Seirbhís Leabharlainne 7 Taighde Library & Research Service

Briefing Paper

Long Covid

Definition, incidence and healthcare issues (v.2.0)

Enquiry Nos. 2022/26 and 2023/756

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Abstract

This paper is an updated version of a January 2022 paper looking at Long Covid. It updates some sections based on May 2023 HIQA report on that examined the epidemiology of the condition and consequently set out relevant advice to the Health Service Executive.



Contents

Summary	2
Introduction and research question	3
Definition	3
Incidence / Prevalence	5
The impact of Long Covid on health services	7
Recommended treatment / services	10
Social protection	11
Method	12
Appendix - Impact on individuals	13

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Summary

This Briefing Paper is an updated version of a previous L&RS paper on the topic of Long Covid, provided in January 2022. It is revised chiefly based on the findings of a May 2023 Health Information and Quality Authority (HIQA) report: <u>International Review of the Epidemiology of Long Covid</u>.(hereafter the HIQA Report).

Key points of the current paper are:

- The study of 'Long Covid' continues to be an emerging area. The HIQA report highlights that the condition remains "poorly understood".1
- The World Health Organization defines post Covid condition (commonly known as Long Covid) as: "the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation."²
- Long or Post Covid takes in a wide breadth of symptoms that affect many systems in the body. The HIQA report groups these into ten clusters of symptoms. It highlights that those most at risk are women, older people and those who had a severe acute Covid-19 symptoms.
- The original paper provided estimates for prevalence of Long Covid. This information is now outdated, and the HIQA report provides prevalence estimates based on international literature. However, this section has not been revised based on discussions with the Deputy. The HSE is currently undertaking an Irish study of prevalence in one Public Health area.
- The HSE is implementing an Interim 'Model of Care' for Long-Covid. The HIQA report
 describes this as having 'three pillars' these are based around self-directed, GP / primary
 and specialist care levels. The Minister for Health has stated that a tertiary Neurocognitive
 Clinic in St James's Hospital, Dublin is taking referrals from Long Covid clinics around the
 country.
- The HIQA advice to the HSE, based on the findings of its review of international evidence on the epidemiology of Long Covid, can be summarised as follows:
 - resource multi-disciplinary long COVID services,
 - provide additional resourcing for existing services, given the additional burden associated with the management of those experiencing an exacerbation of their preexisting condition and or new-onset conditions equity of access to services including the geographic distribution of services and access for vulnerable populations; and
 - continue public health advice to minimise risk of infection or reinfection and promotion of the COVID-19 vaccination programme to reduce the severity of COVID-19 cases, and potentially the incidence of long COVID.
- There is no specific social protection payment for people experiencing Long Covid. The European Commission has recommended that Covid-19 (but not Long Covid) be designated as an occupational disease in some circumstances. Sources indicated that consideration of Ireland's position is ongoing at Ministerial level.

¹ Health Information and Quality Authority (HIQA) (2023) <u>International Review of the Epidemiology of long Covid.</u>

² World Health Organization (2021) Fact Sheet – Post Covid Condition. 4 July 2023.

Introduction and research question

This paper is a revised version of a paper prepared in January 2022 which examined issues around the condition known as 'Long Covid'. In particular, it provided a definition of the condition, presents a synopsis of the current literature on the incidence of Long Covid and looked at the steps being taken to support those with Long Covid. It has been updated to reflect the current position based chiefly on the HIQA report <u>International Review of the Epidemiology of Long Covid</u>. (hereafter the HIQA Report). Some additional sources have been used to support this, but a review of all the literature in the area was not undertaken.

It remains the case that evidence around Long Covid is still developing. The HIQA report highlights that the condition remains "poorly understood". The dates of all sources used are stated.

A short section on methods follows the main text of this paper.

Definition

The World Health Organization (WHO) has recognised Long-Covid, which it terms 'post COVID-19 condition'. It first developed a clinical case definition of **post COVID-19 condition** by using a consensus methodology. This version (dated October 2021) was developed by patients, researchers and others, representing all WHO regions. The definition in use as of 4 July 2023 is reproduced in Box 1 below.

