Long Covid Advocacy Ireland (LCAI) Statement

8th November 2024

Dear Health Committee Members,

As it has been some months since we spoke to you in the Dail regarding the obstacles facing Long Covid patients in Ireland, we wish to provide an update on the current situation and provide some feedback concerning the evidence given by the HSE at the Oireachtas.

A. Health Oireachtas April 2024

Long Covid Advocacy Ireland (LCAI) would like to extend our gratitude to the committee for their time and dedication to April's committee hearing on Long Covid. We appreciate the opportunity afforded to us to raise our concerns regarding the challenges facing thousands of Long Covid patients in Ireland.

We also appreciate the Health Service Executive taking the time to attend and provide information regarding Long Covid patient services.

Having reflected on the content of the HSE's evidence, there are several concerns we feel compelled to raise, as they directly impact patient care.

1. Neurological Services, Functional Neurological Disorder & Mental Health Approach

In her opening remarks, Siobhain Ni Bhriain stated that *"17% of patients have a diagnosis of Functional Neurological Disorder or functional symptoms."* (of patients referred to St James Long Covid Neurology department for Long Covid symptoms).

She stated that *"there is only one neurologist trained in functional neurological disorders at the moment and with that special interest in people who have suffered from post-viral symptoms."*

Numerous international Long Covid medical experts and researchers have advised that FND is not an appropriate diagnosis for patients with Long Covid.

'With Long Covid continuing to be a leading cause of disability, it is essential that physicians, researchers, and policymakers follow the science - and the science does not point to functional neurological disorder as a driving factor in this wave of illness. New studies document daily the long-term impacts of an acute coronavirus infection on multiple organ systems in the body, including the central nervous system.'

(Putrino et al, 2024)

We conclude that considering long COVID as FND is inappropriate based on differentiating pathophysiologic mechanisms and distinguishing clinical findings.

(Davenport et al, 2024)

We are deeply concerned that Dr Ni Bhriain's choice to specifically highlight that 17% of patients have received a diagnosis of FND suggests that the HSE is placing greater emphasis than is appropriate on functional symptoms and in doing so will increase the risk that Long Covid patients will be negatively impacted by a misunderstanding of this diagnosis.

Setting aside the question of whether it is appropriate to diagnose FND where Long Covid symptoms are present (we believe it is not); we are aware that many clinicians around the country are unfamiliar with the current understanding of FND, and incorrectly believe it to be a psychosomatic or a psychological issue.

Several Long Covid patients who have been diagnosed with FND have informed us that with this diagnosis on their medical record, they're now finding it even harder than ever to access medical care, obtain help with symptom management for existing Long Covid symptoms and also feel they are dismissed when they raise new health concerns.

We are concerned that this may lead to acute medical issues in patients with Long Covid who also have a FND diagnosis (some of which may even be life-threatening e.g. pericarditis) not being investigated.

Regarding the practice of diagnosing Long Covid patients with FND in Ireland, LCAI has three main concerns.

1. The diagnosis of FND in Long Covid patients is not in line with international experts regarding the condition.
2. There is a risk of patients (with an FND diagnosis as well as Long Covid) not receiving adequate medical care because many clinicians have outdated views on the nature of FND and believe it to be psychological.
3. LCAI has been made aware of patients having been given a diagnosis of FND but not actually informed of this by their neurologist and have only become aware through their GP (the neurologist having written to the GP on the outcome of the appointment). This is extremely concerning.

LCAI's concern about the HSE's approach in initially setting up the clinics was compounded by the HSE's subsequent written response to the Joint Committee on Health regarding the allocation of funding to Post-Acute and Long Covid clinics which highlighted a focus on mental health services:

'The HSE worked with mental health services on each site to ensure that close links were developed with the on-site Liaison Psychiatry services to enable smooth pathways of care between the Long Covid clinics and Mental Health Services for those who needed Psychology and/or Psychiatry input.'

It is of ongoing concern as to why the HSE in its responses to the committee repeatedly highlights and prioritises the activity within the neurological and psychology/psychiatry approach rather than placing the same emphasis on cardiology, respiratory, endocrinology, rheumatology etc. all of which are more prevalent within Long Covid symptom lists.

LCAI calls for the HSE to consider the implications and perceptions of an FND diagnosis for patients with Long Covid considering international recommendations.

2. Medication provision in Long Covid Clinics

At the hearing, the HSE shared that clinics are not prescribing medication to patients without evidence that the medication could benefit them. While LCAI understands there is currently no "silver bullet" cure or treatment for Long Covid, a worrying number of patients report not being afforded the opportunity to try any medications to control symptoms when they attend the public clinics.

Dr Brian Kent:

"An important lesson we learned from the earlier stages of the pandemic is that it is really not in the interests of the people who come to Covid clinics for us to throw medication at them with us having no real evidence that they will be of benefit to them."

While we acknowledge the desire to fully understand the pathomechanisms of Long Covid in the context of prescribing, RCTs (Randomised Control Trials) are not required to support the use of well-established medications in decreasing the symptom burden associated with Long Covid (e.g. melatonin for sleep difficulties, low dose amitriptyline for pain, anti-inflammatories for pain etc.).

