Examining the long-term impact of acute COVID-19 disease

Findings from the Follow-up After Disease Acquisition (FADA) Survey

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Glossary of medical/scientific terms

Acute COVID-19 infection	An infectious disease caused by the SARS-CoV-2 virus. Many people infected with SARS-CoV-2 have minor, or even no symptoms, but some people with acute COVID-19 infection can become severely unwell, requiring admission to hospital. Acute COVID-19 can cause a variety of symptoms. These often include fatigue, a cough and a fever (temperature of 38°C or higher), but the virus can attack other parts of the body.
Anosmia	Partial or full loss of the sense of smell.
Bias	A systematic error in research, this can happen when a study is being designed, carried out, or interpreted. Bias can lead to inaccurate conclusions being drawn.
Brain fog	A general, non-medical, term that is used to describe a collection of symptoms that includes a loss in mental clarity, difficulty focussing or concentrating, mental fatigue, difficulties finding words, slowness of thought processes.[1]
Cognitive problems	Problems that affect a person's ability to think, to learn new information, to remember information, to plan things, to concentrate, to make decisions.
Confirmed case of COVID-19	Any person who has tested positive for COVID-19, either on polymerase chain reaction (PCR) test or Rapid Antigen Detection Test (RADT).
Eligibility criteria	Requirements that must be met in order for a person to be included in a study.
Epidemiologic study	A study that looks at how a disease or condition is distributed in a population, and the determinants of health and disease.
Functional ability	The World Health Organization defines functional ability as: "having the capabilities that enable all people to be and do what they have reason to value."[2]
Frequency	How common an illness is with reference to the size of the population at risk of the illness, and includes a measure of time.
Heterogeneity of study design	Differences in methods used across studies and study populations may yield differing results because of this variation.
Inference	In this report, the term "inference" refers to the ability of the findings of the FADA survey to be applied to the general population.

Neurological system (neurology)	The brain, the spinal cord, and the nerves around the body. This system sends and transmits messages to and from the brain to the whole body.
Non-response bias	Bias (see above) that occurs because the characteristics of those who respond to a survey are systematically different to the characteristics of those who do not respond.
Population	A group of individuals who are at risk of a particular disease or condition.
Prevalence	Proportion of a population with a disease at a particular point in time.
Purposeful sampling	A strategy whereby researchers decide on certain groups of people that need to be included in a study and choose participants accordingly.
Random sampling	A technique whereby researchers randomly select members of the population to be included in a study.
Representative sample	A subset of the population that is thought to have similar characteristics to the population.
Respiratory system	The organs involved in breathing.
Retrospective cohort study	A type of study that looks backwards over time to explore relationships between different risk factors and certain health outcomes.
SARS-CoV-2 Variant	Like many viruses, the SARS-CoV-2 virus can change and mutate. This can result in a new strain, or variant, of the virus.
Socio-demographic factors	A combination of social, and demographic factors that help define individuals in a group. These include details like race, sex, ethnicity, marital status, employment status, educational attainment, location of residence.
Stratified random sampling	Researchers divide the population into subgroups based on certain characteristics that they share (for the FADA survey, the subgroups were formed based on the likely variant of the notified acute COVID-19 event). Once the population is divided, each subgroup is randomly sampled (see above definition of random sampling).
Syndemic	The health consequences that occur when two or more health conditions are co-present in multiple members of the population.[3]
Weighting	A statistical technique that researchers sometimes use to adjust the results of a survey so that they are a more accurate representation of the target population.

List of abbreviations

AD-LC	After Definition Long COVID
BC	Before COVID-19
BD-LC	Before Definition Long COVID
C19-YRSm	Modified COVID-19 Yorkshire Rehabilitation Scale
CDC	Center for Disease Control and Prevention
CD-LC	Clinically-diagnosed Long COVID
CDM	Chronic disease management
CI	Confidence interval
CIDR	Computerised Infectious Disease Reporting
ED	Emergency Department
EU/EEA	European Union/ European Economic Area
FADA	Follow-up After Disease Acquisition
GP	General Practitioner
GDPR	General Data Protection Regulation
HCP	Healthcare professional
HIQA	Health Information and Quality Authority
HPSC	Health Protection Surveillance Centre
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
ICU	Intensive Care Unit
IMC	Irish Medical Council
IQR	Inter-quartile range

MA	Meta-analysis
MOC	Model of care
MOH	Medical Officer of Health
NA	Not Applicable
NCD	Non-communicable disease
NIAC	National Immunisation Advisory Committee
NICE	National Institute for Health and Care Excellence
NPI	Non-pharmacological intervention
PCR	Polymerase Chain Reaction
QOL	Quality of life
RADT	Rapid Antigen Detection Test
RCT	Randomised controlled trial
RCGP	Royal College of General Practitioners
RCPI	Royal College of Physicians of Ireland
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SIGN	Scottish Intercollegiate Guidelines Network
SR	Systematic review
UK	United Kingdom
USA	United States of America
VOC	Variant of concern
WHO	World Health Organization

Executive summary

Why did we do this survey?

Long COVID is a recognised consequence of acute COVID-19 infection and, while the Public Health Emergency of International Concern has been declared over, Long COVID is estimated to affect 65 million people globally.[13] This multisystem disorder demands increased recognition, a holistic, patient-centred approach to rehabilitation, and continuing research as advocated by the World Health Organization (WHO) and international guidelines. To better understand the landscape of Long COVID in Ireland and inform continuing development of the Health Service Executive's (HSE) Long COVID Interim Model of Care, this study sought to characterise Long COVID, describe symptom type, severity and impact, and assess health service use and need in an Irish community-based sample.

How did we do this survey?

The HSE Follow-up After Disease Acquisition (FADA) study is a retrospective cohort study of a community-based sample residing in HSE Dublin and Midlands health region. Initiated in March 2023, the FADA survey was distributed to a sample of 49,642, this is 42.5% of adults with a confirmed SARS-CoV-2 infection notified to the Medical Officer of Health from March 01, 2020 to January 31, 2022. Prospective participants were selected from the Computerised Infectious Disease Reporting (CIDR) system using stratified random sampling. Invitations with survey links were sent by SMS to those randomly selected individuals, using an electronic survey platform.

The FADA survey asked respondents to self-report whether they thought they, ever or at time of asking, had Long COVID; a prompt was then provided with a detailed Long COVID definition and respondents were asked the same question; finally, respondents were asked if they were diagnosed with Long COVID by a clinician. Further questions explored the sociodemographic, baseline health and acute COVID-19 characteristics of respondents. Two validated research instruments were included in the survey, namely the Modified COVID-19 Yorkshire Rehabilitation Scale (C19-YRSm) and the EQ-5D-5L quality-of-life Scale.

This report focuses on key outcomes from the FADA survey: reported Long COVID; current health status of those who reported Long COVID; symptom type, severity and impact; and health service utilisation and perceived need. Summary statistics are presented and then profiled by respondent-reported sociodemographics, baseline health and lifestyle factors, vaccination status, and the number and severity of acute COVID-19 events.

What did respondents tell us about their experience of Long COVID?

There were 4,671 valid responses, equating to a response rate of 9.6%. Of these, 2,338 (50.1%) reported ever having Long COVID with 424 (18.1%) of those clinically diagnosed by a doctor.

Long COVID was reported across all age groups, genders, occupations, and prior health statuses. Self-reported Long COVID was more common among females, those in their 40s, healthcare workers and those with multiple baseline chronic illnesses. Those sampled from Wild type and Alpha waves, those with a more severe acute COVID-19 illness, and those unvaccinated against COVID-19 prior to their first SARS-CoV-2 infection were also more likely to report Long COVID.

At the time of survey completion, of those who reported Long COVID, 41.9% reported self-defined recovery from their Long COVID. Recovery rates varied, with 25% reporting recovery within 60 days, and 75% within 120 days. However, 58.1% were still experiencing Long COVID symptoms at the time of FADA survey completion.

Among those still ill with Long COVID, the five most commonly reported symptoms were fatigue, cognitive issues, joint or muscle pain, sleep disturbances and breathlessness. The C19-YRSm assesses 26 symptoms on a scale from 0-3 (0=none to 3=severe). This yields a symptom severity score for each respondent. Scores range from 0-78, with a higher score indicating greater symptom severity. Almost half (47.7%) of respondents reported a minimum of 15 symptoms, with a median score of 20. More than half reported difficulties with usual activities and communication. Other challenges included walking, socialisation and personal tasks. The impact also extended to employment, with one in ten on sick leave or having changed jobs, left their job or retired from work.

The most commonly reported healthcare services used by respondents were General Practitioners (GPs) and online information. On average, respondents with Long COVID visited GPs 4.25 times due to their condition. Respondents also reported utilising a wide range of other healthcare services. Respondents who reported having had or currently having Long COVID at the time of survey completion were also asked about health services they did not engage with for help with their Long COVID illness but they felt would help them. The most commonly reported service was a GP, followed by telephone support and Public Health or Community Nurse.

Understanding the nature and impact of Long COVID is a vital aspect of shaping healthcare policies and improving patient outcomes. The FADA survey, as the largest population-based study of Long COVID in Ireland to date, provides unique insights into the lived experience, health status and healthcare needs of those impacted by this condition. The findings have practical implications for Long COVID health service planning and public health interventions. The population-based sampling strategy of FADA, including only those with notified/confirmed SARS-CoV-2 events, increases validity. The inclusion of validated research instruments facilitates international comparisons.

Much of the existing literature focusses on survivors of hospital admission. This study's inclusion of community patients adds to the breadth of Long COVID research. However, the relatively low response rate to FADA (9.6%) presents a risk of non-response bias and affects the generalisability of the findings. Selection bias, recall bias and the self-reported nature of the survey might impact the validity of the results.

The results suggest a need for further research into Long COVID in Ireland. This includes the planned integration of FADA key questions into the broader Healthy Ireland survey. This should allow a more reliable estimation of the population prevalence of Long COVID. The findings of the FADA survey also serve as a call to action to comprehensively review the HSE's Interim Model of Care for Long COVID to ensure it aligns with the needs of those living with Long COVID. This study also highlights the importance of controlling SARS-CoV-2 transmission in order to reduce the incidence of Long COVID in the population. It also highlights the need for more comprehensive research to identify and develop an appropriate response to complex multi-system disorders and comorbidities.

In conclusion, the FADA survey provides unique and valuable insights into Long COVID in Ireland, highlighting its complex nature, diverse symptomatology, the significant impact on both health and daily life, and the healthcare service use and needs of people affected. Despite the limitations posed by the relatively low response rate, the findings suggest pathways for health service planning and future approach. The FADA survey emphasises the need to continue to provide patient-centred approaches in addressing Long COVID.

Plain English Summary

Long COVID is a condition that affects millions worldwide. Long COVID means that people are not returning to their usual health, or are getting new health problems, after getting ill with COVID-19.

An Irish survey, called FADA, aimed to improve how well we understand Long COVID. The FADA survey asked almost 50,000 people about their health after COVID-19.

Of the people who replied, about half said they had Long COVID. Long COVID was reported across all age groups, genders, occupations, and prior health statuses. Women in their 40s, healthcare workers and people with many health problems were more likely to have Long COVID. Some felt they had recovered, but many still had symptoms like tiredness, trouble thinking, planning and concentrating, pains in their joints and muscles and problems with sleep. This greatly impacted their daily lives and their work. Most went to their GP for help.

Although the survey had limitations, it does show the importance of understanding Long COVID in Ireland, and the need for more awareness in the HSE so services can be improved for people with Long COVID.

1. Introduction

1. Introduction

1.1 Background to Long COVID

The COVID-19 pandemic, caused by Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), has been dubbed the "biggest crisis of our time".[4] By late 2023 in Ireland, almost 1.8 million confirmed COVID-19 cases, including 9,345 related deaths, had been notified to Regional Departments of Public Health.[5, 6] Although most people with acute COVID-19 recover completely, early in the pandemic it became evident that some faced lingering symptoms while others developed long-term health complications following their acute illness. Through connections forged on social media, it was people experiencing debilitating symptoms, long after the acute phase of their illness had passed, who made visible the enduring and diverse symptoms that persisted after acute COVID-19. A new term, Long COVID, was coined to describe this phenomenon.[7] Today, the term Long COVID is broadly employed to characterise persistent symptoms following acute COVID-19 recovery, devoid of alternative explanations.[8] This term encompasses a wide range of manifestations documented in the literature.[9]

1.1.1 Definitions of Long COVID

There are a number of definitions of Long COVID (Fig 1 below). For the purposes of this process, the WHO, NICE and CDC definitions of Long COVID definitions are drawn upon.[10-12] Of these, the combined NICE, SIGN, RCGP definition was deemed the most sensitive and was the basis for questions aimed at identifying those with Long COVID through responses to the FADA survey.

WHO	CDC	NICE/SIGN/RCGP
Post COVID-19 condition	**Post COVID condition**	**Long COVID**
The continuation of symptoms or the development of new symptoms, 3 months after the initial SARS-Cov-2 infection, with these symptoms lasting for at least 2 months without alternative explanation.	An umbrella term for the wide range of health consequences that can be present four or more weeks after infection with SARS-Cov-2, the infection that causes COVID-19.	Definition includes both ongoing symptomatic COVID-19 (from 4-12 weeks) as well as post-COVID-19 symptoms (12 weeks or more) in the desigation Long COVID.

WHO = World Health Organisation
CDC = Centers for Disease Control and Prevention CDC
NICE = National Institute of Clinical Excellence
SIGN = Scottish Intercollegiate Guidelines Network
RCGP = Royal College of General Practicioners

Figure 1 - International Long COVID definitions

1.1.1 Prevalence of Long COVID

An estimated 65 million people globally are living with Long COVID,[13] however, determining its true prevalence is challenging. A Health Information and Quality Authority (HIQA) evidence-review found wide variance in international prevalence rates (1.8%- 53.1%), attributed to heterogeneity of study design, follow-up duration, and Long COVID definitions.[14] In the UK, Long COVID prevalence is estimated at 2.9% of the population.[15] It is difficult to know how these prevalence estimations translate to the Irish context, as there are currently no Irish *population-based* prevalence estimates for Long COVID.

Long COVID impacts people across gender, age groups, ethnic groups, and baseline health status. Emerging evidence within the literature, suggests that Long COVID may be more common among women, people aged between 36-69 years of age, those working in health or social care and those with a pre-existing health condition.[16] However, with the exception of those with pre-existing health conditions, it is difficult to know if this reflects increased likelihood of SARS-CoV-2 infection in these groups, or if these findings reflect a true increase in susceptibility to Long COVID.[15]

Long COVID has been reported following all severities of acute COVID-19 illness, ranging from asymptomatic to severe.[13] In fact, the majority of Long COVID cases are diagnosed in those who were never hospitalised at the time of their initial SARS-CoV-2 infection, and among those with mild acute COVID-19 illness.[17]

1.1.2 Recovery patterns from acute COVID-19 and symptoms of Long COVID

The typical duration of symptoms for those who develop acute COVID-19 illness is two weeks for those with a mild acute illness, or six weeks for those with more severe illness who required hospitalisation during the acute phase of illness.[18]

However, a proportion of those infected with SARS-CoV-2 experience prolonged symptoms, or develop new symptoms, outside of the expected timeframe.[19]

International guidelines, while varying in Long COVID definitions, generally acknowledge three phases of infection and recovery:

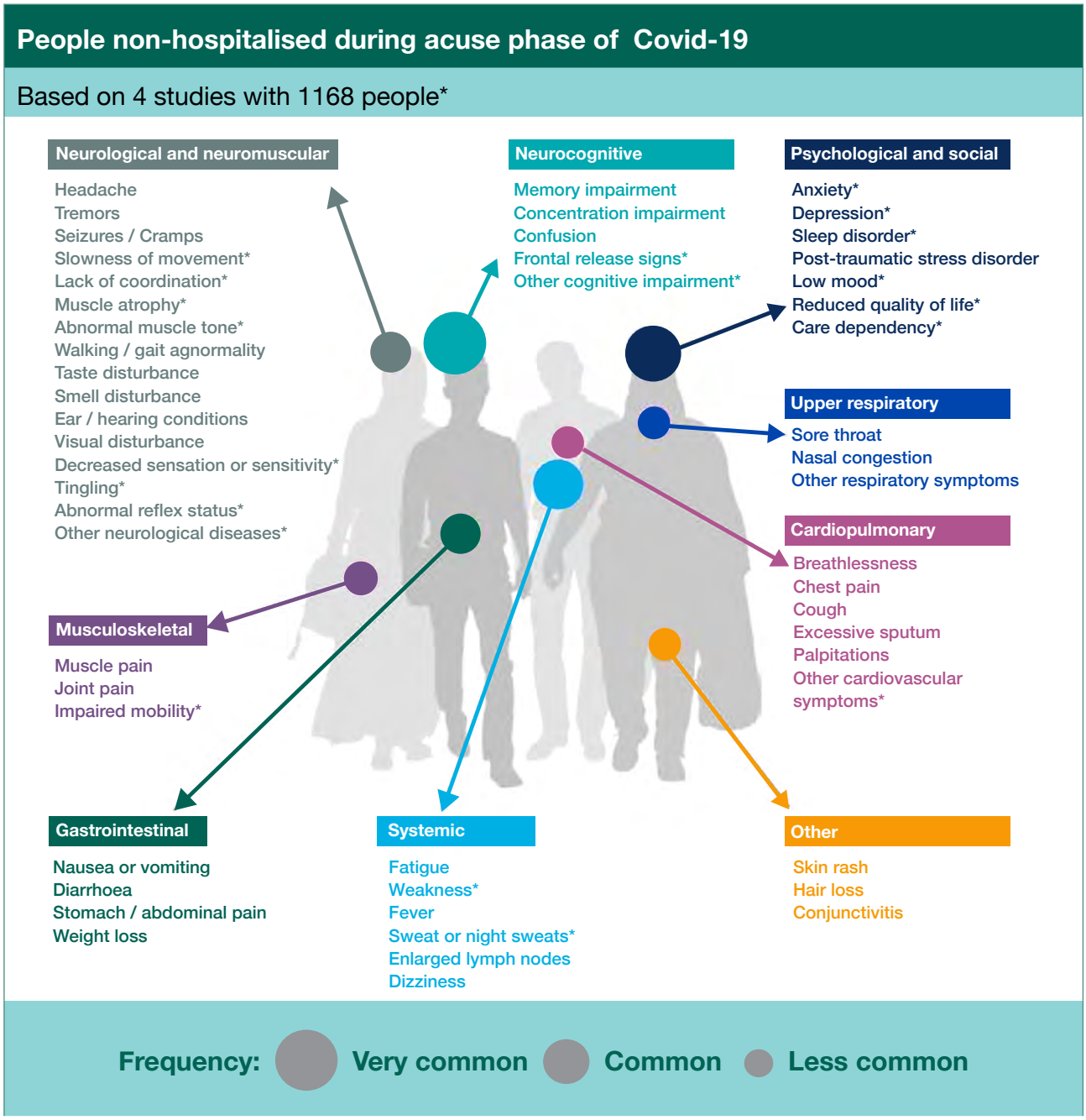
1. Acute infection

2. Post-acute (4-12 weeks)

3. Post COVID (12 weeks and beyond).[20]

Another challenge associated with this complex condition is the diversity of symptoms reported across a variety of organ systems.[9] One study noted involvement of 10 organ systems by a total of 203 symptoms, although the prevalence of individual symptoms varied.[13] Some affected individuals experience continuous symptoms, others a relapsing-remitting or episodic illness, often with different symptoms of fluctuating severity.[21]

Figure 2 - Long COVID symptoms and signs (reproduced from Michelen et al)[22]



Health related outcome measures for Long COVID indicate significantly poorer scores for people experiencing Long COVID than that of the general population.[23] In the UK, a survey of those with Long COVID found many respondents reported negative impacts on general wellbeing (57%), ability to exercise (39%) and ability to work (30%).[24] The same report found 30% of respondents with Long COVID reported experiencing moderate to severe depressive symptoms in the two weeks prior to study participation compared to 16% for those that never had COVID-19. An Irish online survey of those living with Long COVID found a significant adverse impact on functional status with 38% reporting work limitations while 33% reported at least moderate anxiety or depression.[25]

People with Long COVID often report challenges in accessing healthcare professional (HCP) support.[7, 26] A US study on the lived experiences of those with Long COVID found that diagnostic delays and perceived dismissal by healthcare professionals have led to reports of "medical gaslighting."[27] The authors suggest that the heterogenous, fluctuating symptoms of Long COVID make it difficult for healthcare professionals and the general public to understand, which increases the sense of isolation for those affected. Disillusionment with conventional medicine may prompt individuals to turn to self-treatment, or to unregulated treatments with the potential to adversely affect health. Raising awareness is crucial to address Long COVID complexities.[28]

1.2 The Irish Long COVID Model of Care

In September 2021, the HSE launched its Interim Model of Care (MoC) for Long COVID to provide follow-up care and support for patients experiencing persistent symptoms of COVID-19.[29] The MoC provided a framework for how services should be designed and delivered and included GP services, community-based rehabilitation services, and specialist consultant-led clinics.

Many patients experiencing persistent symptoms are managed by GPs through general assessment, advice, education and self-management supports. For some patients however, further assessment and additional supports are required. Several specialised clinics were recommended and developed and included post-acute clinics for patients who were hospitalised with COVID-19 and specialised Long COVID clinics.