Box 1: WHO definition of post Covid-19 condition. July 2023.3

Post COVID-19 Condition, commonly known as long COVID, can affect anyone exposed to SARS-CoV-2, regardless of age or severity of original symptoms.

Definition

It is defined as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.

Symptoms

While common symptoms of long COVID can include fatigue, shortness of breath and cognitive dysfunction over 200 different symptoms have been reported that can have an impact on everyday functioning (see more on this below).

The HIQA report of May 2023 grouped symptoms into categories. The report stated:

"Due to the breadth of symptoms reported across studies, reporting of symptoms was clustered primarily by the bodily system affected in accordance with the approach used in guidelines jointly published by NICE, the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP). These symptom clusters were:

³ World Health Organization (2021) Fact Sheet – Post Covid Condition. 4 July 2023.

- > general
- cardiovascular
- neurological
- respiratory
- > psychological and or psychiatric
- > ear, nose and throat
- musculoskeletal
- gastrointestinal and dermatologic."

A further category was added of 'autonomic nervous system' to capture symptoms reported in the literature around exercise intolerance, sweating and orthostatic intolerance. HIQA expanded on the symptoms under each cluster in the table reproduced below.

Table 1: Clusters of Long Covid Symptoms. HIQA, May 2023.

General	Cardiovascular	Neurologic	Respiratory	Psychologica l/psychiatric	Ear, nose and throat	MSK	Gastrointestina 	Autonomic Nervous System	Dermatologic
Fatigue	Chest tightness	Cognitive impairment	Breathlessne ss	Symptoms of depression	Tinnitus	Joint pain	Abdominal pain	Exercise intolerance	Skin rashes
Fever	Chest pain	Headache	Cough	Symptoms of anxiety	Earache	Muscle pain	Nausea and vomiting	Sweating	Hair loss
Pain	Palpitations	Sleep disturbance	Excess sputum	Symptoms of post- traumatic stress disorder	Sore throat	Mobility impairment	Diarrhoea	Orthostatic intolerance	Conjunctivitis
Muscle weakness	Oedema	Peripheral neuropathy symptoms (pins and needles and numbness)	Oxygen desaturation	Behaviour disorders	Loss of taste and/or smell		Weight loss		
Weakness (if myalgia also listed)	Bleeding	Dizziness	Phlegm		Nasal congestion		Reduced appetite		
Nocturia /incontinence		Delirium (in older populations)	Haemoptysis				Stool problems		
Loss of libido		Visual disturbance					Dysphagia		
		Paraesthesia					Restricted oral intake		
	uladislatal	Sensory overload							

Key: MSK – musculoskeletal.

Note: Symptoms in bold are clustered primarily by bodily system affected in accordance with the approach used in the guidelines jointly published by NICE, SIGN and RCGP. (108)

HIQA highlighted that those most likely to have Long Covid are likely to be women, to be older, and to have been admitted to hospital because of COVID-19.⁴ The Authority also emphasised that it is not known why long COVID occurs.⁵

The WHO European Observatory on Health Systems and Policies, has noted the broader impact arising from the mental and physical health problems of Long Covid:

⁴ https://www.hiqa.ie/hiqa-news-updates/hiqa-highlights-burden-long-covid

⁵ https://www.hiqa.ie/hiqa-news-updates/hiqa-highlights-burden-long-covid

"Long COVID has a serious impact on people's ability to go back to work or have a social life. It affects their mental health and may have significant economic consequences for them, their families and for society."

An Irish study on the impact of Long Covid has also been published, see here. It analysed anonymous responses from 988 people who had covid symptoms for longer than 14 days. The authors reported that "...prolonged, multi-system symptoms which can significantly impact quality of life, affect ability to work and cause significant disability."⁷

In addition to Long Covid, the HIQA report highlighted than an additional impact of Covid-19 may be the exacerbation of existing health conditions, resulting in a greater need for services. The report comments on the implications of this as follows:

"...additional care needs potentially represent a huge burden for the HSE. It is important therefore to ensure that existing services are adequately resourced." (p.16)⁸

This is reflected in its advice to the HSE (see below).