Symptom management must be offered in the public Long Covid clinics to improve quality of life and day-to-day functioning.

Many Long Covid patients are being given the opportunity to trial medications to manage their symptoms (and many experience symptom improvements) under the guidance of their GPs, but the clinics are often not willing to do the same. This is bizarre.

A specialised service has been set up at the expense of the taxpayer and a large number of patient reports suggest those clinics are in many cases doing LESS to help patients manage their illness in comparison to what is available to them at the primary care level.

LCAI calls for the development of Long Covid clinical guidelines with PPI to ensure a consistent approach to symptom management across clinics.

3. Recovery rates

During the hearing, the HSE stated that "*the majority of people with symptoms at three months will thankfully have fewer or no symptoms by 12 months. Data from the UK suggests that the number of people who have symptoms at three months will be approximately halved by 12 months, so most people will get better.*"

Given the absence of systematic capturing of data in Long Covid clinics, LCAI is concerned by this claim. We are unable to find the referenced UK study and would welcome a citation.

LCAI and patients at the clinic have also repeatedly been told by HSE clinicians that Long Covid has a 90% recovery rate yet when we have queried where this statistic has come from, we have not received a response. International studies present data to the contrary: A study by Ballouz et al (2023) reported that 22.9% of individuals infected with SARS-CoV-2 did not fully recover by six months. The proportion of individuals who had an infection who reported not having recovered only marginally decreased to 18.5% at 12 months and 17.2% at 24 months after infection. Another study by Tran et al (2022) found 85% of those who had Long Covid symptoms two months after an infection continued to report symptoms one year later.

There also remains the question of the definition of 'recovery.'

In response to Roisin Shortall's Parliamentary Question 32860/24: *'To ask the Minister for Health the agreed definition of recovery in long-Covid and post-acute Covid clinics; how recovery is measured; if recovery means that patients return to their previous baseline health status; the recovery figures by clinic and year; and if he will make a statement on the matter."*

The HSE's response stated: *"No formal definition of recovery has been determined in patients with Long Covid. Data is currently collected on discharges from Long Covid clinics every month, but patients may be discharged for many reasons and therefore this is not an accurate representation of recovery."*

Considering there is no agreed working definition of recovery, what data is being used to substantiate the above recovery statistic claims?

LCAI is concerned that patients who have not recovered and remain unwell (many unwell for over four years now) are being told that they are in the minority and that the majority have recovered. This may leave patients feeling even more isolated; feeling that they are the exception rather than the norm and this may negatively impact their psychological/emotional well-being.

LCAI is also concerned that inflating recovery rates and referencing figures that are not supported by data will minimise the seriousness of the continuing Long Covid crisis in this country.

LCAI recommends that the HSE provide further information or references regarding the statements around recovery rates.

LCAI also recommends the collation of a wider, more comprehensive, and specifically targeted dataset from patients attending Long Covid clinics to allow for improved analysis of symptoms, onward pathways, and recovery rates.

4. Services for Children

At the hearing, Dr Ni Bhriain, when asked what parents should do if the first consultant they see with their child does not know Long Covid, said the GP can be asked to refer to another consultant.

Senator Frances Black: *"What should parents do when they feel that consultants are not really able to diagnose their children properly?"*

Siobhain Ni Bhriain: *"That is a difficult question because we would not want that to happen to people when they attend services. It is important that people engage with their GPs. If they are not happy with the outcome of the consultation with the paediatrician, I would advise them to seek a second one and to go back to their GP."*

We find this statement to be deeply disingenuous. No GP is likely to write a second referral in such circumstances. For example, if the GP believes the child's symptoms to be psychological (many parents when presenting with a child with Long Covid symptoms are indeed told that the child is likely suffering from anxiety for example) and the first consultant agreed with this assessment because they are uninformed on Long Covid, the GP is extremely unlikely to do a second referral.

If a GP were willing to do a second referral, given what we know about the length of wait lists for public consultants, it would be a matter of years from the time the parent first raised concerns about their child to when they might see a second consultant with no guarantee that the second consultant would be any more knowledgeable or experienced.

Dr Ni Bhriain in response to another question said that most consultants should know about post-viral illness, however, she then stated that one or two have a specialist interest area in post-viral conditions. This is a contradiction and one that highlights the inadequacy of the previous suggestion that a referral to a general paediatrician will be sufficient.

It is clear from feedback from parents that the current approach of not providing specialist Long Covid services for children is not workable.

LCAI recommends that the HSE develops paediatric-specific Long Covid services as part of the wider updated Model of Care for Long Covid incorporating PPI.

5. Interim Model of Care review & the FADA study

The interim model of care was established in September 2021, one of our asks at the hearing was an immediate and urgent review of this model of care, which was always supposed to be temporary.

At the hearing, the HSE suggested that they were holding off on carrying out a review of the interim model of care, based on a recommendation from HIQA, until more data had emerged. Specifically, they were awaiting the results of the FADA study (soon to be published).