Post-acute clinics were established to provide specialist assessment, treatment planning and symptom optimisation for all patients admitted to hospital with acute COVID-19 illness, and for patients in the community, referred by their GP, who are experiencing persistent, concerning respiratory symptoms. Post-acute clinics are led and governed by respiratory consultants.

Specialised Long COVID clinics were also set up to provide specialist assessment and intervention for patients experiencing prolonged, undifferentiated symptoms relating to COVID-19. These are led and governed by infectious disease consultants. The referral criteria include signs and symptoms which develop during or following an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. Of particular relevance are symptoms that are worsening or not improving and are having a

significant impact on psychological well-being and/or causing significant delay to physical recovery and/or limiting the person's ability to return to normal activities. Following a clinically indicated medical work-up and evaluation, patients may be referred for multidisciplinary assessment or for further investigations or specialist input.

The tertiary neurology clinic, located at Saint James's Hospital (SJH), was established to provide further assessment and treatment planning and to optimise the care of patients who are experiencing persistent neurological symptoms associated with their Long COVID illness. Services in this clinic have expanded to include treatment to those with neurological symptoms post COVID-19 vaccine. This clinic is led by and governed by a consultant neurologist. Patients with pre-existing neurological conditions should remain with their primary neurologist.[30] Close collaboration between SJH and other Long COVID sites is essential to ensure a holistic, integrated approach to patient care. GPs may refer patients with suspected neurological symptoms to their local Long COVID clinic to ensure any additional investigations or other treatment needs are met. Referrals that request direct neurology review are triaged by local Long COVID clinics and signposted to the neurology clinic. Criteria for referral from Long COVID clinics to this service are persistent cognitive and/or other neurological symptoms more than 12 weeks following SARS-CoV-2 infection.

In December 2022 HIQA published an international review of clinical guidelines and model of care for Long COVID and found the approaches and recommendations in the Irish Interim Model of Care was broadly consistent with those found in the international literature.[20]

1.3 Report aims and objectives

This report outlines the initial findings from the first population-based survey on Long COVID that was carried out in Ireland to date. The purpose of this report is to investigate the main factors impacting the severity of reported Long COVID in a community-based sample of individuals residing in Ireland and:

1. Estimate the prevalence of Long COVID
2. Describe the symptoms, severity and duration of Long COVID
3. Investigate potential factors that may predispose or protect against Long COVID, including pre-existing health, COVID-19 vaccination status at time of infection and variant on COVID-19 outcomes
4. Describe the healthcare utilisation and preferences of those with ongoing or resolved Long COVID


PERSONAL INFORMATION
First name
Last name
Address
Country
Zip code
City
Phone number
Email address
Male
Female
Other
Date of birth
Month
Day
Year
Cancel
Next

2. Methods

2. Methods

2.1 Study design

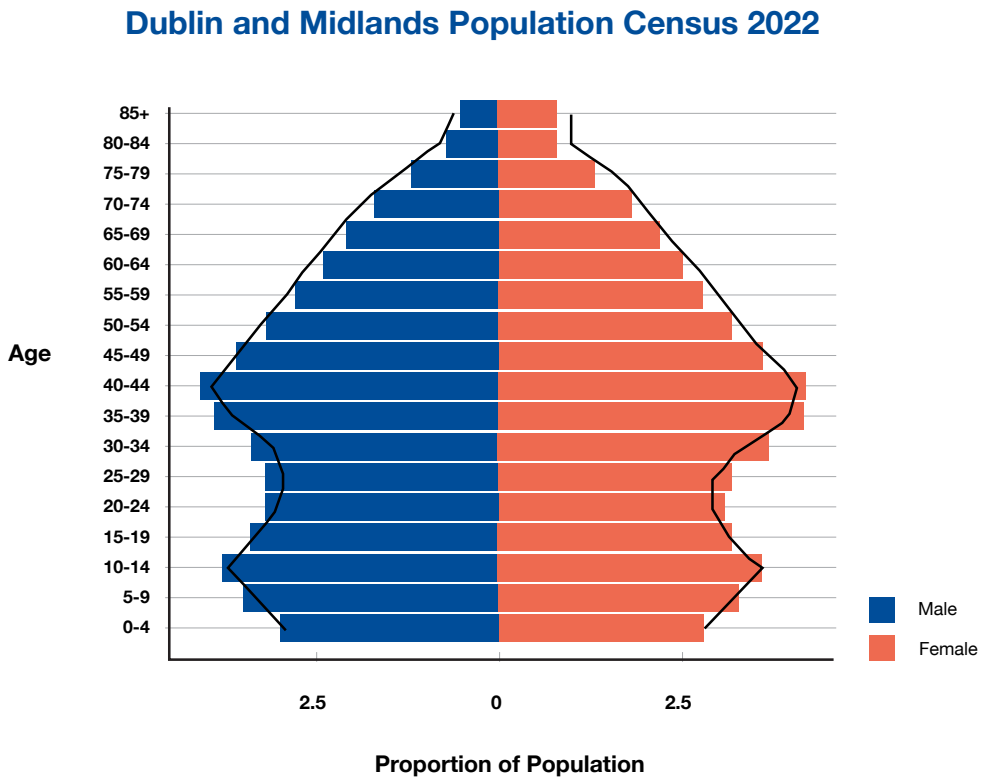
This is a retrospective cohort study (see glossary of medical / scientific terms).

2.2 Study population

The population of interest for this survey was people aged 18 or over, residing in the community, notified to the Department of Public Health - HSE Dublin and Midlands with confirmed SARS-CoV-2 infections between 01/03/2020 and 31/01/2022 inclusive. This HSE region consists of a population of 1,077,639 in counties Kildare, Laois, Offaly, Westmeath and Longford, along with West Wicklow and South Inner City and South-West Dublin (Census 2022) representing 21% of the Irish population (Figure 3).[31] The age, sex structure of the population of this region is very similar to the rest of the country (Figure 4).

Figure 3 - HSE Dublin and Midlands health region

Figure 4 - Gender and age structure of the population of HSE Dublin and Midlands health region compared to the national population structure



During the time period for this study, SARS CoV-2 was circulating in the community and testing was available to the public, although testing availability and strategies evolved over time (see Appendix 1 for a detailed outline). From March 2023, the FADA survey was distributed to a sample of 49,642 adults, randomly selected from the Department of Public Health Computerised Infectious Disease Reporting (CIDR) system. Table 1 summarises eligibility criteria:

Table 1 - FADA survey eligibility criteria

Inclusion criteria	Exclusion Criteria
Confirmed SARS-CoV-2 infection on PCR* or RADT**	Deceased
Notified the Department of Public Health HSE Dublin and Midlands under the Infectious Disease legislation 1982 as amended between 01/03/2020 to 31/01/2022	<18 years of age
≥ 18 years old at time of notified event	Residing in a congregate setting
Residing in the community	International phone number
Valid Irish phone number in the notified database	No or incorrect mobile phone number

*PCR – polymerase chain reaction **RADT – rapid antigen detection test

Children were not included in the study population, as a study of children would require different methodological considerations outside the scope of the current study. In addition, those living in congregate settings were not part of the study population due to difficulties accessing individual phone numbers, as well as concerns that, in certain settings, the risk factors, probable outcomes and viral exposure were likely to differ from that of the general population.

2.3 Study period

The chosen FADA survey period was between 01/03/2020-31/01/2022 because:

- the SARS-CoV-2 virus was known to be widely circulating in the community
- the general population had access to COVID-19 testing with minimum variation in access during the study period.

2.4 Legislative basis and ethical approval

The legislative basis for this work is the Infectious Disease Regulations, 1981 and amendments and the Health Research Regulations, 2018 and amendments.

The Research Ethics Committee in the Royal College of Physicians Ireland (RCPI) provided a favourable ethics review for this study.

2.5 Sampling and sampling frame

Each invited participant had been notified to the Medical Officer of Health (MOH) as a confirmed case of SARS-CoV-2.

To effectively compare the effects of different SARS-CoV-2 variants on Long COVID the sample of the population used was broken into four time periods. These periods represented times when a dominant variant was responsible for the substantial number of notifications of COVID-19 nationally so the time period could be used as a proxy for likely variant with high probability. Participants were selected by stratified, random sampling from each designated pandemic period until and including, 31/01/2022. Variant waves were determined based on data from the Health Protection Surveillance Centre (HPSC), see Appendix 2.

Table 2 describes the number of cases sampled from each period along with the associated dominant variant.

Table 2 - Number of cases sampled per pandemic period

Sample dates	Dominant variant	Total cases	Cases sampled
01/03/2020-25/12/2020	Wild type	15,911	9,814
15/02/2021-31/05/2021	Alpha	9,601	8,434
01/07/2021-30/11/2021	Delta	42,719	16,394
01/01/2022-31/01/2022	Omicron	48,969	15,000
All		**117,200**	**49,642**

For reporting purposes, the probable SARS-CoV-2 variant of the notified SARS-CoV-2 event is the “sampled variant”. In the survey, participants responded to a question reporting the likely timing of the infection that led to their persistent symptoms. The likely SARS-CoV-2 variant was identified based on the onset date of the infection that led to their persistent symptoms. This is known as the “sentinel variant”. Follow-up duration was the difference between the survey completion date and the sentinel onset date.

2.6 Survey platform

An electronic survey platform hosted the survey and prospective respondents were contacted via SMS messaging, a capability integrated to the platform. The HSE retains ownership of data, with access to data permitted only to individuals authorised by the main account holder.

2.7 Development of the questionnaire

Data collected is summarised in Table 3 below. The survey questionnaire is available in Appendix 5, it is colour-coded to reflect the logic of the questions asked to different cohorts within the sample.

Table 3 - Summary of data collected

Type of Information	Relevant Questions
COVID-19 history	Severity Number of SARS-CoV-2 infections Healthcare services engaged for most severe acute COVID-19 infection Vaccination status at first infection
Long COVID definition	Self-reported Long COVID before and after a provided definition (yes, no, or reported as "recovered") Clinically diagnosed Long COVID Onset date of the acute COVID-19 event leading to Long COVID
Assessment of Long COVID symptoms and health related Quality of Life	Two validated research instruments **i.** *Modified COVID-19 Yorkshire Rehabilitation Score* **ii.** *EQ-5D-5L*
Long COVID healthcare utilisation and unmet need	Healthcare services used for Long COVID Unmet healthcare need for those with ongoing and resolved Long COVID
Lifestyle, co-morbidities, socio-demographic factors	Smoking, alcohol consumption, physical activity Occupation Age Education Medical co-morbidities.

2.7.1 Research instruments

The FADA survey included two validated research instruments:

- The Modified COVID-19 Yorkshire Rehabilitation Scale (C19-YRSm)[32]
- The EQ-5D-5L[33]

1 The Modified COVID-19 Yorkshire Rehabilitation Score (C19-YRSm)

This is a validated instrument for assessing Long COVID symptom severity, exploring Long COVID symptoms, requiring the respondent to recall occurrences pre-COVID as well as in the past 7 days. The list of symptoms included is consistent with the more prevalent symptoms identified in the literature review. The questionnaire also addresses functional abilities and prompts self-rating of health over the same periods and occupational impact of Long COVID (See Appendix 2).

2 The EQ-5D-5L

This is an international validated tool which assesses health-related Quality of Life, with questions exploring five dimensions of health including mobility, self-care, usual activities, pain/discomfort and depression/anxiety. It also incorporates a visual analogue scale inviting participants to self-rate their health.

2.7.2 Testing and piloting of the final survey

All questions relating to lifestyle, co-morbidities and sociodemographic factors were taken from pre-existing validated Irish surveys such as the Census and Healthy Ireland.

Several original questions were included and their validity was established through the application of cognitive interviewing, an evidence-based method to investigate whether a survey question achieves its intended purpose.[34] This was conducted by the research team with members of the general public who fit the inclusion criteria for the survey.

The survey was piloted, on a small cohort selected at random from the pre-identified sample population, and questions checked for validity in the context of Long COVID.

2.8 Data collection

Communication to the health system and a national media campaign preceded the launch of the survey. This included newspaper and online articles, a social media campaign and several interviews on national radio and television.

Invitations were sent by SMS to those sampled from the study population with embedded links, using the electronic survey platform. Invitations to participate were sent in phases starting on 23rd March 2023. Participants were sent three SMS messages containing two links. The first SMS alerted the participant they had been selected to complete the survey, the second SMS, sent one hour after the first was received, contained a link to the HSE FADA survey webpage which included the participant information leaflet (PIL) which they were invited to read. The PIL outlined the survey background, purpose, methods, types of questions, consent, ethics review, General Data Protection Regulation (GDPR) and provided both a phone number and email address to contact the research team with any concerns or queries. A third SMS was sent the next day containing a personalised link to the survey itself. The electronic survey was compatible with a PC and a mobile phone. The first five questions were explicit consent questions. The participant was locked out of the survey if they did not

answer in the affirmative to all consent questions. Where no response was received, two reminders were sent.

Simple random sampling, stratified by specific pandemic period, was employed. Random numbers were allocated to potential participants and sorted accordingly. Participants were then selected in ascending order for each specific pandemic period. Data collection concluded on 7th July, 2023.

2.9 Data preparation

Collected responses were meticulously checked for errors and ambiguities. R programming language was used to perform the cleaning and transformation of the survey responses. This included the cleaning of the questions to generate labels for the variables for the dataset and the transformation of the variables to the right datatype based on the nature of the questions.

2.10 Identifying those with Long COVID: prompted and unprompted responses

Self-reported Long COVID was determined based on three questions as follows. Participants were asked: **"Do you think you have, or ever had, Long COVID?"** The response options were:

a. Yes, I still have it
b. Yes, but I have recovered now
c. No

The answer to this question was deemed the unprompted response.

Immediately after this question a definition of Long COVID was provided as follows:

"Long COVID" means your symptoms carry on for 4 weeks or more, even after your COVID-19 infection has cleared. Long COVID can also mean that you are having new health problems after your COVID infection has resolved. Long COVID can cause different problems that change over time. These symptoms have no other explanation and generally have an impact on day-to-day functioning. The most common symptoms of Long COVID are:

- Lung or chest problems – like breathlessness, cough or chest pain
- Fatigue or feeling tired all the time
- Pain – where any part of your body can hurt
- Brain problems – like finding it hard to focus, getting headaches, feeling dizzy or having problems sleeping
- Stomach problems – like feeling pain in your tummy, feeling sick, having diarrhoea or loose or watery poo, having no appetite, losing weight
- Mental health problems – like feeling more depressed or worried than usual
- Skin problems – like unusual rashes
- Ear nose and throat problems – like a change in your sense of taste or smell, earaches, sore throat or ringing in your ears

After reading the information above participants were asked: ***"Do you think you have, or ever had, Long COVID?"*** The response options were:

a. Yes, I still have it
b. Yes, but I have recovered now
c. No

The answer to this question, deemed a prompted response, was also recorded.

Finally, they were asked "***Were you ever diagnosed with Long COVID by a doctor?"*** The response options were *Yes or No*.

This led to the formulation of Long COVID survey case definitions (Table 4). The duration required for case definition fulfilment was based on the WHO[10] and NICE/SIGN/RCGP definitions.[12] The duration requirement led to exclusions (n=19).

Table 4 - Survey case definitions

BD-LC Before definition Long COVID	AD-LC After definition Long COVID	CD-LC Clinically-diagnosed Long COVID
Respondents who answered one of the yes options to the 1st question	Respondents who answered one of the yes options to the 2nd question	Respondents who indicated a clinical diagnosis of Long COVID
Some BD-LC group changed their response to no when they read the definition	This includes all CD-LC participants It also includes some BD-LC participants who answered no before the definition	

2.11 Analysis

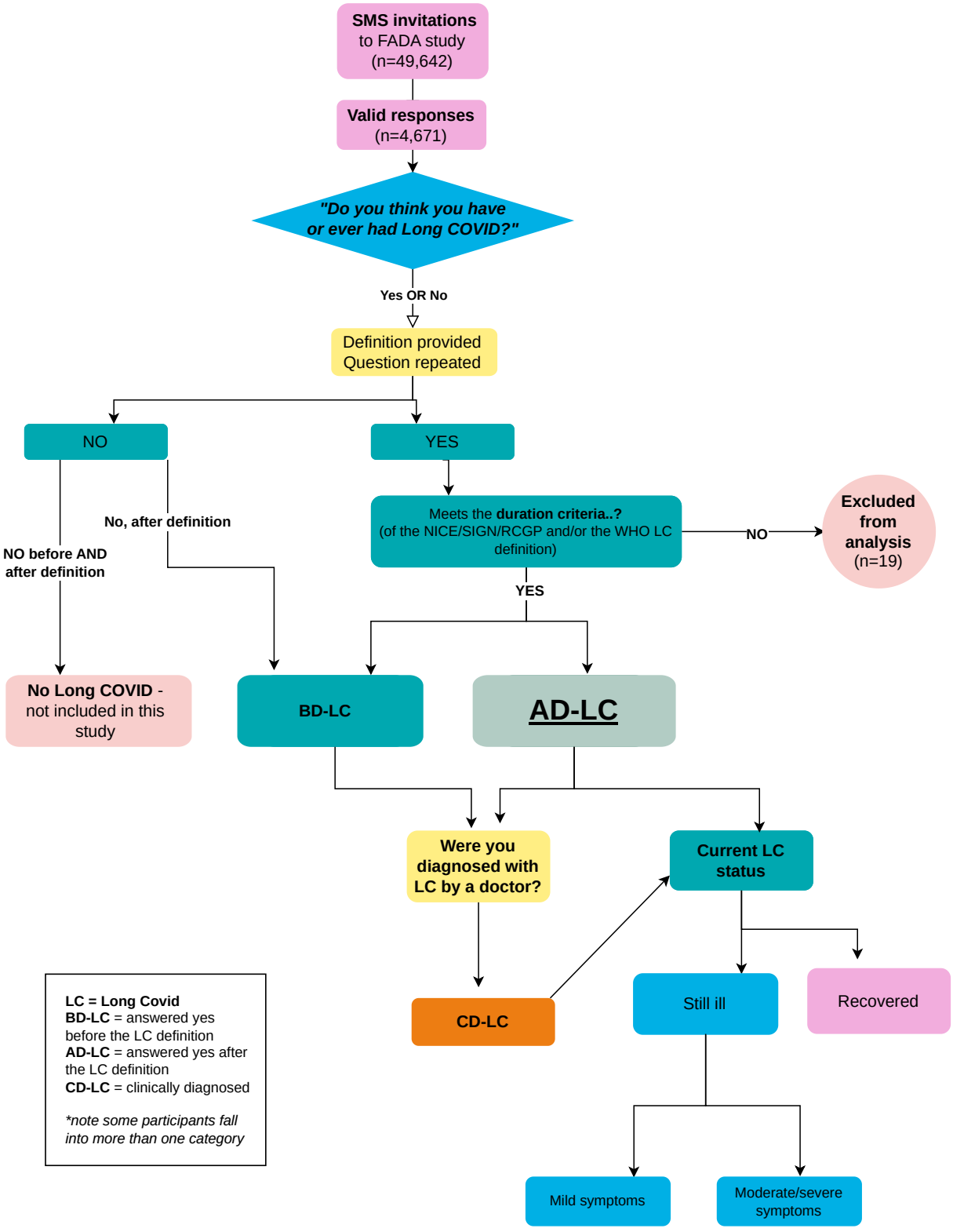
There are essentially three groups of interest in this study:

1. Individuals who tested positive for COVID-19 but do not report Long COVID
2. Individuals who tested positive for COVID-19, who reported Long COVID but who also reported recovery at time of survey completion
3. Individuals who tested positive for COVID-19, report symptoms of Long COVID and were still ill with Long COVID at time of survey completion.

Statistical analysis is presented identifying significant differences between the cohorts in the study in areas such as health status, quality of life and healthcare utilisation.

Comparisons are also drawn between those who self-report as having Long COVID and those who had COVID-19 but didn't go on to develop Long COVID. Figure 5 below demonstrates the analysis pathway.

Figure 5 - FADA Survey data analysis pathway



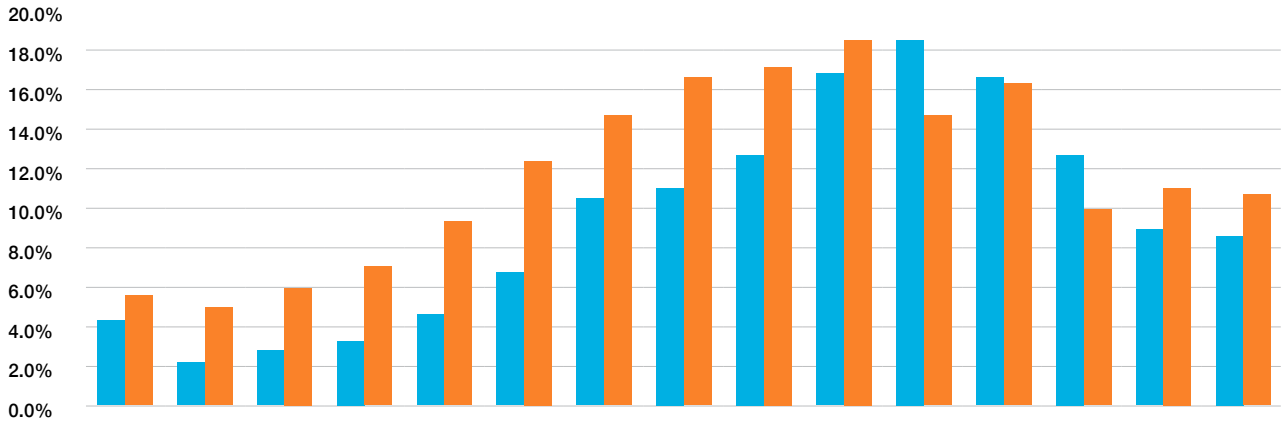
3. Results

3. Results

3.1 Profile of invitees and respondents

In total, 117,200 people in the Dublin and Midlands Region were notified as having a confirmed SARS-CoV-2 infection in the periods of interest between 1st of March 2020 and 31st of January 2022 (Table 2); of these, 49,642 (42.4%) were invited to participate in FADA, and valid responses were received from 4,671 (9.6%). The overall response rate per COVID-19 wave was 10.7%, 8.0%, 8.9% and 9.9% for Wildtype, Alpha, Delta and Omicron respectively. Figure 6 provides a summary of the overall response rate to FADA by gender and age group and full details are tabulated in Appendix 4.