Incidence / Prevalence

NOTE: Though this section is outdated, and the HIQA report provides prevalence estimates based on international literature. However, this section has not been revised based on discussions with the Deputy.

HIQA noted that: Long COVID places a large burden on healthcare services. In studies based on self-reported data, estimates for the prevalence of long COVID in the general population ranged from 15% to 53%.⁹

The HSE is undertaking data collection on its <u>FADA study of Long Covid</u> and in communication with the Library & Research Service a HSE official stated: "Data collection is ongoing, with another round of text invites sent this afternoon. We would anticipate having preliminary results available in quarter 4 this year." (dated 19 June 2023). This survey will assess the prevalence of Long Covid. It is not a national study. It focuses on people who have had Covid-19 and are living in Longford, Westmeath, Laois, Offaly, Kildare, West Wicklow and South Dublin (HSE Public Health Area B).

9 https://www.higa.ie/sites/default/files/2023-05/Long-COVID-Infographic.pdf

⁶ Rajan S, Khunti K, Alwan N, et al.(2021) <u>'In the wake of the pandemic: Preparing for Long COVID'</u> Policy Brief, No. 39. Copenhagen (Denmark): European Observatory on Health Systems and Policies.

⁷ O' Mahony L, Buwalda T, Blair M *et al.* Impact of Long COVID on health and quality of life [version 1; peer review: 2 approved]. *HRB Open Res* 2022, **5**:31 (https://doi.org/10.12688/hrbopenres.13516.1)

⁸ HIQA (2023) as before.

¹⁰ Private email communication from HSE official, 19 June 2023.

In the context of enormous healthcare efforts in treating acute illness and implementing vaccination programmes, Long Covid has been called a "hidden an iceberg of long-term illness"¹¹.

Various studies published by authors around the world give different incidence rates for Long Covid. The incidence reported/estimated seems to be affected by the methods used – for instance – whether the population studies is patients who were in hospital or those who were never admitted to hospital. Some key papers found:

- A HSE Review of Evidence undertaken in 2020 stated:
 - "In a study by Carfi et al among patients who had recovered from COVID-19 at a Rome hospital, 87.4% reported persistence of at least one symptom, most often fatigue, dyspnea [shortness of breath], joint pain, chest pain and cough. According to Greenhalgh et al, approximately 10% of people experience prolonged illness after COVID-19." 12
- A frequently cited number is 10% figure report by the authors Greehalgh et al in their 2020 paper referred to in the HSE quote above. This estimate was based on the UK COVID Symptom Study, in which people enter their ongoing symptoms on a smartphone app. This percentage is lower than that cited in many published observational studies, that look at just people who were admitted to hospital or attending specialist clinics.¹³
- An August 2021 review found:
 - "The incidence of post-COVID syndrome is estimated at 10-35%, while for hospitalized patients it may reach 85%."
- A University of Oxford Study published in September 2021 and using US health records found that:
 - "37% of people had at least one long-COVID symptom diagnosed in the 3-6 month period after COVID-19 infection. The most common symptoms were breathing problems, abdominal symptoms, fatigue, pain and anxiety/depression." ¹⁵

This study was based on those with health records of electronic health records (EHRs) data from 81 million patients including 273,618 COVID-19 survivors. These survivors had sought medical assistance for their symptoms (hence their symptoms were identifiable in their health records).