Dr Ni Bhriain stated:

"HIQA recommended that we wait until more evidence emerges, we will have the FADA report in June which may indicate it is time for a review."

(Note as of 1st Nov, the FADA study has not yet published its results)

Thus, the HSE has not even committed to reviewing the interim model of care (now over 3 years old) even after the FADA study has published its results.

We have received no satisfactory response as to why the interim model of care has not been updated. There has been a great deal of research and an enormous amount of experience accrued by clinicians at home and abroad in managing this illness since 2021.

This should be reflected in an updated version of the model of care so that this knowledge can be applied in caring for patients immediately. Why are we waiting for the results of a small symptom-based Irish study before reviewing the interim model of care?

In July 2023, HIQA in their publication ***'Interventions to Improve Long Covid; A systematic review'***; also advised that a clinical guideline would be useful.

'The development of long-term Covid clinical guidelines would be useful to guide practitioner and patient decisions about appropriate healthcare.'

A clinical guideline, with PPI, would allow the public clinics to apply a standardised approach to patient care (there is currently huge inconsistency in the approach taken by the various clinicians at the different public clinics) and improve the quality of care being received by patients across the board. Yet to date, this suggestion has not been taken on board.

LCAI recommends that the FADA study be published as a matter of urgency so that it does not delay further the development of a new Model of Care for Long Covid.

LCAI recommends that the HSE reviews the Interim Model of Care with PPI and develops an updated model which accounts for three years of additional research and understanding of Long Covid in line with the HIQA recommendations of 2023.

6. Initial first-visit clinic assessments

The HSE (Dr Ciaran Bannan of St James Hospital) stated at the hearing that all patients presenting to Long Covic clinics, regardless of symptoms, will receive a *"comprehensive medical assessment"*, including documenting vital signs such as blood pressure and pulse, and *"further focused investigations, where an ECG, chest x-ray, etc. will be performed."*

He was then asked, *"Would that be for all patients.""* (David Cullinane)

He then responded, *"Yes, that would be for all patients."*

While Dr Bannon was presumably referring specifically to services at St. James Hospital, this statement does not accurately reflect the experience of patients throughout Ireland. LCAI conducted a public survey in May 2024 to better understand the experience of Long Covid patients in Ireland. Of 131 respondents who had accessed a public Long Covid clinic, only 68% reported being given a blood test, 36% an ECG, 28% an x-ray, 27% a pulmonary function test, 15% 24-hour heart monitoring, 7% a CT scan, and 6% an MRI.

LCAI attended the Dáil Éireann hearing to communicate the lived experiences of the Long Covid patient community. It is distressing to hear the patient experience yet again being dismissed.

LCAI calls for the development of Long Covid clinical guidelines with PPI to ensure a consistent approach to symptom management across clinics.

7. Use of the €6.6m annual Budget

At the hearing, Deputy Shortall expressed surprise that with a budget of €6.6 million annually (note that this also funds the post-acute clinics, however many of them have been closed/amalgamated, those that remain are seeing small numbers of patients), the clinics are only operating for a maximum of between 2.5 hours and 5 hrs per week with Limerick only operating a clinic every second week.

Deputy Shortall then asked that after the hearing, the HSE send a breakdown of how the funds were being used. The HSE confirmed that they would indeed forward that information afterwards.

However, when Deputy Shortall received this data, she was dissatisfied with what was provided and submitted a PQ question in August to obtain clarification.

'To ask the Minister for Health to provide a breakdown of the funding provided to Long Covid and post-acute Covid clinics by clinic and year in tabular form and the direct contact hours with Long Covid patients in these clinics.'

The answer from the HSE contained the following.

'Unfortunately, it is not possible to provide you with the information as you have requested it.'

The HSE advised in their response that this inability was because of changes in how they account for the spending of the funds, a change from national to regional reporting.

They also advised.

'The information on the provision of direct patient contact hours for Long Covid patients in the clinics is not collected.'

This response is unsatisfactory. Even if the data (breakdown of fund spending) is not comparable between 2023 to 2024 due to process changes, the data itself should be available.

Overall, following the evidence heard at the hearing and the subsequent communication from the HSE LCAI feels that there is a concerning lack of transparency in how funds allocated to care for Long Covid patients in Ireland are being spent.

We accept the HSE's position that clinicians working at the clinics are putting in hours on behalf of their Long Covid patients outside of clinic hours, however, many clinics have been funded for full-time positions, and it is clear that these clinicians are not engaged full-time in duties related to their Long Covid clinic. For example, Dr Ni Bhriain highlighted the appointment of a Consultant Neurologist to deliver a clinic at St James's Hospital, a role that is listed as 1 WTE in the evidence supplied by the HSE. However, in the same submission, it is indicated that the clinic only operates 9-12 pm on Wednesdays and 1.30-4 pm on Thursdays or less than 0.2 WTE of clinic time based on a 35-hour week. In total, St James's Hospital has an allocated WTE of 10.8 and a corresponding cost of €1.58 million but is currently delivering just 7.6 hours of clinic time each week. St James's is by no means an exception as a review of the evidence would show the same picture of limited clinical hours compared to funded WTE at each of the hospitals. While LCAI of course appreciates that clinic time is just the most visible component of clinical services even a conservative reading of the evidence submitted would question how allocated funds are being expended.