Figure 6 - Overview of study population, sample and response rate by gender and age group



	18-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+
Male	4.3%	2.4%	3.0%	3.4%	5.1%	6.6%	9.5%	11.1%	13.1%	17.5%	18.3%	16.6%	13.3%	9.6%	8.4%
Female	5.9%	5.5%	6.1%	7.7%	9.8%	13.3%	14.6%	17.0%	17.6%	18.3%	15.0%	16.4%	10.5%	11.7%	10.7%

Age Group

There was variation in response rate to FADA across gender and age group. For males, the overall response rate was 7.5%, while for females the overall response rate was 11.2%; the response rate for females was higher across each COVID-19 wave.

Tables 5, 6, 7 and 8 summarise the sociodemographic, baseline health and COVID-19 infection features of those who responded. Overall, 62% were female, the mean age was 47 years, 64.8% had third level education, and 21.8% worked in a healthcare facility. While 66% had no prior chronic illness, 33% had at least one chronic illness; illnesses reported are itemised in Table 7. When asked to recall various health behaviours at the time of their first SARS-CoV-2 infection, over half of respondents (54.7%) reported taking at least 30 minutes of

physical activity 5 days or more per week, over half (55.5%) were non-drinkers or consumed alcohol less than weekly, and 16.8% identified as current smokers (either daily or occasional). While 44.1% reported one SARS-Cov-2 infection, 55.9% reported two or more. 33% reported the episode of acute COVID-19 with which they were sickest was either severe or somewhat severe, and while 46.5% did not seek any care, 5.7% reported they were admitted to hospital and 1.5% reported they were admitted to ICU. Of those who completed the survey, 23.3% of the respondents were identified for sampling from a notification of an acute COVID-19 event during the Wild type wave, 14.7% Alpha, 31.3% Delta and 30.7% Omicron. 32% of respondents had not been vaccinated at the time of their first acute COVID-19 event.

Table 5 - Sociodemographic characteristics of respondents

Sociodemographic characteristics	n	%
Sex (total)		
Female	2,894	62%
Male	1,777	38%
Age		
Mean (sd)	47 (15)	
Marital status (total)		
Divorced/separated	277	7.4%
Married/cohabiting/civil partnership	2,631	70.6%
Never married/single	678	18.2%
Widowed	141	3.8%
Location of residence (total)		
Rural	1,028	27.7%
Urban	2,698	72.3%
Highest level of education (total)		
Primary school or less	142	3.8%
Second level	1,171	31.4%
Third level	2,415	64.8%
Work in a healthcare setting (total)		
No	2,906	78.2%
Yes	812	21.8%
Ethnicity (total)		
White Irish and Other White	3,411	91.7%
Asian or Asian Irish, Chinese or any other Asian background	190	5%
Other, including mixed background	49	1.3%
Black or Black Irish African or any other Black background	72	2%

Table 6 - Baseline health characteristics of respondents

Baseline health characteristics	n	%
Number of chronic illnesses at time of first acute COVID-19 event		
None	3,101	66.4%
1	987	21.1%
2	379	8.1%
3 or more	204	4.4%
Number of days per week of physical activity ≥30 minutes, at time of first acute COVID-19 event		
None	178	4.8%
1 day	126	3.4%
2 days	293	8.0%
3 days	561	15.3%
4 days	506	13.8%
5 days	843	23%
6 days	314	8.5%
7 days	851	23.2%
Frequency of alcohol consumption at time of first acute COVID-19 event		
Daily	59	1.6%
5-6 times/week	84	2.2%
3-4 times/week	453	11.9%
1-2 times/week	1,092	28.8%
1-3 times/month	731	19.2%
< once a month	581	15.3%
No alcohol consumed for > 6 months	319	8.4%
Never	479	12.6%
Current smoking status at time of first acute COVID-19 event		
Non-smoker	3,184	83.2%
Smokes cigarettes daily	387	10.1%
Smokes cigarettes on occasion	257	6.7%
EX- smoking status at time of first acute COVID-19 event		
Never smoked	2,188	69.4%
Previously smoked daily	513	16.2%
Previously smoked occasionally	449	14.4%
Pregnant at time of an acute COVID-19 event?		
No	4,238	97.3%
Yes	99	2.7%

Table 7- Characteristics of respondents' acute COVID-19 illnesses

Characteristics of acute COVID-19 illness(es)	n	%
Likely SARS-CoV-2 variant of notified acute COVID-19 event, "sample variant"		
Wild type	1,088	23.3%
Alpha	684	14.7%
Delta	1,463	31.3%
Omicron	1,436	30.7%
Number of confirmed/suspected acute SARS-CoV-2 infections		
1	1,994	44.1%
2	1,771	39.2%
3	600	13.3%
4	97	2.2%
5	28	0.6%
>5	28	0.6%
Severity of illness during most severe acute COVID-19 event		
No symptoms	289	7.5%
Mild	861	22.5%
Moderate	1,419	37.0%
Somewhat severe	1,079	28.2%
Severe - hospitalised	184	4.8%
Health services used during most severe acute COVID-19 event		
GP	1,740	45.5%
Hospital admission	217	5.7%
ICU admission	58	1.5%
Emergency Department attendance	176	4.6%
Ambulance Service	112	2.9%
Other	191	5.0%
None	1,778	46.5%
Number of doses of COVID-19 vaccine received prior to first acute COVID-19 event		
0	1246	32.0%
1	553	14.2%
2	1137	29.2%
3	634	16.3%
4	322	8.3%

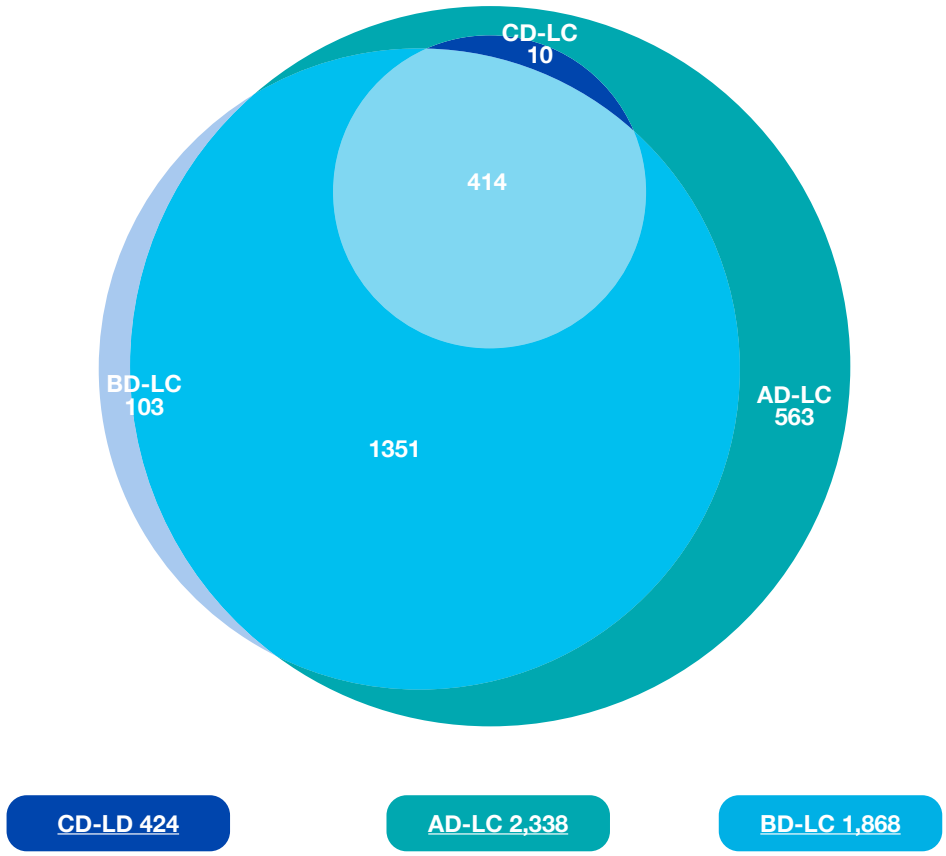
Table 8 - Pre-morbid chronic health conditions reported by respondents, prior to their first acute COVID-19 event

Pre-morbid medical conditions	n	%
Alcohol or substance misuse	27	0.6%
Allergies	243	5.2%
Arthritis, e.g. osteoarthritis or rheumatism	250	5.4%
Autoimmune disease e.g. lupus, rheumatoid arthritis, Crohn's	175	3.7%
Blood borne virus (e.g. HIV)	<10	<0.5%
Cancer	69	1.5%
Chronic lung disease e.g. COPD or asthma	309	6.6%
Dementia or memory loss	14	0.3%
Diabetes	197	4.2%
Fibromyalgia	73	1.6%
Heart problems e.g. angina, a previous heart attack or heart failure	114	2.4%
Kidney problems e.g. chronic renal impairment	51	1.1%
Liver disease	31	0.7%
Mental health difficulties, e.g. depression, anxiety	352	7.5%
Migraine	215	4.6%
Stomach, bowel or digestion problems	313	6.7%
Stroke or neurological disorder, e.g. Parkinson's disease, MS, Motor Neuron Disease	35	0.7%

3.2 What was the current status of respondents following acute COVID-19 infection?

When asked if they thought they have, or ever had, Long COVID (without prompting with a definition) 1,868 (40%) provided an affirmative response. After considering a definition of Long COVID, 2,338 (50.1%) provided an affirmative response; 103 of those who reported Long COVID before presentation of the definition provided a negative response after the definition, while 1,765 provided an affirmative response to both. Finally, 424 respondents indicated they were diagnosed with Long COVID by a doctor, of which 414 reported Long COVID before and after the definition, while 10 reported Long COVID after the definition only. Figure 7 - illustrates responses across these questions.

Figure 7- Overview of responses to three questions to identify respondents with reported Long COVID



Note on abbreviations:

BD-LC: Participants reporting Long COVID before reading the definition

AD-LC: Participants reporting Long COVID after reading the definition

CD-LC: Clinically-diagnosed Long COVID

Taking account of the information summarised in Figure 7, this report will focus on the AD-LC participants, these are the respondents who reported Long COVID after considering the definition (n=2,338), which included all those who also reported a doctor diagnosis of the condition.

3.3 How did those who reported Long COVID compare to those who did not?

The sociodemographic, baseline health and COVID-19 features were compared between respondents who reported Long COVID and those who did not. These comparisons are summarised in Tables 9, 10 and 11.

Reported Long COVID was more common among females, and those who worked in a healthcare facility. Those with reported Long COVID were slightly younger (mean age 46, standard deviation [sd] 14.5) than those who stated they did not have Long COVID (mean age 49, sd 15). In terms of baseline health, reported Long COVID was more common among people with a greater number of chronic illnesses at the time of their first SARS-CoV-2 infection; it was also more common among people reporting higher baseline levels of physical activity and non-drinkers or those whose frequency of alcohol consumption was less than once per month, although the differences were small. Self-reported Long COVID was less common among those who reported being pregnant at the time of a SARS-CoV-2 infection. Finally, in terms of acute COVID-19 illness characteristics, reported Long COVID was more common among those sampled from Wild type and Alpha waves, those reporting a higher number of SARS-CoV-2 infections, more severe illness during their most severe acute COVID-19 event and being unvaccinated (with COVID-19 vaccine) at the time of the first acute COVID-19 event.

Table 9 - Comparison of sociodemographic characteristics by reported Long COVID status

Sociodemographic characteristics	Self-reported Long COVID				
	Yes		No		p value
	n	%	n	%	
Sex					p=0.000[a]
Female	1543	55.7%	1,226	44.3%	
Male	795	47.0%	895	53.0%	
Age					p=0.000[b]
Mean (sd)	46 (14.5)		49 (15)		
Marital status					p=0.012[a]
Divorced/separated	361	53.3%	316	46.7%	
Married/cohabiting/civil partnership	1,217	46.4%	1,407	53.6%	
Never married/single	137	49.6%	139	50.4%	
Widowed	69	49.3%	71	50.7%	
Location of residence					p=0.783[a]
Rural	496	48.4%	528	51.6%	
Urban	1,289	47.9%	1,403	52.1%	
Highest level of education					p=0.249[a]
Primary school or less	59	41.8%	82	58.2%	
Second level	552	47.3%	614	52.7%	
Third level	1,174	48.7%	1,237	51.3%	
Work in a healthcare setting (total)					p=0.000[a]
Yes	449	55.6%	359	44.4%	
No	1,331	45.9%	1,569	54.1%	
Ethnicity (total)					p=0.002[a]
White Irish and Other	1,643	48.3%	1,758	51.7%	
Asian or Asian Irish, Chinese or any other Asian background	86	45.0%	104	55.0%	
Other, including mixed background	28	57.1%	21	42.9%	
Black or Black Irish African or any other Black background	24	33.0%	48	67.0%	

a = Pearson chi-squared *b= t test*

Table 10 - Comparison of baseline health characteristics by reported Long COVID status

Baseline health characteristics	Self-reported Long COVID				
	Yes		No		p value[a]
	n	%	n	%	
Number of chronic illnesses at time of first acute COVID-19 event					p=0.000
None	1,431	49.4%	1,464	50.6%	
1	520	53.0%	462	47.0%	
2	242	63.7%	138	36.3%	
3 or more	145	71.8%	57	28.2%	
Number of days per week of physical activity (≥30 mins), at time of first acute COVID-19 event					p=0.029
None	65	36.7%	112	63.3%	
1 day	66	52.8%	59	47.2%	
2 days	130	44.4%	163	55.6%	
3 days	267	47.6%	294	52.4%	
4 days	260	51.4%	246	48.6%	
5 days	422	50.1%	420	49.9%	
6 days	152	48.6%	161	51.4%	
7 days	405	47.9%	441	52.1%	
Frequency of alcohol consumption at time of first acute COVID-19 event					p=0.000
Daily	22	37.9%	36	62.1%	
5-6 times/week	27	32.5%	56	67.5%	
3-4 times/week	176	38.9%	277	61.1%	
1-2 times/week	503	46.1%	588	53.9%	
1-3 times /month	379	52.1%	349	47.9%	
< once a month	301	51.8%	280	48.2%	
No alcohol consumed for > 6 months	177	55.8%	140	44.2%	
Never	228	47.9%	248	52.1%	
CURRENT smoking status at time of first acute COVID-19 event					p=0.865
Non-smoker	1,522	47.9%	1,655	52.1%	
Smokes cigarettes daily	121	47.3%	135	52.7%	
Smokes cigarettes on occasion	179	46.5%	206	53.5%	
EX- smoking status at time of first acute COVID-19 event					p=0.254
Never smoked	1,053	48.2%	1,130	51.8%	
Previously smoked daily	219	48.8%	230	51.2%	
Previously smoked occasionally	227	44.3%	285	55.7%	
Pregnant at time of an acute COVID-19 event?					p=0.004
No	2,087	51.0%	2,004	49.0%	
Yes	36	36.4%	63	63.6%	

a = Pearson chi-squared

Table 11 - Comparison of acute COVID-19 characteristics by reported Long COVID status

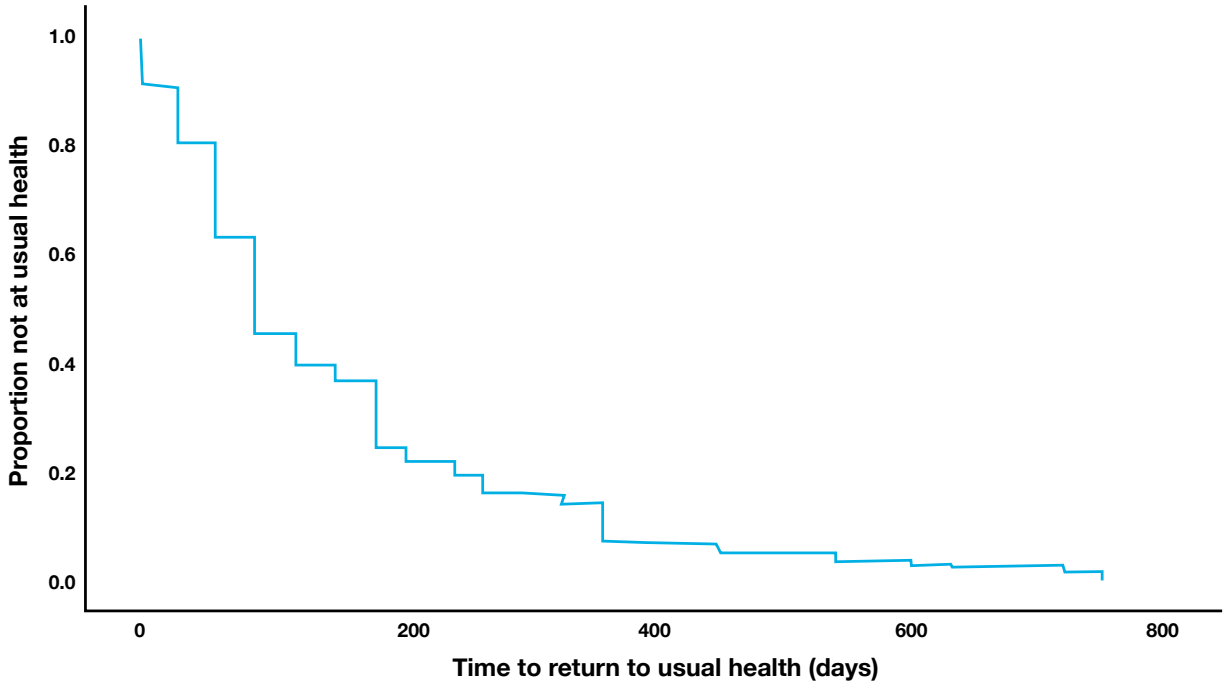
Characteristics of acute COVID-19 illness(es)	Self-reported Long COVID				
	Yes		No		p value[a]
	n	%	n	%	
Likely SARS-CoV-2 variant of notified acute COVID-19 event, "sample variant"					p=0.000
Wild type	671	64.1%	376	35.9%	
Alpha	391	60.4%	256	39.6%	
Delta	712	51.0%	683	49.0%	
Omicron	564	41.2%	806	58.8%	
Number of confirmed/suspected acute SARS-CoV-2 infections					p=0.000
1	821	41.8%	1,144	58.2%	
2	1,004	57.3%	747	42.7%	
3	402	68.6%	184	31.4%	
4	75	77.3%	22	22.7%	
5	22	81.5%	5	18.5%	
>5	9	33.3%	18	66.7%	
Severity of illness during most severe acute COVID-19 event					p=0.000
No symptoms	44	15.1%	247	84.9%	
Mild	222	25.8%	638	74.2%	
Moderate	597	42.2%	819	57.8%	
Somewhat severe	812	75.5%	263	24.5%	
Severe - hospitalised	145	78.4%	40	21.6%	
Health services used during most severe acute COVID-19 event					
GP	1,096	63.2%	637	36.8%	p=0.000
Hospital admission	162	74.7%	55	25.3%	p=0.000
ICU admission	48	82.8%	10	17.2%	p=0.000
Emergency Department attendance	153	86.9%	23	13.1%	p=0.000
Ambulance Service	91	81.3%	21	18.8%	p=0.000
Other	113	59.2%	78	40.8%	p=0.050
None	1,245	70.2%	528	29.8%	p=0.000
Number of doses of COVID-19 vaccine received prior to first acute COVID-19 event					p=0.000
0	704	56.5%	541	43.5%	
1	226	40.9%	326	59.1%	
2	476	42.0%	656	58.0%	
3	300	47.5%	331	52.5%	
4	140	43.6%	181	56.4%	

a = Pearson chi-squared

3.4 What is the current status of people with more complicated recovery pattern?

Of those who indicated they had Long COVID, 979 (41.9%) reported they felt they had recovered at the time of FADA survey completion, while 1,359 (58.1%) reported they were still ill. Among those reporting they felt they had recovered at the time of FADA survey completion, a quarter (25%) had recovered within 60 days, half (50%) had recovered within 90 days and three-quarters (75%) had recovered within 180 days. Time to recovery is summarised in Figure 8:

Figure 8 - Time to return to usual health for those reporting recovery from Long COVID (n=857)



3.5 Did people reporting they were still ill with Long COVID have different characteristics to those who reported Long COVID who felt they had recovered?

The sociodemographic, baseline health and COVID-19 features were compared between respondents who reported Long COVID and those who reported recovery from acute COVID-19. These comparisons are summarised in Tables 12, 13 and 14.