- A policy paper by the WHO European Observatory on Health Systems and Policies used the 10% figure for longer-term impact, stating¹⁶:
 - "COVID-19 can cause persistent ill-health. Around a quarter of people who have had the virus experience symptoms that continue for at least a month but one in 10

¹² HSE National Health Library and Knowledge Team (2020) What is the latest evidence about the existence of long-COVID or post-COVID and its persistence for COVID-19 survivors? What evidence is currently available on the management of patients who have post viral fatigue syndrome due to COVID-19? https://hselibrary.ie/wp-content/uploads/2021/01/Evidence-Summary-COVID-19-Long-COVID.pdf

¹⁵ Over a third of COVID-19 patients diagnosed with at least one long-COVID symptom | University of Oxford

¹¹ Sivan, M, Rayner, C and Delaney, B (2021) 'Fresh evidence of the scale and scope of long covid - The NHS must reconfigure services to manage enduring multimorbidity following covid-19', BMJ, 1 April 2021; https://www.bmj.com/content/373/bmj.n853

¹³ Greenhalgh T, Knight M, A, Court C, Buxton M, Husain L. Management of post-acute covid-19 in primary care BMJ 2020; 370:m3026 doi:10.1136/bmj.m3026; https://www.bmj.com/content/370/bmj.m3026.long

¹⁴ https://www.sciencedirect.com/science/article/pii/S0188440921000813?via%3Dihub

¹⁶ Rajan S, Khunti K, Alwan N, et al.(2021) 'In the wake of the pandemic: Preparing for Long COVID' Policy Brief, No. 39. Copenhagen (Denmark): <u>European Observatory on Health Systems and Policies</u>.

are still unwell after 12 weeks. This has been described by patient groups as "Long COVID"." [the 12 week mark meets the WHO definition for post-Covid condition].

Given the variation in findings and emerging nature of the evidence, it is worth noting that:

- The lowest estimate for those not hospitalised with acute Covid-19 but experiencing symptoms of Long Covid after a minimum of 12 weeks, appears to be 10%.
- In terms of health service needs, the Greenhalgh study cited above states "many such patients recover spontaneously (if slowly) with holistic support, rest, symptomatic treatment, and gradual increase in activity."
- As 1,145,968 people in Ireland have tested positive for Covid-19 (reported 24 January 2022)¹⁷.
- However, it is widely acknowledged that many people have been infected but not tested and therefore not counted in official statistics, meaning the actual number is higher.
- So, using the official figure of Covid-19 cases and the estimate from the literature, we can estimate the number of people in **Ireland** who have had Covid-19 and who are/who will experience Long Covid **at a minimum of 114,500** (based on case data on 24 January 2022 and rising in proportion to Covid-19 case numbers as infections continue). This is a rough estimate, not supported by any specific Irish data.
- Not all of this group may require health services.
- As Covid-19 case numbers grow, the number of Long Covid cases will also grow, proportionately.

In terms of policy planning, it would be useful to know how severe symptoms are and how long they last. Research for this paper did not specifically seek out this information and there was no substantial information on it identified in the papers that were reviewed.

It may be of interest to note that:

- Long Covid Ireland Facebook page has over 2,500 followers.
- In the UK the Office for National Statistics (ONS) is running regular surveys of the
 population on Covid-19 infection and impacts: See:
 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/6january2022

The impact of Long Covid on health services

NOTE: This section has not substantially revised as though the HIQA study is concerned with the impact on health services, it is not drafted in way that correlates to this question directly.

However the parts of the Report that speak to this heading directly are integrated below along with some information from other sources.

¹⁷ https://www.ecdc.europa.eu/en/cases-2019-ncov-eueea

The HSE has been putting in place an Interim Model of Care for Long Covid. The HIQA Report describes this as having 'three pillars': based around self-directed, GP / primary care and specialist levels care. In more detail, these are:

- 1) "Patient-led rehabilitation and recovery (with an online support and education platform to manage symptoms at home).
- 2) General assessment, support and rehabilitation (supported by General Practice and primary care rehabilitation)
- 3) Specialist assessment, support and rehabilitation (by means of specialist acute hospital clinics supported by primary care health and social care professionals with early discharge back to primary care for ongoing follow-up where appropriate."¹⁸

The extract below, from an Oireachtas Health Committee debate in October 2022, describes how and where these services were to operate. This is set out in the opening statement of a Department of Health official appearing before the Committee. In it she names the sites of **eight post-acute Covid clinics** and **seven long Covid Clinics** and points out that two of these hospitals are running combined post and long-Covid clinics (so counted on both lists). However, it is notable, that there were exchanges later in this debate with regard to the extent to which the model was operational.¹⁹ Recruitment difficulties were cited as the key obstacle to overcome in this area.