This is important as every time a question is submitted to the Minister for Health regarding the care of Long Covid patients in Ireland, a copy-and-paste reply is received, where the minister references the '€6.6 million' being allocated annually to Long Covid patient care. However, the inability to adequately account for ongoing expenditure calls into question whether funding is being appropriately utilised to deliver the Long Covid services it was allocated for.

Given the amount of negative feedback, LCAI has received from patients including but not limited to:

- Dissatisfaction with service overall.
- Infrequent appointments with consultants,
- Delayed access to support services,
- Being pushed for discharge despite being still unwell or being discharged without their knowledge

There is a concerning lack of transparency regarding the spending of funds. Given the importance of Long Covid services, LCAI wants to ensure that every euro of funding is being appropriately targeted towards maximising the benefit for Long Covid patients.

LCAI recommends that the HSE reviews the Interim Model of Care with PPI and develops an updated model which accounts for three years of additional research and understanding of Long Covid in line with the HIQA recommendations of 2023.

LCAI also recommends that the HSE ensures that data regarding the allocation of future funding is collected in a manner that is consistent and transparent.

B) Current situation for Long Covid patients - Autumn 2024

Over six months on from the Oireachtas hearing, LCAI would like to provide the Committee, the HSE and the Long Covid community with an update on some of the issues currently facing patients. While LCAI has focused on the issues that are currently of greatest concern, there are many, many more problems across all areas, such as social welfare access, access to education for children with Long Covid, issues over accommodations being made by both public and private employers to aid patients in returning to work etc, stigma etc.

FADA Study and the Interim Model of Care

The Interim Long Covid Model of Care was finalised in September 2021, circa 18 months from the onset of the pandemic and at a point when research and knowledge of Long Covid were still in their infancy. The Model of Care has not been reviewed since then. In the intervening 38 months since its publication thousands of research papers, including some internationally acclaimed Irish research, have now been published on Long Covid and a new understanding is rapidly emerging, yet this does not seem to translate to knowledgeable, informed care on the ground in Ireland.

In October 2022, this committee was told that while knowledge around Long Covid was still emerging, clinical guidelines would be developed. In 2023, HIQA recommended that clinical guidelines for Long Covid be developed. LCAI and the HSE presented to this committee in April 2024 and no clinical guidelines had been developed and the Interim Long Covid Model of Care remained unreviewed. In their evidence to the committee, the HSE suggested that the FADA report in June *'may indicate it is time for a review.'* A note on the Interim Long Covid Model of Care indicates that the guidance developed and finalised in 2021 is effective from August 2023 and is due to be reviewed in August 2026. No further 'training' has been provided to GPs and other clinical practitioners on Long Covid since 2021 except for a 2023 article focusing on how to refer to the Long Covid clinics with no further training scheduled for 2025.

The HSE 'Values in Practice' are to:

- Provide care of the highest quality
- Deliver evidence-based best practice
- Listen to the views and opinions of our patients and the people who use our services…

For Long Covid patients in November 2024, that translates to

- a Model of Care that was developed based on then-current but limited knowledge.
- which has not been reviewed in over three years
- which does not therefore consider the evidence-based best practices developed internationally over that period
- which has evidenced flaws and concerns from patients
- which "may" only be reviewed following a delayed study which the HSE themselves have admitted has severe limitations
- and which operates without clinical guidelines.

Clean Air

The Health and Safety Authority (HSA) published a new code of practice for indoor air quality in May 2022. Under this guidance, all workplaces - including schools, healthcare facilities, and public transport - must consistently keep CO_2 levels under 1,000 ppm.

If CO_2 levels cannot be kept under 1,000 ppm through natural or mechanical ventilation, air filters should be used to remove harmful contaminants. Despite this, many of these spaces are not meeting these requirements.

Many parents have reported that CO_2 monitors previously provided to schools by the Department of Education are no longer being used, and air filters purchased by schools or donated by parents are not being turned on or maintained (e.g., cleaning/replacing filters).

Despite the €64 million allocated by the department for minor works grants to improve air quality in schools, [the long, complicated application process, coupled with the lack of awareness and urgency due to failed public health communication] has deterred many schools from applying, with only 46 applications received since 2021.

As a result, personal CO_2 monitors sent in with children show levels two to three times the legal limit set out by the HSA in some instances. Studies have shown that up to 70% of household transmission of Covid-19 begins with children, and classrooms with high CO_2 levels (>2000 ppm) are significantly more likely to report outbreaks.

The new clean air guidance does not seem to be being applied in many public spaces.

Many Long Covid patients feel that they are unable to safely access healthcare with the current situation. Clean Air strategies will help to reduce transmission of Covid thereby reducing future new cases of Long Covid. However, the benefits of Clean Air extend beyond Covid. Reducing the spread of all viral infections is an easy decision in terms of reducing absences due to illness in schools and the workplace. Cleaning the air also reduces allergens and studies show that clean air improves cognitive function in school children.