Gender and age profile was similar across both groups, however, compared to those who reported recovery, reporting continuing illness with Long COVID was more common among those with lower levels of educational attainment and in some ethnic groups. In terms of baseline health, reporting continuing illness with Long COVID was more common among people with a greater number of baseline chronic illnesses; it was also more common among people reporting higher levels of physical activity before their first SARS-CoV-2 infection, although the differences were small, and also more common among people who reported they smoked. Finally, in terms of the features of acute COVID-19 illness, reporting continuing illness with Long COVID was more common among those reporting a higher number of SARS-CoV-2 infections, and those reporting a more severe illness during the acute COVID-19 event identified by the participant as their most severe. There was no clear difference in reported resolved versus continuing illness by number of vaccine doses received prior to first acute COVID-19 illness, and the likely SARS-CoV-2 variant which immediately preceded the onset of Long COVID ("sentinel" variant).

Table 12- Comparison of the sociodemographic characteristics of respondents with Long COVID, those with self-defined reported recovery versus those who self-report being still ill

Sociodemographic characteristics	Self-reported Long COVID, current status				
	Self-reported "recovery" from Long COVID		"Still ill" with Long COVID symptoms		p value
	n	%	n	%	
Sex					p=0.25[a]
Female	659	42.7%	884	57.3%	
Male	320	40.3%	475	59.7%	
Age					p=0.16[b]
Mean (sd)	46 (15)		46 (14)		
Marital status					p=0.52[a]
Divorced/separated	135	60.8%	87	39.2%	
Married/cohabiting/civil partnership	498	40.9%	719	59.1%	
Never married/single	50	18.1%	226	81.9%	
Widowed	29	42.0%	40	58.0%	
Location of residence					p=0.53[a]
Rural	192	38.7%	304	61.3%	
Urban	520	40.3%	769	59.7%	
Highest level of education					p=0.02[a]
Primary school or less	17	28.8%	42	71.2%	
Second level	193	35.0%	359	65.0%	
Third level	501	42.7%	673	57.3%	
Work in a healthcare setting					p=0.06[a]
No	514	38.6%	817	61.4%	
Yes	196	43.7%	253	56.3%	
Ethnicity					p=0.002[a]
White Irish and Other	643	39.1%	1000	60.9%	
Asian or Asian Irish, Chinese or any other Asian background	42	48.9%	44	51.1%	
Other, including mixed background	10	35.7%	18	64.3%	
Black or Black Irish African or any other Black background	16	66.7%	8	33.3%	

a = Pearson chi-squared *b = t-test*

Table 13 - Comparison of baseline health characteristics of respondents with Long COVID, those with self-defined reported recovery versus those who self-report being still ill

Baseline health characteristics	Self-reported Long COVID, current status				
	Self-reported"recovery" from Long COVID		"Still ill" with Long COVID symptoms		p value[a]
	n	%	n	%	
Number of chronic illnesses at time of first acute COVID-19 event					p=0.000
None	658	46.0%	773	54.0%	
1	199	38.3%	321	61.7%	
2	84	34.7%	158	65.3%	
3 or more	38	26.2%	107	73.8%	
Number of days per week of physical activity (≥30 minutes), at time of first acute COVID-19 event					p=0.008
None	28	43.1%	37	56.9%	
1 day	25	37.9%	41	62.1%	
2 days	60	46.2%	70	53.8%	
3 days	128	47.9%	139	52.1%	
4 days	112	43.1%	148	56.9%	
5 days	151	35.8%	271	64.2%	
6 days	53	34.9%	99	65.1%	
7 days	143	35.3%	262	64.7%	
Frequency of alcohol consumption at time of first acute COVID-19 event					p=0.597
Daily	10	45.5%	12	54.5%	
5-6 times/week	11	40.7%	16	59.3%	
3-4 times/week	71	40.3%	105	59.7%	
1-2 times/week	209	41.6%	294	58.4%	
1-3 times /month	159	42.0%	220	58.0%	
< once a month	105	34.9%	196	65.1%	
No alcohol consumed for > 6 months	65	36.7%	112	63.3%	
Never	93	40.8%	135	59.2%	
CURRENT smoking status at time of first acute COVID-19 event					p=0.012
Non-smoker	628	41.3%	894	58.7%	
Smokes cigarettes daily	44	36.4%	77	63.6%	
Smokes cigarettes on occasion	54	30.2%	125	69.8%	
EX- smoking status at time of first acute COVID-19 event					p=0.069
Never smoked	449	42.6%	604	57.4%	
Previously smoked daily	92	42.0%	127	58.0%	
Previously smoked occasionally	78	34.4%	149	65.6%	
Pregnant at time of an acute COVID-19 event?					p=0.453
Yes	17	47.2%	19	52.8%	
No	856	41.0%	1231	59.0%	

a = Pearson chi-squared

Table 14 - Comparison of acute COVID-19 characteristics of respondents with Long COVID, those with self-defined reported recovery versus those who self-report being still ill

Characteristics of acute COVID-19 illness(es)	Self-reported Long COVID, current status				
	Self-reported "recovery" from Long COVID		"Still ill" with Long COVID symptoms		p value
	n	%	n	%	
Likely variant of SARS-CoV-2 infection that led to Long COVID ("sentinel variant")					p=0.088[a]
Wild type	326	41.1%	468	58.9%	
Alpha	113	41.1%	162	58.9%	
Delta	139	38.5%	222	61.5%	
Omicron	79	48.8%	83	51.2%	
Omicron since 01.02.2022	124	36.0%	220	64.0%	
Number of confirmed/suspected acute SARS-CoV-2 infections					p=0.00[a]
1	370	45.1%	451	54.9%	
2	428	42.6%	576	57.4%	
3	152	37.8%	250	62.2%	
4	21	28.0%	54	72.0%	
5	3	13.6%	19	86.4%	
>5	3	33.3%	6	66.7%	
Severity of illness during most severe acute COVID-19 event					p=0.000[a]
No symptoms	27	61.4%	17	38.6%	
Mild	100	45.0%	122	55.0%	
Moderate	288	48.2%	309	51.8%	
Somewhat severe	269	33.1%	543	66.9%	
Severe - hospitalised	44	30.3%	101	69.7%	
Health services used during most severe acute COVID-19 event					
GP	395	36.0%	701	64.0%	p=0.000[a]
Hospital admission	51	31.5%	111	68.5%	p=0.005[a]
ICU admission	13	27.1%	35	72.9%	p=0.036[a]
Emergency Department attendance	39	25.5%	114	74.5%	p=0.000[a]
Ambulance Service	30	33.0%	61	67.0%	p=0.079[a]
Other	46	40.7%	67	59.3%	p=0.797[a]
None	255	48.3%	273	51.7%	p=0.001[a]
Duration of Long COVID illness in days					
Mean (sd)	160 (164)		764 (288)		p=0.000[b]
Number of doses of COVID-19 vaccine received prior to first acute COVID-19 event					p=0.617[a]
0	278	39.5%	426	60.5%	
1	98	43.4%	128	56.6%	
2	187	39.3%	289	60.7%	
3	115	38.3%	185	61.7%	
4	62	44.3%	78	55.7%	

a = Pearson chi-squared b = t-test

3.6 What is the nature of symptoms and their impact for those still ill with Long COVID symptoms at the time of FADA survey completion?

The frequency of different symptoms causing problems in the last seven days identified by participants with reported Long COVID who stated they were still ill at the time of FADA survey completion is summarised in Figure 9a. These symptoms were selected by respondents from the "symptom severity" section of the Modified COVID-19 Yorkshire Rehabilitation Screening (C19-YRSm) Scale. The five most commonly reported symptoms were fatigue, cognitive problems, joint or muscle pain, sleep problems and breathlessness. Almost all (99.1%) respondents reported more than one symptom from the "symptom severity" section: almost half (47.7%) reported 15 or more symptoms; almost one-in-five (19.2%) reported 20 or more symptoms (Table 15). Respondents also identified symptoms causing problems in the last seven days from the "other symptoms" section of the Modified COVID-19 Yorkshire Rehabilitation Screening (C19-YRSm) questionnaire and the frequency of these is summarised in Figure 9b.

Figure 9 - Frequency of "more common" and "other" symptoms over the past 7 days in those Still ill with Long COVID

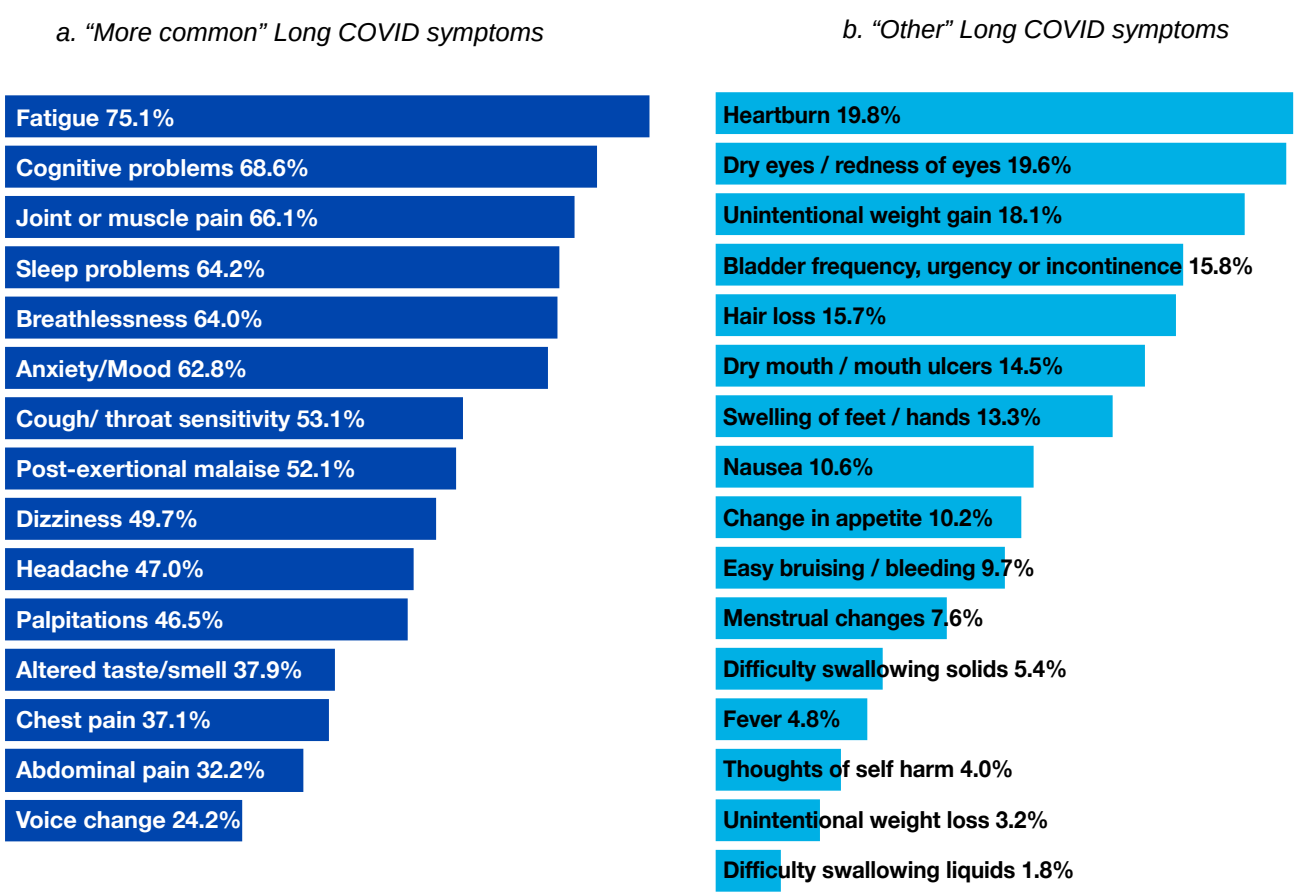
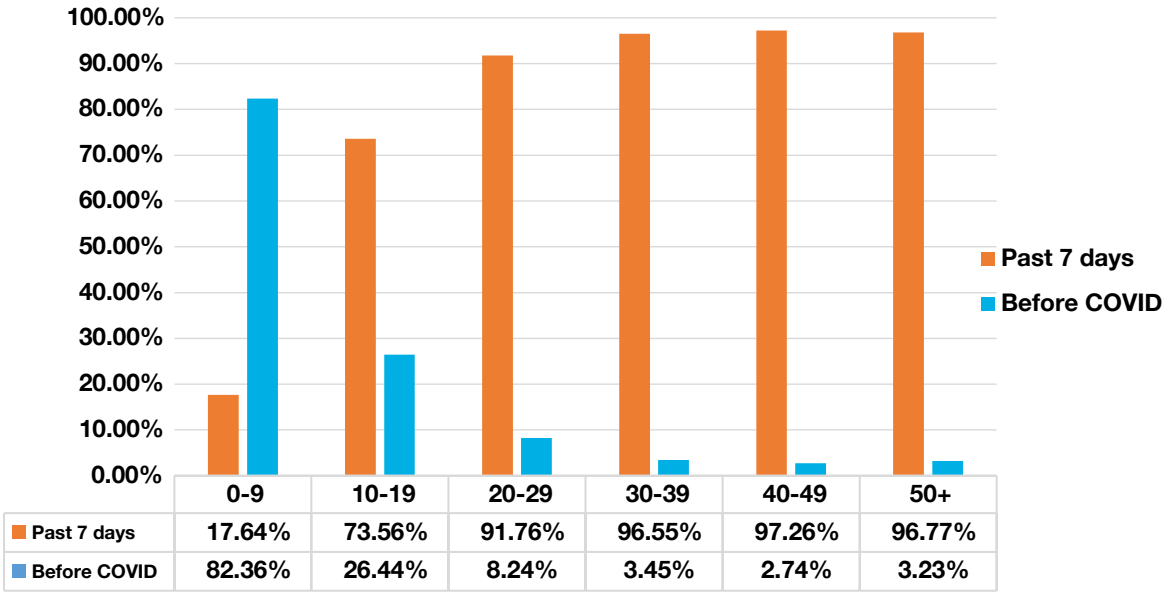


Table 15 - The number of symptoms reported in the last 7 days from the “symptom severity list” among people still ill with reported Long COVID

Number of symptoms	Percentage (%)
0-4	6.1
5-9	18.7
10-14	27.6
15-19	28.5
≥20	19.2

Respondents still ill with reported Long COVID rated severity in the last seven days of each potential symptom from the “symptom severity” section of C19-YRSm to yield an overall symptom severity score from 0 to 78, with a higher score indicating greater symptom severity. The median C19-YRSm symptom severity score was 20 (interquartile range 13-29) for the last seven days prior to FADA survey completion; this compared to a median score of 3 (interquartile range 1-7) based on respondent self-assessment of their status before their first SARS-CoV-2 infection. The frequency of C19-YRSm symptom severity score categories for the last seven days and before COVID-19 is illustrated in Figure 10.

Figure 10 - The frequency of COVID-19 Yorkshire Rehabilitation Scale score categories among respondents with reported Long COVID



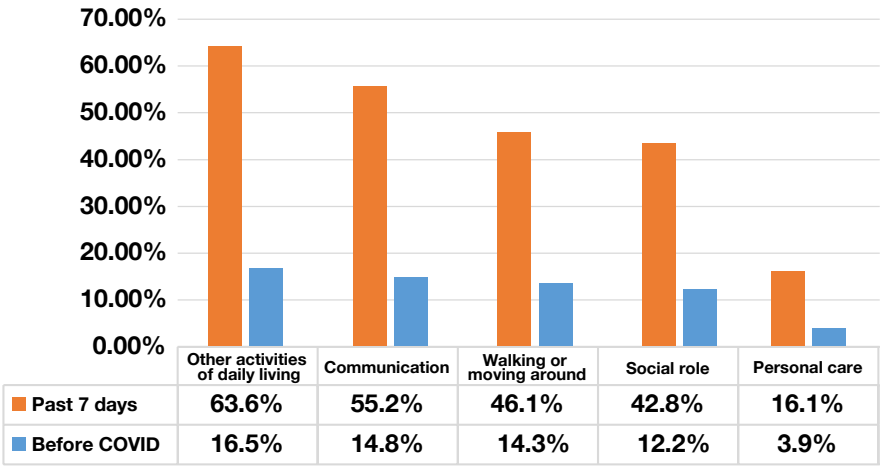
	0-9	10-19	20-29	30-39	40-49	50+
Past 7 days	17.64%	73.56%	91.76%	96.55%	97.26%	96.77%
Before COVID	82.36%	26.44%	8.24%	3.45%	2.74%	3.23%

Respondents still ill with reported Long COVID also rated their functional ability across five domains through the C19-YRSm questionnaire. Over half reported difficulty doing usual activities (63.6%) and difficulty with communication (55.2%); difficulty with walking, socialisation and personal tasks was also commonly reported. Respondents who were still ill with Long COVID symptoms were more likely to report difficulty with self-assessed functional ability when compared with prior to COVID-19. This is illustrated in Figure 11.

A breakdown of reported functional impairment in the last seven days by level of severity is presented in Table 16. Focusing on severe level of reported functional impairment for the last seven days, 13.1% of respondents still ill with reported Long COVID reported a severe level of impact in at least one domain; 6.4% reported a severe level of impact in one domain only; 3.6% reported a severe level of impact in two domains only; and 3.4% reported a severe level of impact in three or more domains.

While just over half of respondents (52.1%) who indicated they were still ill with Long COVID, reported changes in their working arrangements related to their COVID-19 illness, almost one-in-five (17.4%) were on reduced working hours or had changes made to their role/working arrangements, and approximately one-in-10 (10.9%) were on sick leave or had to retire/ change job (Table 17).

Figure 11- Frequency of reported difficulty with functional ability among respondents still ill with reported Long COVID



	Other activities of daily living	Communication	Walking or moving around	Social role	Personal care
Past 7 days	63.6%	55.2%	46.1%	42.8%	16.1%
Before COVID	16.5%	14.8%	14.3%	12.2%	3.9%

Table 16 - Frequency of difficulty with functional disability by levels of severity among respondents still ill with reported Long COVID

Functional domain (detail given to respondent)	Level of severity (%)			
	None	Mild	Moderate	Severe
Difficulty with communication (includes difficulties with word finding and understanding others)	44.8%	28.7%	21.2%	5.3%
Difficulties with walking or moving around	53.9%	24.6 %	17.6%	4.0%
Difficulties with personal tasks like using the toilet or getting washed and dressed	83.9%	10.7 %	4.1%	1.3%
Difficulties doing wider activities such as household work, leisure/sporting activities, paid/ unpaid word, study, shopping	36.4%	29.7%	25.2%	8.6%
Problems with socialising or interacting with friends or caring for dependents (related to your illness and not due to social distancing or lockdown measures)	57.2%	20.9%	16.1%	5.9%

Table 17 - Frequency of employment impacts report by respondents still ill with reported Long COVID

Impact on work	n	%
No change	548	52.1%
Changes to role/working arrangements such as working from home or lighter duties	81	7.7%
Reduced working hours	102	9.7%
On sick leave	53	5.0%
Had to retire/change job	62	5.9 %
Lost job	34	2.3 %
Other change	181	17.2%

The EuroQol 5 Dimension 5 Level (EQ-5D-5L) measured quality of life across five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. As summarised in Table 18, over half of those still ill with reported Long COVID also reported some problem with anxiety/depression (55.3%) and usual activities (51.5%); almost half reported some problem with pain/discomfort (48.9%) and almost one-third reported some problem with mobility (31.3%). Regarding the severity of these problems, approximately 1-in-15 reported problems with anxiety/depression (7.0%), usual activities (6.3%) and pain/discomfort (6.2%) as severe or extreme.

Table 18 - Frequency of quality of life by problem level among respondents still ill with reported Long COVID

EQ-5D-5L Domain	Level of functional impairment				
	No problems	Mild problems	Moderate problems	Severe problems	Extreme problems
Mobility	68.7%	18.5%	9.5%	3.2%	0.1%
Usual activities	48.5%	31.2%	14.0%	4.6%	1.7%
Self-Care	87.5%	7.9%	3.7%	0.7%	0.2%
Pain/Discomfort	51.1%	26.8%	15.9%	5.5%	0.7%
Anxiety/Depression	44.7%	32.4%	15.9%	5.5%	1.5%

3.7 Did people with more severe Long COVID symptoms have different characteristics to those with mild Long COVID symptoms?

The C19-YRSm symptom severity scores for respondents still ill with reported Long COVID were grouped into mild (scores of 0 to 26) and moderate/severe (scores of 27-78) categories. The sociodemographic, baseline health and COVID-19 features were compared between respondents still ill with reported Long COVID who had mild versus moderate/severe symptom severity scores. These comparisons are summarised in Tables 19, 20 and 21.

Moderate/severe symptom severity scores were more common among females, and some differences in frequency of moderate/severe symptom severity scores were also observed across marital status. In terms of baseline health, moderate/severe symptom severity scores were more common among people with a greater number of chronic illnesses; moderate/severe symptom severity scores were also more common among people reporting higher levels of physical activity before their first SARS-CoV-2 infection, among people reporting less frequent alcohol consumption before their first acute COVID-19 event, and among people who reported they smoked prior to their first SARS-CoV-2 infection. Finally, in terms of the features of acute COVID-19 illnesses, moderate/severe symptom severity scores were more common among those reporting a higher number of SARS-CoV-2 infections, and more severe illness during the acute COVID-19 event when they were sickest. There was a longer duration of illness among those with moderate/severe symptom severity scores versus mild symptom severity scores. Finally, moderate/severe symptom severity scores were more common among those whose likely sentinel variant was Wild type, Alpha or Delta versus Omicron.