Box 2: Extract from contribution of Department of Health official to the Joint Oireachtas Committee on Health, 12th October 2022.²⁰

"The HSE launched its interim model of care for long Covid in September 2021. The model provides a framework for the provision of supports and services for those experiencing prolonged symptoms of Covid-19. The model is being implemented in a phased approach with each hospital group having access to both a post-acute and long-Covid service. This will deliver eight post-acute Covid clinics and six long-Covid clinics around the country.

The following sites have **post-acute Covid clinics**: Mater Misericordiae University Hospital; Connolly Hospital Blanchardstown; St. James's University Hospital; Tallaght University Hospital; Cork University Hospital; University Hospital Limerick; University Hospital Galway; and Letterkenny University Hospital.

Long-Covid clinics are established in Beaumont University Hospital; St. James's University Hospital; St. Vincent's University Hospital; Cork University Hospital; University Hospital Limerick; and Galway University Hospital. Both Tallaght University Hospital and St. James's University Hospital are operating combined post-acute and long-Covid clinics.

Some of these clinics have been established in response to local population needs using existing resources and capacity. The HSE is working closely with each of the hospital sites to expand the existing clinics, where needed, to provide a full range of care. The HSE is also examining how existing services in the community can support those with post-Covid or long-Covid symptoms.

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¹⁸ HIQA (2023) as before.p.174.

¹⁹ Debate, Joint Oireachtas Committee on Health, 22 October 2022.

²⁰ Debate, Joint Oireachtas Committee on Health, 22 October 2022.

The number of people that are affected with acute Covid and long Covid remains unknown, but published reports indicate that approximately 10% to 20% of Covid-19 patients experience lingering symptoms for weeks to months following acute SARS-CoV-2 infection." [emphasis added]

In addition to the above, the Minister for Health has indicated that a clinic at St James' Hospital will act as a tertiary referral centre:

"There is a tertiary Neurocognitive Clinic in St James's Hospital, led by a Consultant Neurologist with background in Neurocognitive Disorders, accepting referrals from Long COVID clinics around the country." ²¹

The original Briefing Paper reproduced text provided by the HSE (received 21 January 2022) detailing the agreed, planned Model of Care for Long Covid at that time – with 14 specific clinics. This is set out in the Box below.

Box 3: HSE communication with L&RS on specific Long Covid care.

Office of the Head of Operations, Community Operations - Primary Care, 21 January 2022.²²

The HSE Plans for Long COVID services to patients:

The HSE has developed an interim Model of Care for Long COVID in September 2021. The aim of this Model of Care is to provide a framework for the design and delivery of services for patients experiencing Long COVID. This Model of Care aims to build on existing service provision, in addition to establishing new services and supports across a number of different health care settings including acute hospitals, general practice and community services. A programme manager and clinic leads representing the areas of neurology, respiratory medicine, infectious disease and rehabilitation have been appointed within the HSE to drive implementation of this Model of Care. This work is being overseen by a National Steering Group.

Most particularly in implementation / progress to date - indicating what services are in place and those that are planned / when they are expected to be in place:

Post-Acute and Long COVID clinics have been developed at hospitals across the country to provide follow up care for patients who are experiencing prolonged signs and symptoms of COVID-19. These clinics have been established to address the presenting local need at individual hospital sites.