LCAI welcomed the formation of Clean Air Advocacy Ireland earlier this year, an advocacy organisation dedicated to lobbying for Clean Air strategies in Ireland.

LCAI recommends that the Government raises awareness of and implements the recommendations of the Health and Safety Authority's Code of Practice for Indoor Air Quality and invest in 'clean air' solutions for schools and all other public buildings.

Plan for Winter Surge in cases of Covid and other viruses

In October, Paul Murphy put forward a PQ on behalf of LCAI. He asked the Minister of Health about the plans his department had in place to try and avoid overcrowding in hospitals this winter; and if, he would publicly encourage masking and clean air strategies in medical settings to reduce the spread of infection.

On the 10th of October, LCAI received a response which in summary indicated that the plan was hospital avoidance; to reduce visits to hospitals through vaccination, out-of-hours service availability, injury unit availability etc. and thus avoid the need for emergency room visits and inpatient care.

Whilst LCAI acknowledges these efforts; ensuring that those attending the ERs are only doing so if necessary and not due to lack of other services, there will inevitably be patients who require ER or inpatient care. These numbers will climb quickly during the coming months as Covid-19, RSV, Flu etc. cases rise.

LCAI continues to hear of cases of elderly people being admitted to hospital with minor issues, then catching Covid during their stay and passing away. When cases like this could be prevented or reduced with FFP2 mask-wearing and clean-air strategies, this is grossly irresponsible.

The response did not deal with the very real issue of healthcare-acquired transmission where patients requiring treatment for other health needs are infected with Covid, Flu, RSV, etc. during their time in the hospital. Not only can these preventable infections complicate patients' recoveries, lengthening their stay in hospital, but research also shows significantly higher mortality rates in those who have acquired a Covid infection while in hospital, compared to those in the community. A study by Helanne et al (2023) reported a 30-day mortality rate of 11% among patients who acquired a Covid infection while in hospital during the Omicron wave - despite many having previously been vaccinated. Another study from the Omicron wave reported a fatality rate of 8% among those who acquired a Covid-19 infection while in hospital (Kim et al, 2023).

In 2024, it is well documented in research and publications by the WHO that the predominant mode of SARS-CoV-2 transmission is airborne (e.g., aerosols), rather than droplet or fomite transmission. Disease monitoring and surveillance shows hospital transmission happening frequently, both globally and in Ireland, yet the response did not outline the steps being taken to reduce transmission within hospitals to ensure patients can access services safely.

The response also stated that people *"should not be discouraged from wearing masks."* Many of us at LCAI, as well as Long Covid patients around the country, have been discouraged from wearing masks by healthcare workers and hospital staff, often being painted as 'anxious' for wearing one. We are concerned that the absence of public health messaging supporting mask use is contributing to stigma and urge the HSE to take an active approach in supporting their use.

Another issue is that staff do not have easy access to FFP2 (or higher grade) masks, these masks are extremely effective at reducing Covid spread, but surgical masks are far less so.

LCAI recommends that the Government and the HSE develop and implement an ongoing public awareness campaign that highlights the long-term risks of COVID-19, including Long Covid, and the protections afforded using appropriate mitigation strategies including adequate ventilation, masking, and testing.

Access to vaccine boosters

The HSE must recognise that Long Covid sufferers are often immunocompromised, with many also developing autoimmune conditions. These medically vulnerable patients urgently need access to booster vaccines, and the HSE should ensure an efficient, proactive process for those who wish to receive one.

This winter, Long Covid patients and others who are immunocompromised continue to struggle for the protection and care they deserve. Many prefer the non-mRNA Novavax vaccine yet acquiring it in previous vaccine periods in Ireland has been difficult for vulnerable people.

In late October, the HSE vaccination team contacted many awaiting the Novavax vaccine to advise that it is unavailable in Ireland at present and they could get Pfizer or wait and will be in contact when it is available. The HSE advocates staying up to date with vaccines/boosters. Their response to the PQ regarding the winter surge was highlighted as a first point to encourage the uptake of vaccine boosters. This is their cornerstone for protecting against severe Covid-19, yet they are making it extremely difficult and often impossible for people with Long Covid who are immunocompromised to access appropriate boosters. This leaves so many yet again in a state of limbo, vulnerable to the impact of infection and reluctant to attend hospitals where they are unprotected from infection.

LCAI recommends that the Government ensures that both mRNA-based and protein subunit (Novavax) vaccine boosters are made available to any citizen who wishes to access them.

Severe Long Covid

Long Covid clinics are not willing to hold online appointments (with the Doctors), patients with severe Long Covid who are not able to leave their homes at all or who are unable to travel the distance to the nearest public Long Covid clinic (in some cases 2.5 hours away) have nowhere to find help. (some clinics are offering phone call appointments but only after an initial face-to-face).

The HSE therefore is currently providing no accessible services to some patients with severe Long Covid.

LCAI have been supporting one family affected by very severe Long Covid, the patient has been tube-fed for the last number of months and has been in hospital for the majority of 2024. There are currently no beds dedicated to patients with Long Covid or Myalgic Encephalomyelitis (ME) (this patient has also been diagnosed with post-Covid ME) in Ireland.