Table 19 - Comparison of sociodemographic features for those with reported Long COVID reporting mild versus moderate/severe symptom scores

Sociodemographic characteristics	Self-reported as still ill with Long COVID symptoms				
	Mild Long COVID symptoms		Moderate/Severe Long COVID symptoms		p value
	n	%	n	%	
Sex (total)	**663**		**306**		p=0.000[a]
Male	256	75.7%	82	24.3%	
Female	407	64.5%	224	35.5%	
Age					p=0.677[b]
Mean (sd)	45 (14)		45 (15)		
Marital status (total)	**602**		**282**		p=0.000[a]
Divorced/separated	26	42.6%	35	57.4%	
Married/cohabiting/civil partnership	419	70.7%	174	29.3%	
Never married/single	138	67.3%	67	32.7%	
Widowed	19	76.0%	6	24.0%	
Location of residence (total)	**602**		**282**		p=0.904[a]
Rural	171	68.4%	79	31.6%	
Urban	431	68.0%	203	32.0%	
Highest level of education (total)	**602**		**282**		p=0.329[a]
Primary school or less	19	73.1%	7	26.9%	
Second level	172	64.7%	94	35.3%	
Third level	411	69.4%	181	30.6%	
Work in a healthcare setting (total)	**599**		**282**		p=0.981[a]
No	455	68.0%	214	32.0%	
Yes	144	67.9%	68	32.1%	
Ethnicity (total)	**601**		**280**		p=0.509[a]
White Irish and Other	563	39.1%	264	60.9%	
Asian or Asian Irish, Chinese or any other Asian background	25	77.8%	9	22.2%	
Other, including mixed background	8	61.5%	5	38.5%	
Black or Black Irish African or any other Black background	5	50.0%	2	50.0%	

a = Pearson chi-squared; b = t-test

Table 20 - Comparison of baseline health features for those with reported Long COVID reporting mild versus moderate/severe symptom scores

Baseline health characteristics	Self-reported as still ill with Long COVID symptoms				
	Mild Long COVID symptoms		Moderate/Severe Long COVID symptoms		p value[a]
	n	%	n	%	
Number of chronic illnesses at time of first acute COVID-19 event					p=0.000
None	385	77.2%	114	22.8%	
1	174	66.4%	88	33.6%	
2	73	57.5%	54	42.5%	
3 or more	31	38.3%	50	61.7%	
Number of days per week of physical activity (≥30 minutes), at time of first acute COVID-19 event					p=0.003
None	24	80.0%	6	20.0%	
1 day	20	74.1%	7	25.9%	
2 days	46	74.2%	16	25.8%	
3 days	82	70.7%	34	29.3%	
4 days	98	77.8%	28	22.2%	
5 days	150	66.1%	77	33.9%	
6 days	50	61.7%	31	38.3%	
7 days	130	61.9%	80	38.1%	
Frequency of alcohol consumption at time of first acute COVID-19 event					p=0.036
Daily	6	54.5%	5	45.5%	
5-6 times/week	11	78.6%	3	21.4%	
3-4 times/week	66	75.0%	22	25.0%	
1-2 times/week	177	73.1%	65	26.9%	
1-3 times /month	121	66.5%	61	33.5%	
< once a month	113	70.6%	47	29.4%	
No alcohol consumed for > 6 months	57	61.3%	36	38.7%	
Never	58	56.9%	44	43.1%	
CURRENT smoking status at time of first acute COVID-19 event					p=0.020
Non-smoker	518	70.6%	217	29.4%	
Smokes cigarettes daily	39	61.3%	24	38.7%	
Smokes cigarettes on occasion	56	56.9%	41	43.1%	
EX- smoking status at time of first acute COVID-19 event					p=0.670
Never smoked	356	70.5%	141	29.5%	
Previously smoked daily	70	61.9%	34	38.1%	
Previously smoked occasionally	87	57.7%	37	42.3%	
Pregnant at time of an acute COVID-19 event?					p=0.059
Yes	16	88.9%	2	11.1%	
No	620	68.0%	292	32.0%	

a = Pearson chi-squared

Table 21 - Comparison of Acute COVID-19 characteristics for those with reported Long COVID reporting mild versus moderate/severe symptom scores

Characteristics of acute COVID-19 illness(es)	Self-reported as still ill with Long COVID symptoms				
	Mild Long COVID symptoms		Moderate/Severe Long COVID symptoms		p value
	n	%	n	%	
Likely variant of SARS-CoV-2 infection that led to Long COVID ("sentinel variant")					p=0.047[a]
Wild type	224	64.4%	124	35.6%	
Alpha	76	65.5%	40	34.5%	
Delta	108	67.5%	52	32.5%	
Omicron	54	77.1%	16	22.9%	
Omicron since 01.02.2022	122	75.8%	39	24.2%	
Number of confirmed/suspected acute SARS-CoV-2 infections (total)					p=0.024[a]
1	218	71.2%	88	28.8%	
2	302	71.1%	123	28.9%	
3	107	59.8%	72	40.2%	
4	25	58.1%	18	41.9%	
5	9	69.2%	4	30.8%	
>5	0	0.0%	1	100.0%	
Severity of illness during most severe acute COVID-19 event (total)					p=0.000[a]
No symptoms	12	100.0%	0	0.0%	
Mild	76	83.5%	15	16.5%	
Moderate	202	79.2%	53	20.8%	
Somewhat severe	288	62.5%	173	37.5%	
Severe - hospitalised	35	46.7%	40	53.3%	
Health services used during most severe acute COVID-19 event (total)					
GP	381	65.5%	201	34.5%	p=0.015[a]
Hospital admission	41	49.4%	42	50.6%	p=0.000[a]
ICU admission	13	50.0%	13	50.0%	p=0.041[a]
Emergency Department attendance	42	43.3%	55	56.7%	p=0.000[a]
Ambulance Service	21	44.7%	26	55.3%	p=0.000[a]
Other	27	50.9%	26	49.1%	p=0.005[a]
None	185	81.5%	42	18.5%	p=0.000[a]
Duration of illness in days					
Mean (sd)	160 (164)		764 (288)		p=0.000[b]
Number of doses of COVID-19 vaccine received prior to first acute COVID-19 event (total)					p=0.542[a]
0	234	65.7%	122	34.3%	
1	73	72.3%	28	27.7%	
2	167	68.4%	77	31.6%	
3	105	71.4%	42	28.6%	
4	41	73.2%	15	26.8%	

a = Pearson chi-squared; b = t-test

3.8 What health services were used by those reporting Long COVID, and did these services help?

Table 22 illustrates the health services which respondents reporting using for Long COVID, and their perception of the helpfulness of that service. The most commonly used services were consultations with the GP (42.3%) and accessing information on a website (31.4%); respondents who used a GP reported visiting on average 4.25 times because of the prolonged illness due to COVID-19. Other commonly used services included telephone support, community pharmacist, hospital out-patient visit and emergency department visits. Few respondents reported using community-based health and social care professional services and hospital or community-based rehabilitation services.

Table 23 depicts the health services which were not used by people with reported Long COVID, but which were or are still perceived to be potentially beneficial. For those reporting they are still ill with Long COVID, the three most commonly identified services were GP, telephone support and information on a website. Other community-based health services were also commonly identified by those reporting they are still ill with Long COVID as well as those reporting they were recovered when they completed the survey. In terms of hospital-based services, 12.5% of those reporting they are still ill with Long COVID perceived a hospital out-patient appointment would be beneficial. Community based and hospital-based rehabilitation services were identified as potentially beneficial for 7.2% and 3.7% of those reporting they are still ill with Long COVID respectively.

Table 22 - Health services used by people with reported Long COVID and the perception of their helpfulness

Health service				Perception of usefulness			
	n	%	Average no visits[a]	Yes			No
				Total Yes	Yes, completely	Yes, somewhat	
GP	1,268	42.3%	4.25	94.0%	48.0%	45.8%	6.2%
Information on a website	801	31.4%	n/a	94.0%	37.7%	56.9%	5.4%
Telephone support	391	15.3%	3.5	94.0%	48.2%	45.6%	6.2%
Community Pharmacist	338	13.2%	5	94.0%	49.8%	44.0%	6.2%
Hospital out-patient appointment	290	11.4%	4.3	84.0%	34.8%	49.2%	16.0%
Emergency Department	263	10.3%	2	80.0%	32.6%	47.7%	19.7%
Other	150	5.9%	n/a	n/a	n/a	n/a	n/a
Alternative health providers[b]	134	5.2%	5.4	90.0%	27.5%	62.6%	9.9%
Hospital in-patient	133	5.2%	1.8	91.0%	47.2%	43.2%	9.6%
GP Nurse	124	4.9%	3.5	82.0%	44.4%	37.6%	18.0%
Hospital day-case appointment	95	3.7%	3.5	79.0%	28.4%	50.6%	21.0%
Ambulance Service or Paramedic	83	3.3%	1.4	91.0%	59.2%	31.6%	9.2%
Community Physio	74	2.9%	6.3	89.0%	42.3%	46.5%	11.2%
Community Counsellor or Psychologist	64	2.5%	6.8	85.0%	34.4%	50.8%	14.8%
Public Health Nurse or Community Nurse	52	2.0%	3.7	7.0%	31.1%	42.2%	26.7%
Community OT	36	1.4%	5	82.0%	33.3%	48.5%	18.2%
Hospital-based rehabilitation service	36	1.4%	6.8	99.0%	89.9%	9.0%	1.1%
Home help	32	1.3%	4.4	75.0%	41.7%	33.3%	25.0%
Community Dietitian	29	1.1%	3	77.0%	38.5%	38.5%	23.0%
Home-based rehabilitation service	13	0.5%	4.4	82.0%	18.2%	63.6%	18.2%
Community SLT	7	0.3%	4	100.0%	57.1%	42.9%	0.0%

a – refers to an average of the total number of times service was used

b – such as herbalist, homoeopathist, reflexologist etc.

Table 23 - Health services not used by people with reported Long COVID but perceived as potentially beneficial

Health service	Still ill		Recovered	
	n	%	n	%
GP	426	31.3%	272	27.8%
Telephone support	254	18.7%	204	20.8%
Information on a website	221	16.3%	123	12.6%
Public Health Nurse or Community Nurse	211	15.5%	176	18.0%
Community Physiotherapist	180	13.2%	83	8.5%
Hospital out-patient appointment	170	12.5%	74	7.6%
Community Pharmacist	165	12.1%	133	13.6%
GP Nurse	158	11.6%	118	12.1%
Community Dietitian	152	11.2%	67	6.8%
Community Occupational Therapist	137	10.1%	56	5.7%
Home-based rehabilitation service	98	7.2%	59	6.0%
Hospital day-case appointment	85	6.3%	43	4.4%
Home help	66	4.9%	58	5.9%
Hospital in-patient	62	4.6%	38	3.9%
Hospital-based rehabilitation service	50	3.7%	36	3.7%
Overnight respite care	38	2.8%	28	2.9%
Community Speech and Language Therapist	36	2.6%	33	3.4%

4. Discussion

4. Discussion

The emergence of SARS-CoV-2 in 2019 resulted in a global pandemic of COVID-19 illness, which to date has caused at least seven million deaths worldwide.[35] As early as 2020, there was recognition of a need to acknowledge the persistence of multi-organ symptoms affecting some people in the weeks and months following acute COVID-19 disease, a phenomenon which later became known as Long COVID.[36] This is a complex and emerging health condition, and it is recognised the world is playing "catch up" in its understanding of Long COVID.[37] The World Health Organization called on countries to take a Triple-R approach to Long COVID – Recognise, Rehabilitate and Research.[38, 39]

This report describes the results of the initial findings from Ireland's first population-based survey on Long COVID conducted in 2023 by the Health Service Executive.

4.1 What were the main findings of the FADA survey?

The frequency of reported Long COVID among people who responded to the FADA survey was measured. After considering a definition of the condition 2,338 respondents (50.1%) reported they had or have Long COVID; almost one-in-five of these (18.1%) indicated a diagnosis of Long COVID had been made in their case by a clinician.

In comparison to all respondents, self-reported Long COVID was more common among the following groups:

- females,
- people aged in their early 40s,
- people who worked in a healthcare facility,
- people with a greater number of baseline chronic illnesses,
- people who reported regular exercise prior to their illness,
- people sampled from Wild type and Alpha waves,
- people reporting a higher number of SARS-CoV-2 infections,
- people reporting more severe illness when sickest with acute COVID-19,
- people reporting not having received COVID-19 vaccination prior to their first SARS-CoV-2 infection.

Just under half (41.9%) of those who reported Long COVID, also reported recovery at time of FADA survey completion: a quarter (25%) reported they had recovered within 60 days, half (50%) reported recovery within 90 days and three-quarters (75%) reported they had recovered within 180 days, with the remaining 25% who reported being recovered from Long COVID at time of survey completion, indicating they were ill for longer than 180 days. The remainder, 58.1% reported they were still ill. Compared to those who reported recovery, continuing illness with Long COVID was more common among the following groups:

- people with lower levels of educational attainment,
- people with a greater number of baseline chronic illnesses,
- people who reported regular exercise prior to their illness,
- people who reported they smoked at the time of their first SARS-CoV-2 infection,
- people reporting a higher number of SARS-CoV-2 infections,
- people reporting more severe illness during their most severe acute COVID-19 event.

Among respondents reporting Long COVID who were still ill, the five most commonly reported symptoms were fatigue, cognitive problems, joint or muscle pain, sleep problems and breathlessness. In addition to the top five reported symptoms, anxiety/mood, cough/throat sensitivity and crashing or relapse hours or days after physical, cognitive or emotional exertion impacted over 50% of respondents with Long COVID. Almost all (99.1%) respondents reported multiple symptoms: almost half (47.7%) reported 15 or more symptoms; almost one-in-five (19.2%) reported 20 or more symptoms. Following assessment of reported symptom on a severity score from 0 to 78 (higher score indicating greater symptom severity) for these respondents still ill with reported Long COVID, the median severity score was 20 (interquartile range 13-29) for the last seven days prior to FADA survey completion; this compared to a median score of 3 (interquartile range 1-7) based on respondent self-assessment of their status before COVID-19. Symptoms severity scores were grouped into mild (0-26) or moderate/severe (27-78).

Moderate/severe symptom scores were more common than mild symptom scores among the following groups:

- females,
- people with a greater number of baseline chronic illnesses,
- people who reported regular exercise prior to their illness,
- people who reported they smoked at the time of their first SARS-CoV-2 infection,
- people reporting a higher number of SARS-CoV-2 infections,
- those whose likely sentinel variant was Wild type, Alpha or Delta versus Omicron.
- people reporting more severe illness during their most severe acute COVID-19 event,
- longer durations of time having elapsed since the reported onset of symptoms of the acute COVID-19 event identified as leading to Long COVID ("sentinel event")

The impact of ongoing reported Long COVID on respondents' functional abilities was also quantified. Over half still ill with reported Long COVID also reported difficulty doing usual activities (63.6%) and difficulty with communication (55.2%); difficulty with walking, socialisation and personal tasks was also commonly reported. Compared with self-assessment of functional ability before COVID-19, difficulty with functional ability was more frequently identified in the last seven days by people still ill with reported Long COVID. Overall, 13.1% of respondents still ill with reported Long COVID reported a severe level of impact in at least one functional domain; 6.4% reported a severe level of impact in one domain only; 3.6% reported a severe level of impact in two domains only; and 3.4% reported a severe level of impact in three or more domains. While just over half of respondents (52.1%) still ill with reported Long COVID reported a change in their work related to their COVID-19 illness, almost one-in-five (17.4%) were on reduced working hours or had changes made to their role/working arrangements, and approximately one-in-10 (10.9%) were on sick leave or had to retire/change job.

Quality of life was also measured for respondents still ill with reported Long COVID: over half reported some problem with anxiety/depression (55.3%) and usual activities (51.5%); almost half reported some problem with pain/discomfort (48.9%) and almost one-third reported some problem with mobility (31.3%). Regarding the severity of these problems, approximately 1-in-15 reported problems with anxiety/depression (7.0%), usual activities (6.3%) and pain/discomfort (6.2%) rated as severe or extreme.

Finally, the FADA survey characterised health services used by people who reported Long COVID. The most commonly used services were visits to the GP (42.3%) and accessing information on a website (31.4%); on average respondents who used a GP reported visiting 4.25 times because of the prolonged illness due to COVID-19. Other commonly used services included telephone support, community pharmacist, hospital out-patient visit and emergency department visits. Few respondents reported using community-based health and social care professional services and hospital or community-based rehabilitation services. In general, especially for those services used more commonly, respondents reported they found the services they accessed were somewhat or completely helpful. Of health services which people who reported Long COVID did not access, those most commonly identified as being potentially beneficial were General Practice and telephone support; 12.5% of those who report they were still ill with Long COVID identified a hospital out-patient visit would be potentially beneficial. It should be noted however, the timing of the FADA survey may impact the healthcare utilisation, as it predated the establishment of some hospital sites.

4.2 Do we now know how common Long COVID is in Ireland and how does this fit with other research?

Almost one-in-two people who responded to the FADA survey reported Long COVID. What does this mean for our understanding of how common Long COVID is in Ireland?

Surveys are designed to enable inferences to be drawn about the frequency of health conditions in the general population. The certainty with which we can draw these inferences and the confidence with which we can use this information is critically dependent on the response rate to the survey. In the case of the FADA survey, the response rate was just under 10%. This response rate was low: for comparison, the response rate to the Study to Investigate COVID-19 Infection in People Living in Ireland (SCOPI) in 2020 was 35%;[40] and the response rate to the Healthy Ireland Survey in 2023 was 50%.[41] This may reflect the mode of administration of FADA, which was through SMS link to a web-based survey platform. When the response rate to a survey is low, it means those people who respond may be systematically different to the sample drawn, and these differences may be related to factors being explored in the survey. It is clear from the analyses of responses, that response rate to the FADA survey was systematically different by gender and age group, two key factors that may be related to the various issues being explored in the survey. It is also possible other factors that cannot be easily observed like, for example, the likelihood of someone experiencing Long COVID, the severity of Long COVID and the current health status, are systematically different between those people sampled who responded and those who did not. In summary, the response rate to the FADA survey creates significant potential for non-response bias,[42] which in turn reduces the confidence with which inferences can be made from the results to the occurrence of Long COVID in the general population in Ireland.

In an international review of Long COVID epidemiology published by HIQA in 2023, which included 51 studies (comprising approximately 1.1 million people with a history of COVID-19), the Long COVID prevalence estimates were 15.2% to 53.1% in studies which included self-reported data.[6] The results from the FADA survey are at the higher end of this range. However, when the results are re-weighted for the population level exposure and probability of response, the overall results fall more centrally within this range. As noted by HIQA, and consistent with the findings of other reviews of studies estimating the prevalence of Long COVID,[43, 44] research in this area is complex: studies focusing on people hospitalised with acute COVID-19 disease are often smaller in scale with higher response rates and report higher Long COVID prevalence estimates, but are limited in terms of making inferences about the population as a whole; population-based studies, like the FADA survey, can be challenged with lower response rates. HIQA noted within international registry documents, it was estimated 3.3% of the UK population (January 2023) and 5.9% of all adults in the US (January 2023) were experiencing Long COVID although heterogeneity of study design and Long COVID definitions used render direct comparisons with the FADA survey cohort challenging.[40]

A statistical note on estimating the occurrence of Long COVID from FADA

The survey provides very useful information from respondents about their experience following acute COVID-19 infection. However, due to a moderate to low response rate, it is difficult to estimate population level characteristics such as prevalence of Long COVID. The FADA Team asked for specialist bio-statistical advice on how best to interpret the findings.

In the surveyed population there were a number of subgroups divided by age group, sex and variant to which the individuals were exposed. The number of respondents in these groups were small in many cases, and thus sampling variation meant the proportion ever experiencing Long COVID had a very broad range indeed (from 0% to 100%), with inter quartile range (39%,61%). A strong negative correlation was seen between the response rate in these subgroups and the proportion ever experiencing Long COVID. This lower proportion of respondents reporting ever experiencing Long COVID was observed in subgroups with higher response rates. In the context of a moderate to low response rate overall, this is consistent with this key measure of interest (ever experiencing symptoms of Long COVID) being associated with the probability that someone responds to the survey. The extent to which the topic in a survey is of particular interest to a respondent is a well-recognised feature in survey participation decisions.*

In order to summarise the findings of the survey with respect to prevalence of Long COVID, the responses were weighted according to the population level exposure and probability of response. In particular, the weight of each respondent (by age category, sex and variant) was determined by the number of those exposed at the population level, divided by the number of respondents in that category. This was then multiplied by the inverse of the probability of response, which for those with Long COVID, was sampled from a Beta distribution with parameters (3,5). These parameters were chosen on the basis of the observed correlation between response rate and positivity.

Thus, the reweighted estimates of prevalence (and associated confidence intervals) are those which best estimate the population level prevalence of ever experiencing Long COVID for each of the variants. It should be noted there is likely to be confounding between this and whether or not individuals were vaccinated, but this has not been taken into account in this analysis.