Implementation of the Model of Care will focus on the expansion of existing Post-Acute and Long COVID clinics, in addition to the establishment of new clinics as identified within the Model. There will be a total of fourteen clinics and each hospital group will have access to both Post-Acute and Long COVID clinic. The allocation of new and additional resources to these clinics will ensure that all services are operating to the same high standard of care. A variety of disciplines will need to be recruited to support these clinics, therefore it is difficult to provide precise

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²¹ Minister for Health, Stephen Donnelly, TD, PQ response, 5 July 2023. https://www.kildarestreet.com/wrans/?id=2023-07-05a.427&s=%22long+covid%22#g428.q

²² Private communication with L&RS.

timelines for when these clinics will become fully operational. The implementation team is working with hospital sites to identify gaps in current resources and to drive recruitment.

Pathways to and from GPs and community services will evolve once these have been established.

Recommended treatment / services

This section of the paper is comprehensively updated to include the advice given by HIQA to the HSE on how to manage Long Covid.

The advice specifies the evidence the HSE should consider when planning services as set out in the box below. In line with HIQA's finding outlined above that post-Covid-19 acute infection people may get Long Covid or see pre-existing conditions worsen, it considers long-covid specific services as well as recommending the augmentation of certain existing health services. Further, as the best way to avoid Long Covid is to avoid Covid-19, HIQA recommends that public health advice around prevention continues.

Box 4: HIQA advice to the HSE on handling Long Covid.²³

- Considerations when planning healthcare delivery for long COVID should include:
 - resourcing multi-disciplinary long COVID services that treat those experiencing a continuation of acute COVID-19 symptoms and or the onset of new symptoms with expertise and skill sets targeted to the management of the most common symptoms;
 - additional resourcing for existing services, given the additional burden associated with the management of those experiencing an exacerbation of their pre-existing condition and or new-onset conditions equity of access to services including the geographic distribution of services and access for vulnerable populations;
 - the continuation of public health advice to minimise risk of infection or reinfection and promotion of the COVID-19 vaccination programme to reduce the severity of COVID-19 cases, and potentially the incidence of long COVID;
- This systematic review did not identify evidence of the prevalence of long COVID in Ireland. Given this, and the uncertainty regarding the burden of long COVID internationally, further research relevant to the Irish population may help to inform the delivery of healthcare services for those with long COVID in Ireland.

In its conclusion, the HIQA report stated:

"Long COVID is a complex condition potentially involving a wide range of symptoms and which may result in sustained, significant reductions in quality of life and

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²³ HIQA (2023) as before.

functioning in some individuals and a substantial burden on healthcare systems as well as having a broader economic impact. In planning healthcare delivery for this population, a focus on multi-disciplinary holistic care will likely be necessary."²⁴

Parallel to the HIQA advice to the HSE, is the World Health Organization's (WHO) advice to governments (set out below). This was published in December 2022. The advice includes providing / supporting evidence-based rehabilitation. It also encompasses information sharing, assisting patients navigating health systems, and further research to enhance understanding of the condition and its impact.

Box 5: World Health Organization advice to authorities on Long Covid²⁵

In September 2022, WHO/Europe partnered with Long COVID Europe to develop 3 goals – the 3 Rs – jointly calling upon governments and health authorities to focus attention on post COVID-19 condition (long COVID) and those affected by it through greater:

- recognition and knowledge sharing, where all services are adequately equipped, and no
 patient is left alone or having to struggle to navigate a system that is not prepared, or not
 capable of, recognizing this debilitating condition;
- research and reporting through data gathering and reporting of cases, and wellcoordinated research, with full participation of patients needed to advance understanding of the prevalence, causes and costs of long COVID; and
- rehabilitation that is based on evidence and effectiveness, and is safe for both patients and carers.

Further to this the WHO publishes detailed <u>Living Guidance for Clinical Management of COVID-19:</u> <u>Rehabilitation of adults with post COVID-19 condition</u>. This guidance is updated continually.

Social protection

The original paper outlined that the WHO's European Observatory on Health Systems and Policies cited that part of the policy response to Long Covid would include employment rights and sick pay and disability benefits. The paper looked at the issue of Irish social protection payments at the time (January 2022). Covid-specific unemployment and illness benefit schemes have now closed.²⁶ There is no specific social protection payment for people experiencing Long Covid.