In terms of the very severe end of the spectrum of Long Covid, the lack of knowledge is even more apparent, and the implications of this ignorance are devastating.

The patient in question has deteriorated significantly whilst in the hospital due to the lack of knowledge among staff on how to care for someone with severe Long Covid and ME. The

environment is entirely inappropriate with high noise levels etc. having a severely detrimental impact on the ability to rest. This causes a state of continuous PEM (post-exertional malaise). The issue is compounded by nursing practices that are entirely inappropriate for patients with these illnesses and by incorrect approaches to treatment, approaches that are not in line with international expertise on Long Covid and ME and are not evidence-based.

LCAI recommends that the HSE reviews the Interim Model of Care with PPI and develops an updated model of Long Covid clinics service provision which considers the specific needs and challenges facing Long Covid patients.

GP training by ICGP

LCAI are concerned that no training on Long Covid has been provided to GPs since 2021, particularly since thousands of studies have been published in the last three years.

When LCAI first requested information from ICGP on training provided to GPs (specifically requesting information on ALL and ANY training provided since the first reports of Long Covid), they shared a one-page article in the ICGP forum magazine, which outlined how to refer to Long Covid clinics but did not define Long Covid itself, detail symptoms, management etc.

LCAI reached out to the ICGP again in July 2023 and offered to assist with improving awareness and understanding within the GP community and highlighted the expert input patients represented. LCAI was not taken up on our offer. A second article was published in Forum magazine in November 2023.

During the hearing, Dr Ni Bhriain advised.

"The college has produced an evidence-based guide to support the investigation of patients' conditions."

The 2023 article from Forum magazine is what LCAI believe Dr Ni Bhriain is referring to here. We do not believe this is substantial enough to be called 'a guide' or can be referred to as training.

After the hearing, LCAI followed up with the HSE regarding scheduling a GP training webinar and the HSE informed us in June that they had connected with the ICGP and that they had no available slots for hosting a training webinar for the remainder of 2024. It is deeply concerning that Long Covid is so far down the list of priorities in terms of GP training, Patients are often more aware of current research and go to their GPs prepared, yet the HSE does not appear to be keeping abreast of developments or working with patients to improve GP understanding. This lack of collaboration is to the ongoing detriment of public health.

We asked the HSE that they work with the ICGP as a priority, to book a slot for a webinar for early 2025. The response informed us that the HSE department looking after Long Covid *'has no remit over GP training.'* We believe that no matter the HSE's direct remit it is the HSE's responsibility to work with the ICGP to ensure GPs are informed of and aligned to

international best practice as part of the wider Model of Care and Clinical Guidelines, considering the scale and seriousness of the crisis of Long Covid in our country and the enormous impact that lack of GP knowledge on Long Covid continues to have on patients.

We will be requesting that PPI take place in the design of any future webinars and request to see the content in advance. We hope to see that it is in line with current international expertise and research.

LCAI recommends that the HSE reviews the Interim Model of Care with PPI and develops an updated model which accounts for three years of additional research and understanding of Long Covid in line with the HIQA recommendations of 2023.

LCAI also recommends that the HSE works with the ICGP to develop Long Covid-specific training that is inclusive of current research and understanding of Long Covid diagnosis and treatment.

Graded Exercise

LCAI continues to hear from patients that clinicians in the HSE persist in recommending graded exercise as a treatment for Long Covid.

As per a communication from NICE in 2020, GET is not a treatment for Long Covid. Patients should be screened for PEM (post-exertional malaise) and those who suffer from PEM, should not be recommended exercise programmes The World Health Organisation also advises against exercise as a treatment.

Whilst maintaining movement is important, and light exercise that does not trigger PEM (in mild Long Covid patients) is likely to be safe, the potential detrimental effects of attempting to ‘push through’ symptoms cannot be overstated. Long Covid symptoms are not due to deconditioning, yet LCAI continues to hear that some HSE clinicians are still making this claim.

Unfortunately, patients are not aware of the risks of deteriorating from participating in such exercise programmes and understandably accept the advice given by their clinicians. LCAI is extremely disheartened to hear that instead of making progress in terms of clinicians being educated on the dos and don'ts of Long Covid management, we are moving backwards.

LCAI recommends that the HSE reviews the Interim Model of Care with PPI and develops an updated model which accounts for three years of additional research and understanding of Long Covid in line with the HIQA recommendations of 2023.

LCAI recommends that the new Model of Care carefully considers the risks associated with Graded Exercise Therapy and ensures that patients are appropriately assessed and advised as part of any recommendation.

Lack of access to symptom management continues, and patients are forced to access private care

Unfortunately, since, the public Long Covid clinics are largely not prescribing medications to help with symptom management, patients continue to be forced to see consultants privately. Many patients simply cannot afford this. Some are borrowing money to fund these appointments.

A common theme in feedback to us is that those who are being seen at private Long Covid services have improved functioning and quality of life with private services offering more comprehensive investigations and proactive symptom management. This is tantamount to a two-tier healthcare system with patients of the lowest income again suffering the most.