Overall	**16%**	**(95% CI 10%-33%)**
Wild Type	26%	(95% CI 17%-45%)
Alpha	22%	(95% CI 14%-40%)
Delta	18%	(95% CI 11%-31%)
Omicron	13%	(95% CI 8%-24%)

Prof Cathal Walsh, Professor of Biostatistics, School of Medicine, Trinity College Dublin

*Robert M. Groves, Stanley Presser, Sarah Dipko, The Role of Topic Interest in Survey Participation Decisions, Public Opinion Quarterly, Volume 68, Issue 1, March 2004, Pages 2–31, https://doi.org/10.1093/poq/nfh002

To address the issue with response rate to the FADA survey, key questions from the study used to detect reported Long COVID have been included in the 2024 Healthy Ireland Survey conducted by the Department of Health. A similar approach of including a measure of reported Long COVID has been included in the US population health survey.[45] These results will complement the findings from the FADA survey and inform a better understanding of the occurrence of Long COVID in Ireland.

4.3 How has FADA improved understanding of the landscape of Long COVID in Ireland?

While the response rate to FADA means we cannot confidently draw inferences about the occurrence of Long COVID in Ireland, the detailed information provided by 2,338 individuals reporting Long COVID contributes significantly to our understanding of long-term health impacts and recovery from acute COVID-19 disease.

The NICE/SIGN/RCGP definition of Long COVID adopted for FADA, includes both ongoing symptomatic COVID-19 (4-12 weeks) and post-COVID-19 syndrome (12 weeks or more), Figure 1. Of those who reported Long COVID in FADA, approximately two-in-five (41.9%) report recovery, with half of this group reporting self-defined recovery within three months. These findings are consistent with the international literature, which suggests that some Long COVID symptoms may resolve for some individuals in the short term.

One meta-analysis examining one year of follow-up early in the pandemic found a steep decrease initially in any long COVID symptom from 93% to 55% within 1 month of discharge from hospital, or 1 month after recovery from the acute phase of COVID-19 infection. However, at one year follow-up there was only a marginal decrease to 50% reporting any one Long COVID symptom.[46] Few studies examine recovery using Long COVID definitions and the published literature tends to concentrate on the resolution of specific symptoms or groups of symptoms over time as opposed to complete recovery.[46, 63] There is little generalisable evidence on complete recovery. Population based studies in the UK and USA carried out in 2023 have shown a decrease in the estimated prevalence of Long COVID over time, which could indicate resolution of symptoms and/or reducing incidence of Long COVID.[47, 15]

It is important to note perceived declines in the prevalence of Long COVID over time may also be attributed to alterations in the pathogenicity of circulating SARS-CoV-2 variants, changes in practices around testing for SARS-CoV-2, COVID-19 vaccination campaigns, and other factors.[15]

Of those who were still ill with reported Long COVID, the scope and prevalence of symptom types reported was similar to those reported internationally.[22, 48] The HIQA report found symptoms with the highest prevalence estimates were fatigue (ranging from 2.9% to 69%), cognitive impairment including "brain fog", memory loss and or confusion (ranging from 0.2% to 45.7%), anosmia (ranging from 1.6% to 43.7%), and shortness of breath (ranging from 3.4% to 39.7%) across the studies examined in its review.[14] In a population-based study in the UK, fatigue was the most common symptom reported as part of individuals' experience of Long COVID (71% of those with reported Long COVID), followed by difficulty concentrating (52%), shortness of breath (48%) and muscle ache (47%).[15]

The severity and impact of Long COVID symptoms for respondents was significant. For those still ill with reported Long COVID, nearly a third (31.6%) rated the symptom burden as moderate/severe, over one-in-ten (13.1%) reported a severe impact on functional ability in at least one of five domains assessed, and one-in-ten (10.9%) were on sick leave or had to retire/change job. The severe and impactful burden of Long COVID symptoms for a proportion of people affected has been identified in other population-based studies. In its review, HIQA found a range of estimates concerning the return-to-work status of individuals experiencing Long COVID symptoms. These estimates varied from 6.3% of participants indicating an incapacity to work to 47.1% reporting an inability to resume their previous level of work productivity.[57] A population-based study in the UK found symptoms adversely affected the day-to-day activities of 79% of those with reported Long COVID, with 20% reporting their day-to-day activities had been "limited a lot",[58] while in the US, 26.4% of adults with Long COVID reported significant activity limitations.[47]

4.4 What factors are associated with increasing the risk or protecting against Long COVID?

There were differences in the characteristics of people who reported Long COVID, who reported they were still ill with Long COVID, and who reported greater symptom severity than those who did not.

The relationships between gender, age and Long COVID in this study were mixed. Reporting Long COVID was more common among females and those aged in their 40s; and reporting a greater symptom severity score was more common among females. However, reporting recovery from Long COVID was similar across gender and age groups.

In general, across studies which examined the relationship between gender, age and Long COVID, most have reported Long COVID is more common among people in older age groups and among females.[14] Some of the mixed findings in this study may relate to the low response rate and the potential for non-response bias.

It is clear from this study that Long COVID can affect individuals irrespective of their prior health status; many of those who reported Long COVID, and were still ill and experiencing severe symptoms with significant impact did not report pre-existing illness and engaged in many protective health behaviours, including exercise.

At the same time, there appeared to be an increased susceptibility among those with pre-existing medical co-morbidities at the onset of their first acute COVID-19 event. People with more than one pre-existing chronic illness were more likely to report Long COVID, persistent Long COVID illness, and a greater symptom severity score than those without pre-existing chronic illness. This is consistent with other studies, as summarised in the HIQA review.[60] The interaction between chronic illness and acute COVID-19 disease severity was recognised early in the course of the pandemic.[49] These findings underscore the importance of a strong focus on chronic disease prevention and management to help protect the public against the acute effects of the COVID-19 pandemic as well as its longer-term impacts though Long COVID.

Reporting receipt of COVID-19 vaccination prior to first illness with COVID-19 was not associated, in this study, with improved Long COVID outcomes. However, reported Long COVID was more common among those who were sampled from periods before more widespread access and uptake of COVID-19 vaccination in Ireland; and greater Long COVID symptom severity scores were also more common for people who had an acute COVID-19 infection prior to the infection that led to the onset of their reported Long COVID. Furthermore, reporting Long COVID, continuing illness, and greater symptom severity scores were all more common among people reporting a greater number of COVID-19 infections. Overall, studies point to COVID-19 vaccination as protective against Long COVID: a recent review of studies found the risk of Long COVID was reduced by approximately 36% in those who received two doses of COVID-19 vaccination before SARS-CoV-2 infection, while most of those with ongoing Long COVID did not experience symptomatic changes following vaccination.[50]

4.5 What do the findings mean for the health service response to Long COVID?

The HSE published an Interim Model of Care for Long COVID in 2021,[29] which comprised a three pillar approach:

Pillar 1:	Pillar 2:	Pillar 3:
Patient-led rehabilitation and recovery, comprising an online support and education platform to manage symptoms at home. At present information on Long COVID is provided on the HSE website to patients, and patients have the opportunity to sign up for the "Living Well" programme which is a free self-management programme for people living with a chronic health condition. The Living Well programme is not specific to Long COVID.	General assessment, support and rehabilitation, comprising General Practice and community rehabilitation.	Specialist assessment support and rehabilitation, comprising specialist acute hospitals clinics supported by community health and social care professionals and early discharge back to primary care for ongoing follow up where appropriate.

A 2022 review by HIQA found approaches and recommendations in the HSE's Interim Model of Care are broadly consistent with those identified in this international literature review;[20] however, it also identified an opportunity to specifically emphasise the need for standardised assessment tools and for structured patient follow-up.

Respondents to this survey most commonly report using services aligned to Pillar 1 and 2 of the HSE Interim Model of Care for Long COVID: GP services were used by four-in-ten people with Long COVID (42.3%) and three-in-ten accessed information on a website (31.4%). Relatively few reported accessing services aligned with Pillar 3. Further exploration of service accessibility would be useful to identify potential unmet need. In general, services were perceived as useful, albeit GP services were more positively assessed by users than website information, which points to an important improvement opportunity given the importance of this service to Pillar 1 and the overall model of care. Furthermore, of services not accessed and perceived to be potentially beneficial, GP services and telephone support were more commonly identified. It is clear from this study that people reporting Long COVID have a

wide range of symptoms with a wide continuum of severity and impact. Some have used and some perceive benefit if they could access more specialised hospital-based services and rehabilitation in line with Pillar 3 of the HSE Model of Care. Furthermore, some respondents have complex needs and some have used various services, some of which may have been less helpful, underscoring an opportunity to improve coordination and care pathways across Pillars of the HSE model of Care. The findings align with an ecology of medical care perspective on Long COVID services: many people with Long COVID can be supported to manage their own care with primary and community care services with some people reporting need that requires coordination of care along a pathway to hospital-based specialist services.[18]

The findings from this study, in conjunction with a more certain assessment of the prevalence of Long COVID in Ireland through the forthcoming Healthy Ireland Survey 2024, offer a timely opportunity to conduct a review of the HSE Interim Model of Care informed by a comprehensive assessment of patient needs. This review should also include an analysis of Long COVID service activity. It should involve people with Long COVID and capture their voice and views on how these services should continue to develop into the future.[51]

4.6 Strengths and limitations of study

This study is the largest analysis of those living with Long COVID in Ireland to date. In the Irish context, much of the Long COVID research is summarised in Table 24 below. As depicted, the existing body of evidence in the Irish context is characterised by, small-scale studies, conducted in specialist post-COVID clinics, inhibiting broad generalisation.[52-56] The sample sizes of these studies range from 40-417. The exception to this is a community-based study by O'Mahony et al, who conducted the next-largest study to date in Ireland, inviting 988 Long COVID sufferers to complete an online survey using internationally-validated instruments. This important study yielded similar findings to the FADA survey in terms of the significant functional impact of Long COVID. However, the sampling strategy was not population-based, rather it was promoted on Long COVID online platforms and launched at a webinar. This design impacts the generalisability of the findings from the study.[25]

Table 24 - The FADA Survey in the context of the existing body of evidence in the Irish setting

Authors	Year published	N	Aim	Design/setting
O'Mahoney et al[25]	2023	988 (89% LC*)	To examine impact of prolonged COVID symptoms on QoL	Online survey
Townsend et al[52]	2020	128	To examine prevalence of fatigue in those recovering from COVID	Cross-sectional; attendees of a post-COVID clinic
Townsend et al[54]	2021	153	Respiratory recovery and self-reported health of post-COVID patients	Cross-sectional; attendees of a post-COVID clinic
O'Brien et al[56]	2023	40 (incl 10 Irish)	To examine the lived experience of disability associated with LC.	Qualitative
Doherty et al[57]	2022	114	To investigate the prevalence of burnout and long COVID in senior physicians	Cross-sectional
Kenny et al[53]	2023	417	To examine the impact of variant and vaccine on LC* symptomatology	Prospective cohort
O'Kelly et al[55]	2022	255	To examine COVID recovery	Prospective cohort; attendees of a post-COVID clinic
Hedin et al[58]	2022	270 (incl 20 Irish)	Symptoms at 3 months follow-up after acute COVID-19	International prospective study – patients recruited by GP
HSE FADA Survey	2024	**4,671** (of whom **2,338** reported LC*)	See page 7 of report	Population-based retrospective cohort study, online questionnaire.

**LC = Long COVID*

As well as the size of the FADA survey, this study addresses research gaps, aligning with current public health concerns regarding COVID-19. The findings have practical implications for Long COVID health service planning and public health approach to COVID-19. The population-based sampling strategy of FADA, including only those with notified and confirmed SARS-CoV-2 events, increases validity. Much of the existing literature focusses on survivors of hospital and ICU admission. This study's inclusion of community patients adds to the breadth of Long COVID research. Community-based patients appear to be a distinctive cohort requiring bespoke services.

The cross-sectional design is a limitation, as the time from sentinel SARS-CoV-2 exposure to survey completion varied. The episodic nature of Long COVID for some of those living with the condition may not have been captured by this study design. The sampling strategy employed to determine the likely variant of SARS-CoV-2 may be imprecise. Given that many people in Ireland have had multiple SARS-CoV-2 infections, the event notified on CIDR may not have led to Long COVID. The overall response rate to the FADA survey, 9.6%, introduces uncertainty with respect to inferences around population prevalence. Selection bias could have impacted on the likelihood of participation, those with Long COVID may be more likely to complete the survey. The identification of study participants as having Long COVID was based on self-reported data, without an independent method of validation. Additionally, some symptoms of Long COVID overlap with those of other chronic illnesses, which may affect the accuracy of self-reports. Recall bias might also impact the accuracy of questions related to pre-COVID-19 behaviours and symptoms. The FADA survey was not translated into other languages, precluding the participation of people with limited English, therefore certain groups may be underrepresented in this cohort. The online nature of the FADA survey may have prevented participation of those less digitally-confident. Finally, persons with severe Long COVID may not have been well enough to participate in the survey, thus not capturing this part of the population and their service needs/experiences.

5. Conclusion

5. Conclusion

Since the emergence of COVID-19 disease as a global pandemic in 2020, it has been argued the world has been "playing catch up" with its understanding of Long COVID as a new disease.[37] The FADA survey helps build our understanding of Long COVID in Ireland, recognising the challenge it presents for the people it affects, and informing the continuing development of the Health Service Executive response to meeting needs of people with Long COVID.

While firm conclusions about the frequency of Long COVID cannot be drawn with confidence from the FADA survey, it provides a rich picture of the landscape of recovery from acute COVID-19 disease, through delineating the current health status of people reporting Long COVID, describing the scope of different symptoms, measuring the severity of symptoms and their impact on function, and assessing health services used by people affected.

A number of recommendations arise from the FADA survey.

Mitigating the impact of COVID-19 now and preparing for the future

It is clear from this study that, following acute COVID-19 infection, some people go on to experience multiple symptoms which have potential to be severe and associated with significant functional impact. Controlling SARS-CoV-2 transmission and minimising the incidence of infection is a key population level strategy to mitigate the impact of COVID-19 and its sequelae. A multi-faceted approach is required that combines actions across both individual and collective responsibility including: staying home when sick; mask-wearing; ventilation; hand hygiene; cough etiquette; testing; contact tracing and contact management; public health communication; government-led non-pharmaceutical measures and support when required; and COVID-19 vaccination programmes.[59]

While some people reporting Long COVID in this study were previously well, in addition to the contribution of pre-existing chronic illness to increased risk of severe acute COVID-19 disease, pre-existing chronic illness has also emerged as a risk factor for Long COVID. Preventing and managing chronic condition is also a key population level strategy to mitigate both the acute as well as the long-term impact of COVID-19. Strengthening communicable disease control to ensure preparedness for future pandemics must be matched with strengthening non-communicable disease control to reduce the prevalence of chronic conditions across the population to protect the public from future pandemic threats including legacy of acute infection.

Developing the HSE Model of Care for Long COVID

While this study confirms the appropriateness of the design of the HSE Model of Care for Long COVID, especially its emphasis in Pillar 1 and 2 on self-management support and the role of primary care, it also informs a review to further develop the health service response to Long COVID in Ireland. Despite the detailed information about Long COVID available on the HSE website, specific online education tailored to Long COVID is not widely available. Moreover, the results of this study indicate a potential unmet need within Primary Care services. The findings from this study should be integrated with an assessment of current services and the view, experience and expertise of people affected by Long COVID to determine the volume and characteristics of future services.

Improving our understanding of Long COVID in Ireland

The FADA survey is an important foundation to building the understanding of Long COVID in Ireland. It will be significantly complemented by the forthcoming Healthy Ireland 2024 Survey which will provide a basis to make more confident inferences about the prevalence of Long COVID in Ireland. While the FADA survey captures the experience of people affected by Long COVID, there is an important role for qualitative research on the experience of people with Long COVID in Ireland as well as the experience of people providing care and health services. A second wave of FADA data collection focussing on respondents who reported Long COVID should be undertaken to improve understanding of the natural course of the condition over time, and to explore the evolution of healthcare utilisation. The need for more comprehensive research to identify and develop an appropriate health system response to complex multi-system disorders and comorbidities is also highlighted by this research.

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8. Appendices

Appendix 1: Timeline and summary of COVID-19 testing in Ireland

The COVID-19 pandemic has been referred to as the "biggest public health crisis since the Second World War".[60] The World Health Organization (WHO) declared a pandemic on 11/03/2020, with the then-Taoiseach in Ireland urging individuals to "stay home" shortly thereafter.[61]Legislation allowed the implementation of non-pharmacological interventions (NPIs), protecting public health and the health service. The strategic deployment of public health interventions and a robust COVID-19 vaccination strategy, emerged as a cornerstone in ameliorating the adverse effects of the pandemic. In Ireland, 928,743 COVID-19 cases (aged over 18, not residing in a residential care facility (RCF) and not deceased) were identified with a PCR/Rapid Antigen Detection test in Ireland from March 01 2020 to January 31, 2022. Approximately 13% of those occurred in the HSE Dublin and Midlands Region.

Description of the COVID-19 testing schedule/regime in Ireland

The first case of COVID-19 was detected in Ireland on 29.02.2020. Access to testing at the time was restricted as system capacity was being developed and expanded to meet impending demand. Testing was quite restricted in the first two months of 2020 with approval for a test required by a Specialist in Public Health Medicine who assessed risk based on a stringent set of factors. Once the disease became widespread in the community and COVID-19 cases were contracting the infection within the community, the criteria for PCR testing for detection of COVID-19 were gradually broadened and by mid-late March 2020 included all close contacts of cases and anyone who was displaying symptoms. However, this was restricted because of constraints in the system due to lack of testing infrastructure and capacity. The country was in lockdown with people not permitted to travel more than 2km from their homes other than under strict conditions. The shortfall in the system regarding testing resources forced the difficult decision to focus resources on vulnerable populations. To address the large number of outbreaks and concerns regarding positive and asymptomatic cases, a process of mass screening of asymptomatic (and not previously confirmed COVID-19 positive) residents and staff in RCFs was undertaken in early April 2020, assisted by the National Ambulance Service. This was extended to include employees of meat factories in late-April 2020. However, to facilitate this in the system, testing for people living at home in the community was restricted.

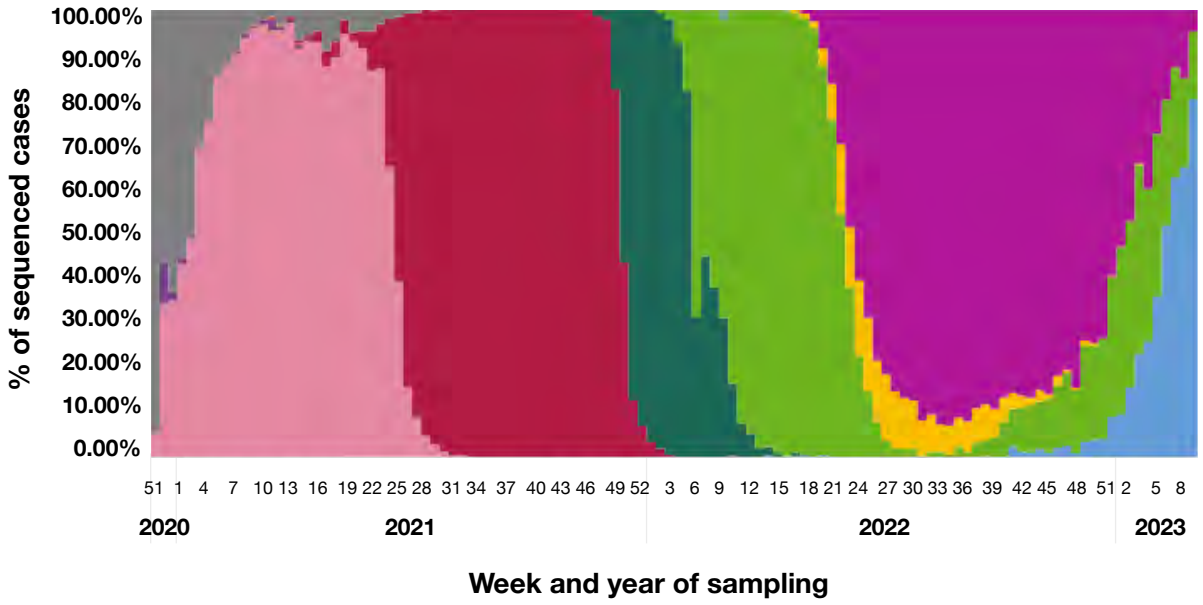
Antigen testing had been the topic of an early review of the REAG subgroup who made a submission on this to the EAG in 2020 (Moynagh et al.)

Additionally, walk-in testing clinics became operational in March 2021. These provided COVID-19 tests for people who were not close contacts of identified cases and were not displaying symptoms of COVID-19. This was to capture people who were infectious with COVID-19 but would not otherwise be detected.

Ireland had a very broad COVID-19 testing regime in place for the duration of 2020 and 2021. In February 2022, in response to the significant increase in COVID-19 spread, the PCR testing system was no longer able to adequately respond to demand. This, coupled with increasing evidence regarding the sensitivity of COVID-19 Rapid Antigen Detection Testing, heavily influenced the decision nationally to move away from our sole dependence on PCR testing to detect COVID-19, to complementing the formal testing regime with informal at-home antigen testing whereby people were asked to self-report positive results to the HSE.