There are some ongoing discussions in the area around workers. These are outlined below:

 The European Commission has recommended that Covid-19 (not Long Covid) be designated as an occupational disease in certain circumstances.²⁷ The recognition and compensation of occupational diseases is a national competence, so EU Member States are able to decide whether or how to respond to this.

²⁴ HIQA (2023) as before.p.186.

²⁵ World Health Organization (Europe) <u>Increasing Recognition</u>, <u>Research and Rehabilitation for Post COVID-19 Condition (long COVID)</u>. [accessed 03/07/2023]

²⁶ https://www.citizensinformation.ie/en/social-welfare/covid19-and-social-welfare/

²⁷ https://ec.europa.eu/social/main.jsp?langId=en&catId=89&furtherNews=yes&newsId=10463

- In May 2023 Minister for Social Protection, Heather Humphries, TD, stated that her Department was in discussions with other relevant Ministers and Departments in relation to the possibility of prescribing Covid-19 and/or Long Covid (the PQ response is not definitive) as an occupational disease (under Section 87 of the Social Welfare Consolidation Act 2005).²⁸ This means a disease acquired through the nature of someone's employment. The designation of an illness in this way means that would be able to access the occupational injuries benefit scheme (providing compensation and income support).
- In relation to public healthcare workers and benefits, on 4 July 2023, the Minister for Health stated that a four month extension to the <u>Temporary Scheme of Paid Leave for Employees Unfit for Work Post Covid Infection</u> had been agreed (now to run to the end of October 2023). However, this extension will only apply to those currently in receipt of the paid leave, with no new applications accepted.²⁹

Method

For this revised paper the original paper was reviewed, along with the HIQA report - International Review of the Epidemiology of long Covid. Revisions were made to the original paper in line with the original structure based on the HIQA report. (The strengths and weaknesses of the HIQA review are discussed therein). Where appropriate, a small number of other, more current sources (e.g. Oireachtas debates) were used to make the paper more current and are referenced. However, the literature search (set out below) for the original paper was not repeated and a wide review of further, more up to date sources was not included.

In the research for the original paper a literature search was conducted of relevant sources / websites including: Cochrane Library, WHO general website, HSE, and the WHO European Observatory on Health Systems and Policy. In addition, thorough online searching using generalist (e.g. Google) and specialist search engines (e.g. Google Scholar and SocINDEX) and databases (e.g. Lenus) was undertaken.

²⁸ See: https://www.oireachtas.ie/en/debates/question/2023-05-23/83/

²⁹ https://www.kildarestreet.com/wrans/?id=2023-07-04a.1651&s=%22long+covid%22#g1652.q

Appendix - Impact on individuals

This section has not been updated.

An extract from a HSE Evidence Review on the subject of long covid is presented in Box A below. This describes the impact of long-covid on individuals based on the evidence available (dated May 2021).

Box A: Long-term impact of Covid-19 infection on individuals – early evidence³⁰

COVID-19 can result in prolonged illness and persistent symptoms, even in young adults and persons with no underlying medical conditions who were not hospitalised (Carfi et al., 2020 and WHO, 2020) Evidence continues to emerge and the true nature of long term effects of COVID-19 infection on some individuals is still being studied. In Carfi's study among patients who had recovered from COVID-19 at a Rome hospital, 87.4% reported persistence of at least one symptom, most often fatigue, dyspnoea, joint pain, chest pain and cough. According to Greenhalgh et al., (2020), approximately 10% of people experience prolonged illness after COVID-19.

Breathlessness, chest heaviness, muscle pain, palpitations and fatigue are among the continuing and debilitating symptoms being reported by people with COVID-19 often months after the onset of the disease and after they have been declared recovered (2020). Mardani (2020) states that longer-term complications may include heart failure, neurological disease and lung disease. Symptoms may include fatigue and brain fog, which may be related to cytokines that cross the blood-brain-barrier and affect the brain (Mahase, 2020 and Mardini, 2020); and may be indicative of a post-viral syndrome associated with COVID-19. Insomnia, general myalgia, dermatological manifestations, exercise intolerance, temperature dysregulation and increased anxiety are other common symptoms (Halpin et al., 2020, Mahase, 2020 and Nath 2020).

