster care. We've lobbied politicians until we're blue in the face Dennis, you're one of them. We've had helpful politicians as parliamentary questions to the Minister for Health. And we continue to receive the same cut and paste answer over and over again.

But today we have an opportunity to appeal to the medical decision makers. We need more outside the box thinking clinics by clinicians who have the time and the interest to keep up with the ever evolving research and figure out how to use it now to help us. Interesting research has happened in Ireland but has not been built upon. Back in 2021 The study in St. James commented that it had been so easy to find participants there are literally 1000s willing and desperate to take part in research.

We need help now, not in five or 10 years time, we're not all spontaneously recovering. People are losing their jobs. They're losing their homes and their families due to long COVID. In some cases, they're literally losing the will to live.

So where do we go from here? Firstly, involve patients right from the ground up in the model of care and in the design of clinics. Secondly, inform patients and importantly GPs on how to recognise and manage long COVID and inform the general public about long COVID. Finally, think bigger and much better. We need a health system to proactively try new things and help find the solution. If things don't change, then things don't change and we need our lives back. Thank you

Sarah O'Connell, Lead Representative for the Republic of Ireland, Long Covid Kids

Colin Pidgeon, Lead Representative for Northern Ireland, Long Covid Kids

'(Long Covid Kids charity are) trying to help families as much as possible. But we don't really have much in the way of resources because there's not anywhere to direct people'

'patients and parents tell us that the approach used in Ireland of go to the GP and then to a paediatrician is not working'

'There are 71,000 children, young people with long COVID In the UK, so on population share, that's about 2000 in Northern Ireland. So extrapolate population wise, it's probably about 6000. across across the whole of Ireland, it's quite a large number of children to just abandon to, to an unresponsive service without thinking carefully about what can be available to them'

LCAI:

Colin highlighted the fact that we desperately need services in Northern Ireland and ROI for children with long covid (currently no specialized services for LC for children in either country).

Research carried out by Derby University and Long Covid Kids, which asked parents about their experiences of services in relation to their child's Long Covid, showed that 50% of respondents were using private healthcare or looking for options abroad.

Esther-Mary D'Arcy, Professional Advisor, Irish Society of Chartered Physiotherapists

'obviously the aim for us as a professional organisation is to ensure that that treatment and symptom management and the activity management energy conservation is absolutely standard across the country'

LCAI - wholeheartedly agree, it is essential that any physio treating a patient with confirmed or suspected long covid be aware of PEM and the needs specific to LC patients

Esther-Mary discussed the long covid hub created by ISCP and available through their website which has a great deal of resources to offer LC patients

Esther-Mary referred to the national recruitment crisis in physiotherapy as having an impact on recruiting physiotherapists to fill the posts for the public LC clinics

Developing long COVID research to underpin and accelerate the delivery of effective responses Professor

John Lambert, Consultant in Infectious Diseases, Mater and Rotunda Hospitals; and Full Clinical Professor, UCD School of Medicine

LCAI - Dr Lambert spoke about some of the research done in the Mater in relation to Long Covid and research internationally. He emphasized the importance that the LC model of care reflect the neurological nature of the symptoms. He also warned against following advice to use graded exercise to treat LC.

'So we've known from.. for over two years now that that a certain percentage of people are not well following their COVID infection. They're physically unwell'

'the long term consequences of COVID can be self life limiting, primarily neurological and neuropsychiatric in nature, and the range of 10 to 30% of those original infections, and they can persist for years'

'..a study from PET scans, brain PET scans on patients with long COVID And it shows hypoperfusion defects in the parts of the brain the posterior part of the brain, the nerves

coming out to the brain, the vagus nerve, dysautonomia, which really explains most of the symptoms'

'And even if you look at the.. guidance on best practice, historically, most of the guidance talked about pushing, pushing graded exercise, which was debunked five years ago. So pacing is a critical component and we need to get that message out'

Understanding the impact of long COVID on health and quality of life and taking forward the results of the recent APC Microbiome study

Professor Corinna Sadlier, Consultant in Infectious Diseases, Cork University Hospital Ireland; and Clinical Professor (Honorary), University College Cork

'we know that COVID is clearly a multi system illness SARS, cov, 2 binds to (ACE2) receptors, these are widely distributed throughout the body, so not just the lungs, they're found in the GI tract, the cardiovascular system, the neurological system, and really, this goes some way to explaining the very varied presentations and symptomatology, that we see with acute COVID and in long COVID'

'There is overlap and symptomatology with previously described post viral conditions such as Myalgic Encephalomyelitis /chronic fatigue symptoms, or sorry chronic fatigue syndrome, and studies have reported that up to 50% of long COVID patients meet clinical criteria for CFS and we do see the relapsing remitting nature.'