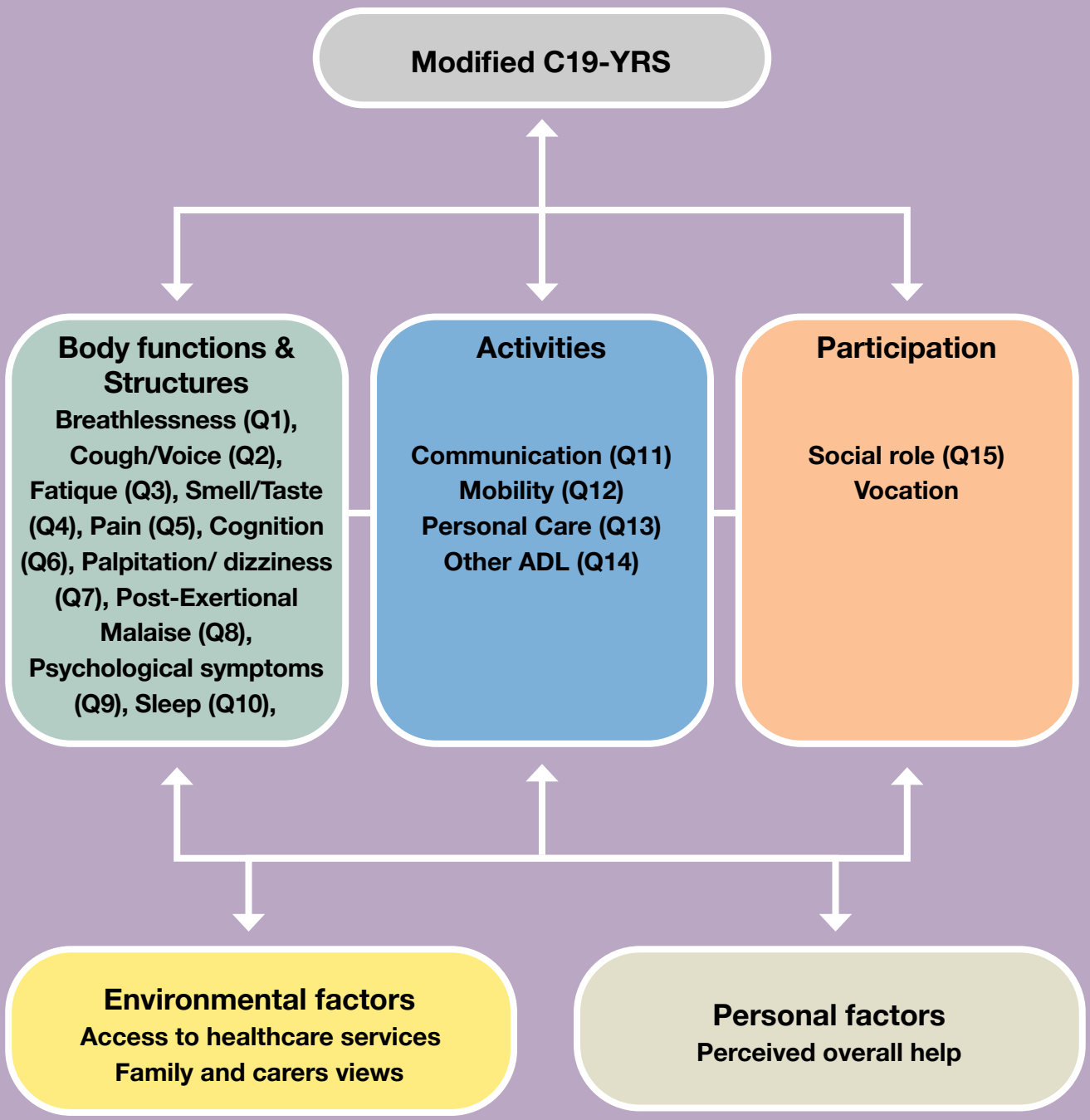
Appendix 2: Designated COVID-19 Pandemic periods in Ireland

COVID pandemic variant waves	Time period
Wild type (wave 1)	Week 10 – 31 2020; 01/03/2020 – 01/08/2020
Wild type (wave 2)	Week 32 – 47 2020; 02/08/2020 – 21/11/2020
Alpha (wave 3)	Week 48 2020 – Week 25 2021; 22/11/2020 – 26/06/2021
Delta (wave 4)	Week 26 – 50 2021; 27/06/2021 – 18/12/2021
Omicron (wave 5)	Week 51 2021; 19/12/2021 – present



COVID pandemic variant waves			
B.1.1.7 (Alpha)	B.1.351 (Beta)	P.1 (Gamma)	B.1.617.2 (Delta)
Recombinant variants	B.A.1 (Omicron)	B.A.2 (Omicron)	B.A.3 (Omicron)
B.A.4 (Omicron)	B.A.5 (Omicron)	Non variant of concern	
Omicron (wave 5)	Week 51 2021; 19/12/2021 – present		

Appendix 3: The Modified COVID-19 Yorkshire Rehabilitation Score (C19-YRSm)



Appendix 4: Response rate by gender, age group and wave

All COVID-19 Waves						
		Population	**Sample**		**Response**	
		n	n	%	n	%
Male	Age 18-19	2,794	1,137	40.70%	49	4.30%
	Age 20-24	6,989	2,936	42.01%	71	2.40%
	Age 25-29	6,341	2,493	39.32%	76	3.00%
	Age 30-34	6,251	2,541	40.65%	87	3.40%
	Age 35-39	6,655	2,711	40.74%	139	5.10%
	Age 40-44	6,852	2,863	41.78%	189	6.60%
	Age 45-49	5,659	2,410	42.59%	230	9.50%
	Age 50-54	4,306	1,846	42.87%	204	11.10%
	Age 55-59	3,343	1,463	43.76%	191	13.10%
	Age 60-64	2,665	1186	33.28%	207	17.50%
	Age 65-69	1,965	887	45.14%	162	18.30%
	Age 70-74	1,396	619	44.34%	103	16.60%
	Age 75-79	841	324	38.53%	43	13.30%
	Age 80-84	460	177	38.48%	17	9.60%
	Age 85+	443	107	24.15%	9	8.40%
Subtotal	***All Males***	***56,960***	***23,700***	***0***	***1,777***	7.50%
Female	Age 18-19	3,011	1,235	41.02%	73	5.90%
	Age 20-24	7,275	3,175	43.64%	175	5.50%
	Age 25-29	6,595	2,785	42.23%	170	6.10%
	Age 30-34	6,825	2,839	41.60%	220	7.70%
	Age 35-39	7,506	3,171	42.25%	312	9.80%
	Age 40-44	7,666	3,398	44.33%	453	13.30%
	Age 45-49	5,815	2,573	44.25%	376	14.60%
	Age 50-54	4,245	1,887	44.45%	321	17.00%
	Age 55-59	3,420	1,572	45.96%	276	17.60%
	Age 60-64	2,657	1,226	46.14%	224	18.30%
	Age 65-69	1,865	874	46.86%	131	15.00%
	Age 70-74	1,317	574	43.58%	94	16.40%
	Age 75-79	794	323	40.68%	34	10.50%
	Age 80-84	554	188	33.94%	22	11.70%
	Age 85+	695	122	17.55%	13	10.70%
Subtotal	***All Females***	***60,240***	***25,942***	***43.06%***	***2,894***	11.20%
Total	**All**	**117,200**	**49,642**	**42.36%**	**4,671**	**9.40%**

Wildtype						
		Population	**Sample**		**Response**	
		n	n	%	n	%
Male	Age 18-19	276	178	64.49%	9	5.06%
	Age 20-24	771	506	65.63%	13	2.57%
	Age 25-29	778	449	57.71%	13	2.90%
	Age 30-34	756	481	63.62%	21	4.37%
	Age 35-39	779	497	63.80%	44	8.85%
	Age 40-44	736	488	66.30%	38	7.79%
	Age 45-49	753	474	62.95%	49	10.34%
	Age 50-54	676	460	68.05%	64	13.91%
	Age 55-59	539	356	66.05%	47	13.20%
	Age 60-64	401	251	62.59%	45	17.93%
	Age 65-69	271	153	56.46%	25	16.34%
	Age 70-74	241	119	49.38%	18	15.13%
	Age 75-79	172	68	39.53%	5	7.35%
	Age 80-84	125	39	31.20%	5	12.82%
	Age 85+	162	22	13.58%	-	0.00%
Subtotal	***All Males***	***7,436***	***4,541***	***1***	***396***	***0***
Female	Age 18-19	298	184	61.74%	9	4.89%
	Age 20-24	897	587	65.44%	29	4.94%
	Age 25-29	845	513	60.71%	28	5.46%
	Age 30-34	896	535	59.71%	51	9.53%
	Age 35-39	892	599	67.15%	66	11.02%
	Age 40-44	928	637	68.64%	97	15.23%
	Age 45-49	816	575	70.47%	83	14.43%
	Age 50-54	717	527	73.50%	114	21.63%
	Age 55-59	597	408	68.34%	70	17.16%
	Age 60-64	401	284	70.82%	58	20.42%
	Age 65-69	271	167	61.62%	24	14.37%
	Age 70-74	207	106	51.21%	13	12.26%
	Age 75-79	174	67	38.51%	7	10.45%
	Age 80-84	201	48	23.88%	5	10.42%
	Age 85+	335	36	10.75%	5	13.89%
Subtotal	***All Females***	***8,475***	***5,273***	***62.22%***	***659***	**12.50%**
Total	**All**	**15,911**	**9,814**	***61.68%***	**1,055**	**10.75%**

Alpha						
		Population	**Sample**		**Response**	
		n	n		n	%
Male	Age 18-19	200	161	80.50%	4	2.48%
	Age 20-24	631	546	86.53%	11	2.01%
	Age 25-29	548	458	83.58%	15	3.28%
	Age 30-34	564	477	84.57%	11	2.31%
	Age 35-39	620	534	86.13%	26	4.87%
	Age 40-44	560	502	89.64%	29	5.78%
	Age 45-49	486	429	88.27%	41	9.56%
	Age 50-54	371	321	86.52%	23	7.17%
	Age 55-59	289	250	86.51%	35	14.00%
	Age 60-64	214	194	90.65%	33	17.01%
	Age 65-69	155	139	89.68%	27	19.42%
	Age 70-74	101	80	79.21%	8	10.00%
	Age 75-79	65	47	72.31%	5	10.64%
	Age 80-84	40	25	62.50%	1	4.00%
	Age 85+	30	22	73.33%	4	18.18%
Subtotal	***All Males***	***4,874***	***4,185***	**85.86%**	***273***	**6.52%**
Female	Age 18-19	233	203	87.12%	10	4.93%
	Age 20-24	596	548	91.95%	19	3.47%
	Age 25-29	534	484	90.64%	30	6.20%
	Age 30-34	550	491	89.27%	36	7.33%
	Age 35-39	636	588	92.45%	57	9.69%
	Age 40-44	563	512	90.94%	61	11.91%
	Age 45-49	462	412	89.18%	43	10.44%
	Age 50-54	319	287	89.97%	52	18.12%
	Age 55-59	284	258	90.85%	33	12.79%
	Age 60-64	202	172	85.15%	27	15.70%
	Age 65-69	129	112	86.82%	16	14.29%
	Age 70-74	100	88	88.00%	11	12.50%
	Age 75-79	53	45	84.91%	2	4.44%
	Age 80-84	40	33	82.50%	3	9.09%
	Age 85+	26	16	61.54%	2	12.50%
Subtotal	***All Females***	***4,727***	***4,249***	**89.89%**	***402***	***9.46%***
Total	**All**	**9,601**	**8,434**	**87.85%**	**675**	***8.00%***

Delta						
		Population	**Sample**		**Response**	
		n	n	%	n	%
Male	Age 18-19	1,318	528	40.06%	19	3.60%
	Age 20-24	2,904	1,142	*39.33%*	20	*1.75%*
	Age 25-29	2,490	934	37.51%	20	2.14%
	Age 30-34	2,353	914	*38.84%*	29	*3.17%*
	Age 35-39	2,345	849	36.20%	35	4.12%
	Age 40-44	2,218	811	*36.56%*	51	*6.29%*
	Age 45-49	1,784	630	35.31%	59	9.37%
	Age 50-54	1,499	557	*37.16%*	48	*8.62%*
	Age 55-59	1,244	440	35.37%	52	11.82%
	Age 60-64	1,103	448	*40.62%*	72	*16.07%*
	Age 65-69	855	335	39.18%	61	18.21%
	Age 70-74	605	260	*42.98%*	50	*19.23%*
	Age 75-79	317	113	35.65%	15	13.27%
	Age 80-84	126	50	*39.68%*	5	*10.00%*
	Age 85+	101	33	32.67%	2	6.06%
Subtotal	***All Males***	***21,262***	***8,044***	***37.83%***	***538***	***6.69%***
Female	Age 18-19	1,235	498	40.32%	29	5.82%
	Age 20-24	2,883	1,171	*40.62%*	68	*5.81%*
	Age 25-29	2,453	985	40.15%	62	6.29%
	Age 30-34	2,446	927	*37.90%*	67	*7.23%*
	Age 35-39	2,594	949	36.58%	99	10.43%
	Age 40-44	2,391	933	*39.02%*	137	*14.68%*
	Age 45-49	1,822	708	38.86%	111	15.68%
	Age 50-54	1,389	522	*37.58%*	76	*14.56%*
	Age 55-59	1,220	479	39.26%	94	19.62%
	Age 60-64	1,077	433	*40.20%*	70	*16.17%*
	Age 65-69	807	342	42.38%	50	14.62%
	Age 70-74	563	213	*37.83%*	39	*18.31%*
	Age 75-79	294	110	37.41%	15	13.64%
	Age 80-84	135	41	*30.37%*	4	*9.76%*
	Age 85+	148	39	26.35%	3	7.69%
Subtotal	***All Females***	***21,457***	***8,350***	***38.92%***	***924***	***11.07%***
Total	**All**	**42,719**	**16,394**	***38.38%***	**1,462**	**8.92%**

Omicron						
		Population	Sample		Response	
		N	n	%	n	%
Male	Age 18-19	1,000	270	27.00%	17	6.30%
	Age 20-24	2,683	742	27.66%	27	3.64%
	Age 25-29	2,525	652	25.82%	28	4.29%
	Age 30-34	2,578	669	25.95%	26	3.89%
	Age 35-39	2,911	831	28.55%	34	4.09%
	Age 40-44	3,338	1,062	31.82%	71	6.69%
	Age 45-49	2,636	877	33.27%	81	9.24%
	Age 50-54	1,760	508	28.86%	69	13.58%
	Age 55-59	1,271	417	32.81%	57	13.67%
	Age 60-64	947	293	30.94%	57	19.45%
	Age 65-69	684	260	38.01%	49	18.85%
	Age 70-74	449	160	35.63%	27	16.88%
	Age 75-79	287	96	33.45%	18	18.75%
	Age 80-84	169	63	37.28%	6	9.52%
	Age 85+	150	30	20.00%	3	10.00%
Subtotal	***All Males***	***23,388***	***6,930***	***29.63%***	***570***	***8.23%***
Female	Age 18-19	1,245	350	28.11%	25	7.14%
	Age 20-24	2,899	869	29.98%	59	6.79%
	Age 25-29	2,763	803	29.06%	50	6.23%
	Age 30-34	2,933	886	30.21%	66	7.45%
	Age 35-39	3,384	1,035	30.59%	90	8.70%
	Age 40-44	3,784	1,316	34.78%	158	12.01%
	Age 45-49	2,715	878	32.34%	139	15.83%
	Age 50-54	1,820	551	30.27%	79	14.34%
	Age 55-59	1,319	427	32.37%	79	18.50%
	Age 60-64	977	337	34.49%	69	20.47%
	Age 65-69	658	253	38.45%	41	16.21%
	Age 70-74	447	167	37.36%	31	18.56%
	Age 75-79	273	101	37.00%	10	9.90%
	Age 80-84	178	66	37.08%	10	15.15%
	Age 85+	186	31	16.67%	3	9.68%
Subtotal	***All Females***	***25,581***	***8,070***	***31.55%***	***909***	***11.26%***
Total	**All**	**48,969**	**15,000**	**30.63%**	**1,479**	**9.86%**

Appendix 5: FADA Study Questionnaire

Below the questions are colour shaded, there is other shading explained throughout

Grey were asked of everyone
Green were asked of those that said they had Long COVID as determined by Q233 still ill
Blue are asked of those that said they are now recovered as determined by Q233 recovered now
Orange Asked depending on response to Q243

Q231 Before we get started please let us know that you are happy to complete this survey. Please visit www.hse.ie/fadasurvey for more information.

Q1 I have read the information for the FADA survey and have had the opportunity to ask questions.	
Yes ☐	**No** ☐
Q2 I understand the information provided and have had enough time to consider it.	
Yes ☐	**No** ☐
Q3 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	
Yes ☐	**No** ☐
5A I understand the answers I provide will be added to my COVID-19 record held securely by the HSE Department of Public Health, Area B.	
Yes ☐	**No** ☐
Q279 I agree to take part in the FADA survey.	
Yes ☐	**No** ☐
Q232 The next few questions will tell us more about your recovery from COVID-19 and help us to understand how you are since you had COVID-19.	

Q1 How many times have you had COVID-19, confirmed through a test or suspected?
1. ☐ **2.** ☐ **3.** ☐ **4.** ☐ **5.** ☐
If you had COVID-19 more than 5 times please include the number here _____

Q2 Have you returned to your usual health following your COVID-19 infection or do you have ongoing symptoms?

- ☐ **Yes, I still have it**
- ☐ **Yes, but I have recovered now**
- ☐ **No**

Q171 Do you think that you have, or ever had, Long COVID?

- ☐ **Yes, I still have it**
- ☐ **Yes, but I have recovered now**
- ☐ **No**

Q233 Most COVID-19 infections get better within 4 weeks.

"Long COVID" means your symptoms carry on for 4 weeks or more, even after your COVID-19 infection has cleared. Long COVID can also mean that you are having new health problems after your COVID infection has resolved.

Long COVID can cause different problems that change over time. These symptoms have no other explanation and generally have an impact on day to day functioning.

The most common symptoms of Long COVID are:

- Lung or chest problems – like breathlessness, cough or chest pain
- Fatigue or feeling tired all the time
- Pain – where any part of your body can hurt
- Brain problems – like finding it hard to focus, getting headaches, feeling dizzy or having problems sleeping
- Stomach problems – like feeling pain in your tummy, feeling sick, having diarrhoea or loose or watery poo, having no appetite, losing weight
- Mental health problems – like feeling more depressed or worried than usual
- Skin problems – like unusual rashes
- Ear nose and throat problems – like a change in your sense of taste or smell, earaches, sore throat or ringing in your ears

Q121 After reading the information above, do you think that you have, or have ever had, Long COVID?

- ☐ **Yes, I still have it**
- ☐ **Yes, but I have recovered now**
- ☐ **No**

Q294 Which statement below best reflects how long you were sick after your COVID-19 infection?

- ☐ **Lasted longer than 4 weeks but resolve within 3 months**
- ☐ **Symptoms continued for longer then 3 months**

Q109 How long from when you got your COVID-19 infection did it take for you to return to usual health?

- ☐ less than 1 month
- ☐ 1 month
- ☐ 2 months
- ☐ 3 months
- ☐ 4 months
- ☐ 5 months
- ☐ 6 months
- ☐ 7 months
- ☐ 8 months
- ☐ 9 months
- ☐ 10 months
- ☐ 11 months
- ☐ 12 months
- ☐ 13 months
- ☐ 14 months
- ☐ 15 months
- ☐ 16 months
- ☐ 17 months
- ☐ 18 months
- ☐ 19 months
- ☐ 20 months
- ☐ 21 months
- ☐ 22 months
- ☐ 23 months
- ☐ 24 months
- ☐ Longer than 2 years

Q122 Were you ever diagnosed with Long COVID by a doctor?

- ☐ Yes
- ☐ No

Q173 When did you get the COVID-19 infection that led you to developing prolonged symptoms?

- ☐ 2020
- ☐ 2020 ~ January
- ☐ 2020 ~ February
- ☐ 2020 ~ March
- ☐ 2020 ~ April
- ☐ 2020 ~ May
- ☐ 2020 ~ June
- ☐ 2020 ~ July
- ☐ 2020 ~ August
- ☐ 2020 ~ September
- ☐ 2020 ~ October
- ☐ 2020 ~ November
- ☐ 2020 ~ December

- [ ] 2021
- [ ] 2021 ~ January
- [ ] 2021 ~ February
- [ ] 2021 ~ March
- [ ] 2021 ~ April
- [ ] 2021 ~ May
- [ ] 2021 ~ June
- [ ] 2021 ~ July
- [ ] 2021 ~ August
- [ ] 2021 ~ September
- [ ] 2021 ~ October
- [ ] 2021 ~ November
- [ ] 2021 ~ December
- [ ] 2022
- [ ] 2022 ~ January
- [ ] 2022 ~ February
- [ ] 2022 ~ March
- [ ] 2022 ~ April
- [ ] 2022 ~ May
- [ ] 2022 ~ June
- [ ] 2022 ~ July
- [ ] 2022 ~ August
- [ ] 2022 ~ September
- [ ] 2022 ~ October
- [ ] 2022 ~ November
- [ ] 2022 ~ December
- [ ] 2023
- [ ] 2023 ~ January

Q174 Were you experiencing Long COVID symptoms before your most recent COVID-19 infection?