LCAI recognises that there may be several issues effecting the referral process, resulting in some public clinics experiencing fewer referrals of late.

Factors effecting the numbers being referred to public LC clinics may include:

- Patients developing Long Covid in the past two years, since the government began to discourage the use of antigen testing, often do not realise they have Long Covid, because they did not initially identify their original infection as Covid.

  Additionally, GPs are often unaware of the myriads of post-viral symptoms attributed to a Covid infection due to their lack of training and awareness. It is therefore taking even longer (or in some cases not happening at all) for patients to figure out the cause of their symptoms and to seek help from Long Covid services.
- LCAI is frequently told by patients that they have given up on obtaining effective symptom management from public clinics and are now having to access services privately.
- We have been advised by some patients that their GP has refused to make a referral to a public LC clinic.

Therefore, LCAI is concerned that the numbers being referred to clinics do not reflect the current number of people suffering from Long Covid in Ireland.

There is now the potential for an entirely false picture of Long Covid, that it is becoming less of a problem with more recent variants, which are not backed up by research. New variants continue to trigger Long Covid.

LCAI calls for the development of Long Covid clinical guidelines with PPI to ensure a consistent approach to symptom management across clinics.

Data collection at the public Long Covid clinics

During the hearing, LCAI members flagged the concerning lack of data collection at the clinics. This was again highlighted by Deputy Roisin Shortall in the questions she put to the HSE.

LCAI raised their concern regarding the lack of qualitative patient data being collected and measured by the clinics. Deputy Shortall concurred with these concerns. Apart from individual data on patient files, there are no systems in place to capture information on such matters.

- Onward specialist referrals
- Covid Variant
- Number of infections
- Severity and duration of symptoms,
- Treatments offered and outcomes,
- Info re: exacerbation of pre-existing medical conditions
- info re: on-set of new conditions,
- Recovery time from onset of symptoms,
- Reasons for discharging patients e.g. breakdown of self-discharge / clinic discharge/clinic discharge against patients' preference
- Breakdown of direct patient contact hours by clinicians in the clinics

The only data available is quantitative pertaining to budget, staffing, statistics on the number of patients availing of the services, numbers discharged and number on waiting lists.

In addition, there is no agreed working definition of Long Covid recovery and no PPI involvement in the clinics or provision for patient feedback. Reason for discharge is not captured currently and several patients have informed us that they were either strongly encouraged to opt for discharge or had been discharged against their request.

Other patients tell us that they opted for discharge because they felt the clinic was not providing any useful medical care. Discharge data must be collected as LCAI fears that discharge numbers would be used to indicate recovery rates which would lead to incorrect recovery estimates.

Of particular concern is that there is no provision for patient feedback.

LCAI recommends the collation of a wider, more comprehensive, and specifically targeted dataset from patients attending Long Covid clinics to allow for improved analysis of symptoms, onward pathways, and recovery rates.

LCAI also recommends that patient feedback is collated as a matter of urgency including for those discharged and that PPI is included in the development of any future Model of Care.

Continuing issues with providing a truly multi-disciplinary approach due to a lack of clinicians.

The multidisciplinary approach at the public Long Covid clinics relies on the availability to patients of several services: Physiotherapy, Psychology (for mental health support) and Occupational Therapy (in addition to regular ID consultant appointments). Most of the clinics do not have all three support clinicians in place - whether because they have not used funding to create that role or an inability to fill the position.

It is also clear that certain clinicians are overloaded. For example, in St James, LCAI is aware of a large patient list under OT, and there is currently only one OT in place. We would strongly advocate that in cases like this, additional staff are taken on to ensure that patients have timely access to the support services that they need.

There is currently no OT at St Vincent's Hospital as they have been unable to fill the post.

One patient informed us that she had been waiting for Occupational Therapy to be provided by the St Vincent's Hospital clinic for 18 months and when she queried about it she was told that the wait list was long, and she was not sick enough to be seen with priority.

Since there is currently no OT in place in Vincents at the clinic itself, LCAI is unsure of what active wait list this patient has been placed on. If this is a wait list for general OT services that presents a problem as OT appointments for Long Covid patients must be carried out by an OT with knowledge and experience of Long Covid.

LCAI recommends that the staffing profile of Long Covid clinics as part of the wider HSE review of the Interim Model of Care with PPI and develops an updated model which accounts for three years of additional research and understanding of Long Covid in line with the HIQA recommendations of 2023.

Update on SLWP

As the committee is aware, a small cohort of healthcare workers infected during the early part of the pandemic remain chronically ill with Long Covid and depend on the HSE's ***Temporary Scheme of Paid Leave for Public Health Employees unfit for work post Covid-19 infection***. This scheme has received several short-term extensions, the most recent of which was in June 2024. While patients welcomed the further 12-month extension, new, more stringent conditions were applied requiring each individual to attend Occupational Health reviews every three months and provide supporting letters from treating consultants on each occasion. Patients have raised several concerns:

Future Uncertainty

Most importantly, there are concerns as to what will happen in June 2025. On previous occasions, as the scheme neared its expiry, patients have repeatedly faced a cliff edge. Past extensions were granted - often post-expiration of the scheme - only after intense advocacy.