In a purposive sample of 100 survivors assessed four to eight weeks after discharge from hospital, Halpin et al.,(2020) found that new illness-related fatigue was the most common reported symptom by 72% of participants who had required treatment in an intensive care unit and 60.3% managed in hospital wards without needing ICU care. The next most common symptoms were breathlessness (65.6% in ICU group and 42.6% in ward group) and psychological distress (46.9% in ICU group and 23.5% in ward group). Marshall (2020) and Kemp et al.,(2020) suggest that the virus may injure multiple organs, and although the most severe infections also cause the worst long-term impacts, even mild cases can have life-changing effects notably a lingering malaise similar to chronic fatigue syndrome. Potential long-term effects include damage to the lungs, to the immune system, to the heart, and to the brain, resulting in neurological complications such as delirium, confusion and memory loss (Marshall, 2020).

⁰ Crowley, P. and Hughes, A. (2021),The

³⁰ Crowley, P. and Hughes, A. (2021),The impact of COVID-19 pandemic and the societal restrictions on the health and wellbeing of the population, and on the health service capacity and delivery: A plan for healthcare and population health recovery, Version 2 (May 2021). Dublin: National QI Team, Health Service Executive; see: https://www.hse.ie/eng/about/who/qid/covid-19-qi-learning/qi-resources-to-support-learning-from-covid19/covid-19-pandemic-impact-paper-2021.pdf

Olfactory dysfunction is another lingering symptom with up to 10% of patients reporting persistent loss or distortion of smell or taste eight weeks after symptom onset (Hopkins et al., 2020, Fjaeldstad, 2020 and Vaira et al., 2020). Chary et al., (2020) however, conclude that although olfactory and gustatory dysfunctions related to COVID-19 are frequently reported and prevalent in mild symptomatic forms of the disease, recovery in most cases seems rapid and complete. Carvalho-Schneider et al., (2020) recommend a prolonged medical follow-up of patients with COVID-19 regardless of the severity of initial clinical presentation.

One of the most insidious long-term effects of COVID-19 is its least understood: severe fatigue (Marshall, 2020 and Townsend et al.,2020). Over the past nine months, an increasing number of people have reported crippling exhaustion and malaise after having the virus. Symptoms such as foggy thoughts, breathlessness and exhaustion resemble chronic fatigue syndrome, also known as myalgic encephalomyelitis (CFS/ME); comparisons with CFS/ME are frequent in the literature (Rubin, 2020, Mardini, 2020, Marshall, 2020, Lyons et al., 2020, Mahase, 2020 and Rooney et al., 2020).

Pero et al.,(2020) speculate that psychiatric illness and fatigue may also be a long-term effect of COVID-19, as it was previously for the SARS epidemic. Lyons et al., (2020) also caution about the potential for a significant and persistent negative mental health impact based on previous experience with other pandemics.

Rooney et al.,(2020) conclude that physical function and fitness are impaired following SARS-CoV infection and impairments may persist up to two years' post-infection. However, there are concerns related to the impact of graded exercise therapy for managing post-viral fatigue in patients recovering from COVID-19, with NICE acknowledging that graded exercise therapy may not be appropriate for some patients (Torjesen, 2020). There are no definitive, evidence-based recommendations for the management of post-acute COVID-19as yet. Therefore, patients should be managed pragmatically and symptomatically e.g. antipyretic for fever, breathing techniques for chronic cough, home pulse oximetry for monitoring breathlessness, pulmonary rehabilitation, staged return to exercise (BMJ, 2020). Greengalgh et al.,(2020) state that patients recover spontaneously (if slowly) with holistic support, rest, symptomatic treatment and gradual increase in activity. Indications for specialist assessment include clinical concern along with respiratory, cardiac or neurological symptoms that are new, persistent, or progressive.

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