- [ ] Yes
- [ ] No

EQ-5D-5L

Q1 Here we want to understand more about how you are today. Even if you are feeling well now, please answer the questions. It is important for us to know that you have made a full recovery from COVID-19. On the following screens, please tap the statement that best describes your health TODAY. Your mobility TODAY

- ☐ I have no problems in walking about
- ☐ I have slight problems in walking about
- ☐ I have moderate problems in walking about
- ☐ I have severe problems in walking about
- ☐ I am unable to walk about

☐ **Q1 On the following screens, please tap the statement that best describes your health TODAY. Your usual activities TODAY (e.g. work, study, housework, family or leisure activities)**

- ☐ I have no problems doing my usual activities
- ☐ I have slight problems doing my usual activities
- ☐ I have moderate problems doing my usual activities
- ☐ I have severe problems doing my usual activities
- ☐ I am unable to do my usual activities

Q1 On the following screens, please tap the statement that best describes your health TODAY. Your self-care TODAY

- ☐ I have no problems washing or dressing myself
- ☐ I have slight problems washing or dressing myself
- ☐ I have moderate problems washing or dressing myself
- ☐ I have severe problems washing or dressing myself
- ☐ I am unable to wash or dress myself

Q1 On the following screens, please tap the statement that best describes your health TODAY. Your pain / discomfort TODAY

- ☐ I have no pain or discomfort
- ☐ I have slight pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have severe pain or discomfort
- ☐ I have extreme pain or discomfort

Q1 On the following screens, please tap the statement that best describes your health TODAY. Your anxiety / depression TODAY
☐ I am not anxious or depressed ☐ I am slightly anxious or depressed ☐ I am moderately anxious or depressed ☐ I am severely anxious or depressed ☐ I am extremely anxious or depressed
Q1 On the following screens, please tap the statement that best describes your health TODAY.
Q1 We would like to know how good or bad your health is TODAY. **On the next screen you will see a scale numbered 0 to 100.** **100 means the best health you can imagine.** **0 means the worst health you can imagine**
Q1 On the following screens, please tap the statement that best describes your health TODAY.

Q229 How would you rate your health TODAY? This scale is numbered 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Please move the slider on the point scale to indicate how your health is TODAY.

	0	10	20	30	40	50	60	70	80	90	100
											

Modified Yorkshire Rehabilitation Screening Tool for Long COVID

Q200 Please answer the questions below to the best of your knowledge. 'Now' refers to how you feel NOW /this week (last 7 days). " BEFORE COVID " refers to how you were feeling prior to contracting the illness.

	none; no problems	mild problem; does not affect daily life	Moderate problem; affects daily life to a certain extent	Severe problems; affects all aspects of daily life; life disturbing
Breathlessness At Rest (NOW)				
Breathlessness At Rest (BEFORE COVID-19)				
Breathlessness changing position. e.g. from lying to sitting or sitting to lying (NOW)				
Breathlessness changing position. e.g. from lying to sitting or sitting to lying (BEFORE COVID-19)				
Breathlessness on dressing yourself (NOW)				
Breathlessness on dressing yourself (BEFORE COVID-19)				
Breathlessness on walking up a flight of stairs (NOW)				
Breathlessness on walking up a flight of stairs (BEFORE COVID-19)				
Cough\throat sensitivity (NOW)				
Cough\throat sensitivity (BEFORE COVID-19)				

Change of voice (NOW)				
Change of voice (BEFORE COVID-19)				
Fatigue levels in your usual activities (NOW)				
Fatigue levels in your usual activities (BEFORE COVID-19)				
Altered smell (NOW)				
Altered smell (BEFORE COVID-19)				
Altered taste (NOW)				
Altered taste (BEFORE COVID-19)				
Chest pain (NOW)				
Chest pain (BEFORE COVID-19)				
Joint pain (NOW)				
Joint pain (BEFORE COVID-19)				
Muscle pain (NOW)				
Muscle pain (BEFORE COVID-19)				
Headache (NOW)				
Headache (BEFORE COVID-19)				
Abdominal pain (NOW)				
Abdominal pain (BEFORE COVID-19)				

Problems with concentration (NOW)				
Problems with concentration (BEFORE COVID-19)				
Problems with memory (NOW)				
Problems with memory (BEFORE COVID-19)				
Problems with planning (NOW)				
Problems with planning (BEFORE COVID-19)				
Palpitations in certain positions, activity or at rest (NOW)				
Palpitations in certain positions, activity or at rest (BEFORE COVID-19)				
Dizziness in certain positions, activity or at rest (NOW)				
Dizziness in certain positions, activity or at rest (BEFORE COVID-19)				
Crashing or relapse hours or days after physical, cognitive or emotional exertion (NOW)				
Crashing or relapse hours or days after physical, cognitive or emotional exertion (BEFORE COVID-19)				
Feeling anxious (NOW)				
Feeling anxious (BEFORE COVID-19)				
Feeling depressed (NOW)				

Feeling depressed (BEFORE COVID-19)				
Having unwanted memories of your illness or time in hospital (NOW)				
Having unwanted memories of your illness or time in hospital (BEFORE COVID-19)				
Having unpleasant dreams about your illness or time in hospital (NOW)				
Having unpleasant dreams about your illness or time in hospital (BEFORE COVID-19)				
Trying to avoid thoughts or feelings about your illness or time in hospital (NOW)				
Trying to avoid thoughts or feelings about your illness or time in hospital (BEFORE COVID-19)				
Sleep problems, such as difficulty falling asleep, staying asleep or oversleeping (NOW)				
Sleep problems, such as difficulty falling asleep, staying asleep or oversleeping (BEFORE COVID-19)				
Difficulty with communication/word finding difficulty/ understanding others (NOW)				
Difficulty with communication/word finding difficulty/ understanding others (BEFORE COVID-19)				

Difficulties with walking or moving around (NOW)				
Difficulties with walking or moving around (BEFORE COVID-19)				
Difficulties with personal tasks such as using the toilet or getting washed and dressed (NOW)				
Difficulties with personal tasks such as using the toilet or getting washed and dressed (BEFORE COVID-19)				
Difficulty doing wider activities, such as household work, leisure/ sporting activities, paid/ unpaid work, study or shopping (NOW)				
Difficulty doing wider activities, such as household work, leisure/ sporting activities, paid/ unpaid work, study or shopping (BEFORE COVID-19)				
Problems with socialising/interacting with friends* or caring for dependents (*related to your illness and not due to social distancing or lockdown measures) (NOW)				
Problems with socialising/interacting with friends* or caring for dependents (*related to your illness and not due to social distancing or lockdown measures) (BEFORE COVID-19)				

Q125 Other symptoms Please select any of the following symptoms that you have experienced since your illness, in the last 7 days . Please also select any previous problems that worsened for you following your illness.

- ☐ Fever
- ☐ Skin rash/ discolouration of skin
- ☐ New allergy such as medication, food, etc.
- ☐ Hair loss
- ☐ Skin sensation (numbness/tingling/itching/nerve pain)
- ☐ Dry eyes/ redness of eyes
- ☐ Swelling of feet/ swelling of hands
- ☐ Easy bruising/ bleeding
- ☐ Visual changes
- ☐ Difficulty swallowing solids
- ☐ Difficulty swallowing liquids
- ☐ Balance problems or falls
- ☐ Weakness or movement problems or coordination problems in limbs
- ☐ Tinnitus (ringing in your ears)
- ☐ Nausea
- ☐ Dry mouth/ mouth ulcers
- ☐ Acid reflux/ heartburn
- ☐ Change in appetite
- ☐ Unintentional weight loss
- ☐ Unintentional weight gain
- ☐ Bladder frequency, urgency or incontinence
- ☐ Constipation, diarrhoea or bowel incontinence
- ☐ Change in menstrual cycles or flow
- ☐ Waking up at night gasping for air (also called sleep apnea)
- ☐ Thoughts about harming yourself

Q126 Did you experience any other symptoms since your illness in the last 7 days that are not listed above. Please also include any previous problems that have worsened for you following your illness

Q127 How good or bad is your health for each of the time periods listed below? For this question, a score of 10 means the BEST health you can imagine. 0 means the WORST health you can imagine.

	0	10	20	30	40	50	60	70	80	90	100
Over the last 7 days											
Pre-COVID											
Your health when you were at your sickest (with your prolonged illness due to COVID-19)											

Q130 What is your Occupation? If you have retired please indicate your occupation before you retired.

Q131 Has your COVID-19 illness affected your work?
☐ No change ☐ On reduced working hours ☐ On sickness leave ☐ Changes made to role/ working arrangements (such as working from home or lighter duties) ☐ Had to retire/ change job ☐ Lost job ☐ Any other comments or concerns? _____

Q175 Other comments or concerns regarding your employment?

Q132 Would your partner, family or carer like to add anything from their perspective? If so, this is a space for them to do so.

Q241 Now we have some questions about the different types of health care you have received to help you with any symptoms or health problems you developed after your COVID-19 infection.

Q243 Which healthcare services did you use during your prolonged illness after your COVID-19 infection? Please select all that apply and include telephone, video and virtual consultations as well as face to face. Even if you feel better now we want to know about services that you used.

- ☐ Information on a website
- ☐ Telephone support
- ☐ GP
- ☐ GP Nurse
- ☐ Public Health Nurse or Community Nurse
- ☐ Emergency Department
- ☐ Ambulance Service or Paramedic
- ☐ Community Pharmacist
- ☐ Community Physiotherapist
- ☐ Community Occupational Therapist
- ☐ Community Speech and Language Therapist
- ☐ Community Dietitian
- ☐ Community Counsellor or Psychologist
- ☐ Home help
- ☐ Home-based rehabilitation service
- ☐ Hospital-based rehabilitation service
- ☐ Overnight respite care
- ☐ Hospital out-patient appointment
- ☐ Hospital day-case appointment
- ☐ Hospital in-patient
- ☐ Alternative Health providers, like herbalist, homoeopathist, reflexologist, etc.
- ☐ Other

The questions in the this section were piped based on the response provide in Q243

Q244 What website did you find most helpful for your prolonged illness due to COVID-19?

Q263 Thinking about that website, was it helpful?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q245 How many times did you seek telephone support for your prolonged illness due to COVID-19?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q260 What Telephone support did you access?

Q265 Thinking about the Telephone support service, was it helpful?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q265 Thinking about the Telephone support service, was it helpful?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q119 How many GP consultations did you have because of your prolonged illness due to COVID-19?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q246 Thinking about your health after your COVID infection, were GP consultations helpful?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q143 How many GP Nurse consultations did you have because of your prolonged illness due to COVID-19? (please include in-person as well as virtual and telephone consultations)

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q247 Thinking about your health after your COVID infection, did you feel you benefited from using GP Nurse?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q150 How many Public Health Nurse (PHN) or community nurse visits did you have because of your prolonged illness due to COVID-19? Please include visits to your home and visits to the health centre as well as virtual and telephone consultations.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q248 Thinking about your health after your COVID infection, did you feel using that your visits to the PHN or community nurse helped you?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q146 How many times did you visit the Emergency Department because of your prolonged illness due to COVID-19?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q249 Thinking about your health after your COVID infection, did you feel that visiting the Emergency Department helped you?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q280 How many times did you use the Ambulance service for your prolonged illness due to COVID-19? Please include both in-person, over-the-phone and virtual.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q281 Thinking about your health after your COVID infection, did you feel you benefited from engaging with the Ambulance service?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q277 How many times did you consult with a pharmacist for your prolonged illness due to COVID-19? Please include both in-person, over-the-phone and virtual.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q278 Thinking about your health after your COVID infection, did you find that your contact with your Pharmacist was helpful?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q240 How many times did you see a physiotherapist because of your prolonged illness due to COVID-19? Please include both in-person and virtual consultations.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q252 Thinking about your health after your COVID infection, did you feel you benefited from visiting a Physiotherapist?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q153 How many times did you have to see an Occupational Therapist because of your prolonged illness due to COVID-19, please include both in-person and virtual consultations?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q255 Thinking about your health after your COVID infection, did you feel you benefited from visiting an Occupational Therapist?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q152 How many times did you have to see a Speech and Language Therapist because of your prolonged COVID-19 illness due to COVID-19, please include both in-person and virtual? consults?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q253 Thinking about your health after your COVID infection, did you feel you benefited from visiting a Speech and Language Therapist?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q155 How many times did you have to see a Dietitian because of your prolonged illness due to COVID-19, please include both in-person and virtual consults?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q254 Thinking about your health after your COVID infection, did you feel you benefited from visiting a Dietitian?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q157 How many sessions did you have with a Counsellor/Psychologist because of your prolonged illness due to COVID-19, please include both in-person and virtual consults?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q256 Thinking about your health after your COVID infection, did you feel you benefited from visiting a Counsellor/Psychologist?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q159 How many Home Help or personal care attendant hours per week do/did you receive because of your prolonged illness due to COVID-19, that you did not need before you had COVID-19?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q256 Thinking about your health after your COVID infection, did you feel you benefited from visiting a Counsellor/Psychologist?
☐ Yes, completely ☐ Yes, somewhat ☐ No
Q269 Thinking about your health after your COVID infection, did you feel you benefited from having home help?
☐ Yes, completely ☐ Yes, somewhat ☐ No
Q271 How many home-based rehabilitation sessions did you have because of your prolonged illness due to COVID-19?
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ 10 or more
Q272 Thinking about your health after your COVID infection, did you feel you benefited from the home-based rehabilitation sessions?
☐ Yes, completely ☐ Yes, somewhat ☐ No

Q273 How many hospital-based rehabilitation sessions did you have because of your prolonged illness due to COVID-19?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q274 Thinking about your health after your COVID infection, did you feel you benefited from the hospital-based rehabilitation sessions?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q169 How many times were you admitted to the respite facility or rehabilitation facility for an overnight stay because of your prolonged illness dur to COVID-19?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q266 Thinking about your respite facility or rehabilitation facility admission, was it helpful?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q147 How many times did you visit a HSE Outpatient Clinic because of your prolonged illness due to COVID-19, other than a HSE Long COVID Clinic?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q251 Thinking about your health after your COVID infection, did you feel you benefited from visiting the HSE Outpatient Clinic?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q267 Please specify the type of Outpatient clinic you visited, if more than one please include all.

Q275 How many times did you attend hospital for a day procedure because of your prolonged illness due to COVID-19?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q276 Thinking about your health after your COVID infection, did you feel you benefited from your procedure?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q162 How many times have you been admitted to hospital overnight for your prolonged illness due to COVID-19

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more
- ☐ More than 10 admissions to hospital because of Long COVID

Q161 How many consultations did you have with an alternative or complementary health provider like herbalist, homoeopathist, reflexologist, etc. because of your prolonged illness due to COVID-19?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 10 or more

Q270 Thinking about your health after your COVID infection, did you find that using complementary or alternative health providers was helpful?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No

Q215 Please specify the number of sessions/visits with a healthcare professional (other than those listed previously) because of your prolonged illness due to COVID-19.
Q282 Please specify the type of healthcare you used if not included in the previous list.
Q283 Here is the list of services again. Please think of services you DID NOT USE but think would help you now in your recovery?
Q284 We want to know about services that you think would benefit you in dealing with your prolonged illness from COVID-19? Please choose up to 3 services, you did <u>not</u> use that you think would benefit you most now.
☐ Information on a website ☐ Telephone support ☐ GP ☐ GP Nurse ☐ Public Health Nurse or Community Nurse ☐ Community Pharmacist ☐ Community Physiotherapist ☐ Community Occupational Therapist ☐ Community Speech and Language Therapist ☐ Community Dietitian ☐ Home help ☐ Home-based rehabilitation service ☐ Hospital-based rehabilitation service ☐ Overnight respite care ☐ Hospital out-patient appointment ☐ Hospital day-case appointment ☐ Hospital in-patient

Q258 Although you feel better now, we want to know about services that you think would have benefited you in dealing with your prolonged illness from COVID-19? Please choose up to 3 services, you did NOT use, that you think would have benefited you most when you were ill.

- ☐ Information on a website
- ☐ Telephone support
- ☐ GP
- ☐ GP Nurse
- ☐ Public Health Nurse or Community Nurse
- ☐ Community Pharmacist
- ☐ Community Physiotherapist
- ☐ Community Occupational Therapist
- ☐ Community Speech and Language Therapist
- ☐ Community Dietitian
- ☐ Home help
- ☐ Home-based rehabilitation service
- ☐ Hospital-based rehabilitation service
- ☐ Overnight respite care
- ☐ Hospital out-patient appointment
- ☐ Hospital day-case appointment
- ☐ Hospital in-patient

Q1 Sometimes your COVID-19 illness may be affected by whether or not you were vaccinated against COVID-19 (your vaccination status). Please let us know more about your vaccination status when you had COVID-19. How many doses of a COVID-19 vaccination had you received the first time you got COVID-19?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4

Q114 When was the last time that you had COVID-19?

- ☐ Within the last 2 weeks
- ☐ Between 2 and 4 weeks ago
- ☐ Between 4 and 8 weeks ago
- ☐ Between 8 and 12 weeks ago
- ☐ more than 12 weeks ago

Q111 How would you describe your COVID-19 symptoms? If you had COVID more than once please provide details for the infection that you felt sickest.

- ☐ No symptoms
- ☐ Mild – experienced one or more symptoms but you were not very sick
- ☐ Moderate – experienced one or more symptoms and maybe needed a couple of days resting
- ☐ Somewhat severe - experienced one or more symptoms and you were very sick
- ☐ Severe – hospitalised

Q115 Please tell us about the health services you used the time that you were sickest with COVID-19

- ☐ Consulted with GP (either virtually or in-person)
- ☐ Admitted to hospital
- ☐ Admitted to ICU
- ☐ Visited the Emergency Department.
- ☐ Ambulance Service
- ☐ Other
- ☐ None

Q191 We are interested to see if having certain health problems affects how people recover from COVID-19. Thinking back to before you had COVID-19 for the first time, were you living with any of these long-term health conditions (please select all that apply)?

- ☐ No health problems
- ☐ Chronic lung disease, eg. COPD or asthma
- ☐ Heart problems eg. angina, a previous heart attack or heart failure
- ☐ Autoimmune Disease eg. Lupus, rheumatoid arthritis, Crohn's
- ☐ Diabetes
- ☐ Mental health difficulties eg. depression, anxiety
- ☐ Cancer
- ☐ Kidney problems eg. chronic renal impairment
- ☐ Arthritis eg. osteoarthritis or rheumatism
- ☐ Dementia or memory loss
- ☐ Alcohol or substance abuse
- ☐ Stomach, bowel or digestion problems
- ☐ Stroke or neurological disorder eg. Parkinson's disease, MS, Motor Neuron Disease
- ☐ Liver Disease
- ☐ Blood Borne virus eg. HIV
- ☐ Allergies
- ☐ Migraine
- ☐ Fibromyalgia

Q192 Thinking back to before you had COVID-19 for the first time, did you smoke tobacco products?

- ☐ Yes, daily
- ☐ Yes, occassionally
- ☐ No

If no to Q192
past smoking If you did not smoke when you got COVID-19 for the first time, had you ever smoked tobacco products in the past?

- ☐ Yes, daily
- ☐ Yes, occassionally
- ☐ No

Q196 Thinking back to before you got COVID-19 for the first time, how often did you consume alcohol?

- ☐ Never
- ☐ Daily
- ☐ 5-6 times a week
- ☐ 3-4 times a week
- ☐ 1-2 times a week
- ☐ 1-3 times a month
- ☐ Less than once a month
- ☐ I hadn't had an alcoholic drink for 6 months or more
- ☐ Don't know

If drink alcohol in Q196
Q203 Before you got COVID-19 for the first time, thinking of a typical day on which you had an alcoholic drink, how many standard drinks would you drink? A standard drink is: half a pint of beer, a small glass of wine or a pub measure of spirits. Number of standard drinks?

Q204 We are interested in how much physical activity you did before your first COVID-19 infection and if this has changed since you got COVID-19. Before your first COVID-19 infection, on how many days of the week were you physically active for a total of at least 30 minutes per day?

- ☐ None
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7

Q6 Overall, how physically active are you now compared to before you got COVID-19 for the first time?

- ☐ A lot more
- ☐ A little more
- ☐ About the same
- ☐ A little less
- ☐ A lot less

If answered no to Q121 – do not now and never had Long COVID

Q293 What is your Occupation? If you have retired please indicate your occupation before you retired.

Q6 Overall, how physically active are you now compared to before you got COVID-19 for the first time?

- ☐ A lot more
- ☐ A little more
- ☐ About the same
- ☐ A little less
- ☐ A lot less

Q188 The following questions are to find out a little bit more about you and your background. We are interested to see if there are factors that affect how people recover from COVID-19. We would be very grateful if you could answer the following questions. Which of the following groups do you consider you belong to?

- ☐ White Irish
- ☐ White Irish Traveller
- ☐ Any other White background (specify) _____
- ☐ Black or Black Irish African
- ☐ Any other Black background (specify) _____
- ☐ Asian or Asian Irish
- ☐ Chinese
- ☐ Any other Asian background (specify) _____
- ☐ Other, including mixed background (specify) _____

Q11 Were you ever pregnant when you had COVID-19?

- ☐ Yes
- ☐ No

Q3 Do you work in a healthcare setting?
☐ Yes ☐ No
Q3 3. What is the highest level of education you have completed to date?
☐ Primary school or less ☐ Secondary level ☐ Third level
Q4 4. Would you describe the place you are living as:
☐ Urban (living in a town or city) ☐ Rural (living in a village, small village or in the countryside)
Q4 4. Would you describe the place you are living as:
☐ Urban (living in a town or city) ☐ Rural (living in a village, small village or in the countryside)
Q6 6. What is your current marital status?
☐ Married/Cohabiting/civil partnership ☐ Never married/Single ☐ Divorced/Separated ☐ Widowed
Q285 What age are you? (Please tell us your current age)
Q295 Is there anything else that you would like to add that you think is important for us to know?

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