This creates a cycle of patients receiving letters from their employers advising them the scheme will end, requiring visits to GPs and application for sick leave, and then when the scheme is extended or reinstated, necessitating sick leave adjustments and tax credit corrections involving follow-up with the Department of Social Welfare and Revenue. This process is incredibly stressful and exhausting for chronically ill individuals.

Increased Demands of Severely Ill Workers

Healthcare Workers qualifying for this scheme have been seriously unwell for several years with many housebound. The requirement to repeatedly endure long trips for in-person reviews with occupational health doctors often results in significant exhaustion and symptom exacerbation.

Financial Strain

There have been reports of public Long Covid clinics refusing to provide the necessary documentation to any patient under their care. These patients are left with no option but to see consultants privately to meet the requirements of the scheme. The requirement to provide consultant letters every three months therefore presents a significant financial burden.

Inadequate Standard Sick Leave

As previously outlined, the standard sick leave scheme is inadequate to support those affected with Long Covid. It provides full pay for three months, 50% pay for three months and following that, if TRR is granted 37% of pay for a limited period. Many of this cohort have been seriously unwell for over four years. The need for a longer-term scheme which can adequately support these healthcare workers remains.

Those availing of this scheme were infected with Covid-19 at work in the initial stages of the pandemic, pre-vaccination and often with inadequate PPE while much of the country was advised to stay safe at home and all non-essential businesses and services were closed. Their sacrifice was applauded by the government and the public at the time, and they paid an extremely high price for their efforts. We must continue to support them fully.

It should also be recognised that healthcare workers who did not qualify for this scheme but who developed Long Covid also following a workplace-acquired Covid infection have been financially deserted. Similarly, other frontline workers carried and continue to carry a higher burden of exposure risk. Ireland is an outlier among European Countries in terms of recognising Covid-19 as an occupational illness and this should be re-examined as a matter of urgency.

LCAI recommends that a permanent, sustainable support system for healthcare workers affected by Long Covid be established.

Response from the HSE over the suggested Cork Clinic Pilot

Following the Oireachtas hearing, a proposal was issued to the team of CUH Long Covid clinic in Apr '24 and presented to the team by the Clinical Psychologist on behalf of LCAI in May '24. This proposal sought to have Cork pilot a model of best practice whereby PPI would be important to the planning and evaluation of the clinic and its services.

The proposal aimed to improve service provision and harness the collective knowledge and experience of both clinicians working in Long Covid clinics and patients with lived experience of Long Covid. Working collaboratively would better serve those with Long Covid and enable measurement of the work being done which in turn would drive research, clinic procedures and funding streams.

The establishment of a Working Group was recommended to review the current service, highlight current or potential issues and identify any existing gaps in service provision. It was proposed that Cork Long Covid clinic consider piloting this initiative in partnership with LCAI.

After several attempts to get a response from CUH, LCAI was informed that the proposal had been given to the national steering committee for consideration. We sought a response in writing in August '24.

A written reply was finally received on 26/9/24 stating that the LCAI proposal was presented *'to the programme manager and the clinical lead of the National Clinical Programme for Infectious Diseases both in May and Sep'24, who felt efforts to develop national services would be best coordinated centrally by the HSE rather than individual centres. Additionally, it is hoped the HSE Public Health-driven FADA Survey will help better understand and inform Long Covid care and is expected to report in the not-too-distant future. I understand this may be disappointing.'*

After putting so much effort into devising this proposal and consistently offering to provide PPI to help the HSE improve services for Long Covid patients, LCAI found this response again ignores the needs of the patients and is very disappointing.

LCAI recommends that the HSE review the Interim Model of Care with PPI and develops an updated model which accounts for three years of additional research and understanding of Long Covid in line with the HIQA recommendations of 2023.

In Summary

LCAI's mission is to advocate for services and support for Long Covid patients across Ireland. In doing so we engage with Long Covid patients daily and hear their real-life experiences, frustrations, and fears. The engagement we have with Long Covid sufferers and their experience of Long Covid services and clinics is worryingly at odds with the picture presented in the evidence provided by the HSE to the committee. It is LCAI's view that the public Long Covid clinics and wider healthcare services are not fit for purpose and will continue to be so without a detailed review that includes significant PPI.

LCAI is therefore disappointed at the HSE's continuing failure to deliver best practice Long Covid services. To meet the needs of Long Covid patients the HSE must commit to immediately reviewing the Interim Model of Care, developing Clinical Guidelines, and ensuring that GPs are provided with relevant up-to-date information.

LCAI is calling for an urgent review of the Interim Model of Care regardless of the data published by the FADA study.

There continues to be an overwhelming number of issues facing the Long Covid community in Ireland. LCAI hopes to see the next government and the incoming Oireachtas for Health members take a stronger stance on addressing these issues with a greater urgency that reflects the fact that Long Covid continues to represent an ongoing health crisis here in Ireland and worldwide.

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