'We have made progress in terms of identifying potential mechanisms for long COVID, including immune dysregulation, possibly due to partial persistence or reactivation, which Professor Lambert alluded to gut dysbiosis, immune priming or autoimmunity and clotting abnormalities at neurological dysfunction, signaling, particularly in the brainstem and vagal nerve. So clearly, we're dealing with a very complex condition, and which may be due to one or a combination of these mechanisms'

'we also identified abnormalities or differences in terms of microbiome in patients with acute COVID and in patients with persistent COVID symptoms. And we are progressing research in this area with national and international collaborators at really with the hope of further clarifying the mechanism or pathogenesis, that that is driving this condition, and which we would hope to allow us to develop targeted therapeutics at for long COVID'

LCAI -Dr Sadlier spoke in support of the LC patient community and also detailed some of the research she has done in relation to LC

See Dr Sadliers study, Impact of Long Covid on Quality of Life
<https://hrbopenresearch.org/articles/5-31>

Assessing international models of care and clinical approaches to long COVID services and implementing areas of best practice into Ireland's approach

Professor Daniel Altmann, Department of Immunology and Inflammation, Imperial College London

'By by their condition. In the UK, we estimate that as 3.4% of the total working population affected. So just think what that means in terms of, you know, productivity and the economy. And why would we not want to try and grapple with this rather seriously?'

'we do know that we see people gradually getting better, and drifting away from the clinics and drifting away from long COVID groups. We also know that some people who are severely affected really don't get better the long COVID groups are full of people who are two and three years into their long COVID journey'

' I enjoyed reading the HSC in Ireland, interim model of care document we've already spoken about this morning. And yet, I, I look at those documents, and I think but if the aspirations are so laudable, why are we so far off achieving that that level of care and delivery, and why all of the long COVID suffers, and I speak to so dissatisfied and desperate and disgruntled. And..we mustn't forget that long COVID in children is slightly.. less common, but still a very, very big deal, but it's destroying children's lives and their education'

LCAI - Prof Altmann spoke of the importance of ensuring that appropriate level of action is taken by the health service to execute the plans they are making , in relation to long covid, many countries have been good to presenting a care plan, but actually putting it into effect is a different story

Addressing the impact of long COVID on Ireland's workforce - supporting return to employment including for health and care staff, issues for employers, and developing the workforce to effectively deliver long COVID clinics

-Dr Aoife Laffan, Consultant Neurologist, St James's Hospital, Dublin

'Further development of neurological services specific to long COVID will be necessary with recruitment of more staff and allied healthcare professionals with neurology experience. But I..encourage the support of existing neurological, neurological and rehabilitation pathways, particularly the migraine pathway or headache pathway and cognitive pathway, as there are a proportion of patients who, when and if appropriate, could be seen within these pathways, but they will need to be supported'

'Professor Lambert has mentioned that neurological services are needed for long COVID On average, there is one neurologist per 1000 people in Europe. There's one neurologist for 45,000 people in Ireland, and we have varied and very often limited access to allied health care professionals with neurology experience, both inpatients and outpatients, and within the

community, there are more than 23,000 people on a waiting list for neurology clinics. And I think if the need for neurology care for long COVID is now recognised, I'm here to advocate for that. But I also have to advocate for the..more than 800,000 people in this country, who have a neurological condition. And I would hope that this is considered really when we're looking at the model of care and planning and implementing services in the future'

LCAI - Dr Laffan acknowledged she has seen patients who have symptoms consistent with Long Covid following Covid vaccination. It was good to hear this acknowledged.

Phil Ní Sheaghdha, General Secretary, INMO

'we believe that the important next steps are that we accept that this is as recommended by the European institutions and under who in fact, that countries should treat long COVID as an occupational injury, where the criteria has been set out that there are provisions made to protect healthcare workers'

'So the important points for a workforce is that they are protected when they go to work, that the PPE provision is correct, that the employer looks out for them in the event that that doesn't work, and that they become ill, and that they have long term effects. The occupational health systems requires a lot more information, a lot more education, as do the HR functions of the employers, a lot more education that this (long covid) is real'

'They're (healthcare workers with LC) experiencing enormous out of pocket expenses, by seeking their own private in physio, private OT, private rehabilitation. And, in fairness, if they were not healthcare workers, many of them will not be in the situation that they are now'

LCAI - Phil emphasized the dire situation many nurses and healthcare workers find themselves in, having contracted Covid 19 at work, now unable to work due to Long Covid, many feeling forced down the path of early retirement (some in their 30s). She highlighted that it is crucial that plans are made to fairly support these individuals

Mary Connaughton, Director, CIPD Ireland

.'.what it comes down to is how does an employer respond when an employee raises the issue of having long COVID? And how do they manage that absence? And how do they manage that return to work.., I'd know that many employers would be unaware of and the details around long COVID'

'when it is a neurological disease, it is always harder to deal with..business people are not necessarily educated around neurological issues. And yet the symptoms can come across as if

maybe it is anxiety, and there'll be a question over the seriousness of the illness and the symptoms that the person is talking about. And I mean, what we do know is it's very helpful, the earlier the communication starts, so that the employer is aware early on and gets maximum information and maximum opportunity far and, and educate themselves around what the issue is..'

Mary spoke about the challenges to employees with long covid in the private sector, with many employees only having a number of weeks of sick leave provided by an employer, or in some cases, none. She emphasized the need to consider what happens for an employee with long covid from when they first become unwell and have to navigate this process with their employer who likely has little knowledge of long covid and its complexities. She noted that a big problem was the delay in patients finding medical advice and care in a timely manner, without having clear communication from the GP and consultant it can be difficult for the employer to understand what the patient needs. The issue of what accommodations an employer should make for an employee in terms of a phased return to work etc, was also discussed. Mary advised LC patients to speak to their employer early in their illness, and regularly to try to ensure best outcome.